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Ethics on the Ground: Egg Donor Agency Behavior in an Unregulated Legal Environment and the Growth of Ethical Norms in a New Field

By

Janette Denevan Catron

A dissertation submitted in partial satisfaction of the

requirements for the degree of

Doctor of Philosophy

in

Jurisprudence and Social Policy

in the

Graduate Division

of the

University of California, Berkeley

Committee in charge:

Professor Kristin Luker, Chair Professor Calvin Morrill Professor Jennifer Johnson-Hanks

Fall 2014

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#### ABSTRACT

### Ethics on the Ground: Egg Donor Agency Behavior in an Unregulated Legal Environment and the Growth of Ethical Norms in a New Field

by

#### Janette Denevan Catron

#### Doctor of Philosophy in Jurisprudence and Social Policy

#### University of California, Berkeley

#### Professor Kristin Luker, Chair

This dissertation explores the ways in which egg donor agencies make decisions in the absence of law, and what normative regulations and meanings, moral and otherwise, those decisions create. I analyze what resources and beliefs agency decision-makers employ in the day-to-day running of their organizations, and whether decision-makers consider the myriad ethical implications of their business.

Based on semi-structured interviews with agency decision-makers, primarily in California, as well as other infertility field professionals, I find that, rather than modeling their organizations on other egg donor agencies or analogous institutions as might be predicted by new institutionalism, egg donor agency decision-makers fall back on their personal moral beliefs when making on-the-ground decisions in the course of running their agencies. I examine agency decision-makers' responses to uncertainty in their (new) field and to pressures from outside their field to explore how decisionmakers incorporate their moral beliefs into their organizations.

The following chapters demonstrate how this particular group of agency decisionmakers think about the complex questions that arise in the course of bringing together infertile people and egg donors for the purpose of creating a baby. I find that agency decision-makers are often ambivalent about the ethically questionable aspects of egg donation, such as the commodification of human eggs and the potential exploitation of egg donors, and they overcome their ambivalence using a variety of strategies aimed at minimizing any damage to egg donors and intended parents while simultaneously enabling the ultimate goal of helping people to build their families.

This dissertation also shows how agency decision-makers navigate in an unregulated legal environment. They criticize those members of the field they deem to be unethical

in order to show themselves in a positive light by contrast, and they affiliate themselves and their agencies with established professionals, such as physicians and infertility clinics, in order to share in those professionals' legitimacy. Finally, in the absence of regulation, a small number of agency decision-makers have conceived a nonprofit organization, in some respects similar to a professional body, intended to create a set of ethical standards specific to egg donor and surrogacy agencies.

Ultimately, this dissertation demonstrates that although agency decision-makers reference their own moral beliefs when making day-to-day decisions for their agencies, those individual beliefs are translated to the organizational level, as predicted by an inhabited institutions theoretical approach. And as predicted by an institutional logics perspective, each individual agency decision-maker does not exist in a vacuum, but instead is subject to multiple institutional logics (such as societal ethics, family, medical professional, mental health professional, and egg donor agency). Counterintuitively, however, all of this diversity—diversity of personal beliefs and diversity of institutional logics—results in a convergence of egg donor agency practices into an emerging set of ethical norms and a shared moral meaning: the value of taking good care of agency clients and donors, and the joy of helping people have babies.

For my three boys

# **Ethics on the Ground:**

# Egg Donor Agency Behavior in an Unregulated Legal Environment and the Growth of Ethical Norms in a New Field

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### CHAPTER ONE

### Introduction: New Technology, New Organizations, No Law

### **Prologue:**<sup>1</sup> Where do Egg Donor Agencies Come From?

It was the 1990s. Jennifer, a young woman new to college, kept seeing personal ads for egg donors whenever she read the college paper, placed by couples in need. Her brother, a double major in biology and philosophy, was fascinated by the ads, and when one in particular seemed to be describing his sister, he brought her the paper and told her that she was who this couple was looking for.

Jennifer was affected by the ads; she felt terrible for these unknown people who couldn't have a child, but she thought, no. She was too young, not ready to make a major decision like that. She knew how little she knew. Nothing about the medical process. Nothing about the legal process. Nothing about the social and emotional elements of egg donation. Nothing. And very little about the couple.

After college, Jennifer continued to see such ads, only now they were placed through a company called an agency. They stuck in her head; the thought of donating her eggs stayed with her. After seeing a number of these ads, curiosity got the best of her, and she called an agency just to find out what it was all about.

She asked the agency a lot of questions. She wanted to take it slow, though—no meeting the potential parents until she was sure of herself, because she didn't want to be pressured into anything. She received the application to become an egg donor from the agency, and sat on it for a month. When she found out that the owner of the agency was herself a mother through egg donation, Jennifer was moved enough to send in the application.

Within two weeks she was matched with an intended mother in her mid-thirties, a breast cancer survivor. In this early era of egg donation, when most donors were fully anonymous, Jennifer met her recipient. They went out to dinner. People who saw them thought they were sisters. They talked and cried together. Jennifer learned that she was responsible for giving her new friend a renewed sense of hope in life.

<sup>&</sup>lt;sup>1</sup> Paraphrased from the personal anecdotes of two of my interviewees; names are pseudonyms.

Jennifer knew that she was doing something very, very important.

\*\*\*\*\*

When she was twenty-two years old, Amy read a newspaper article about infertile couples attempting to conceive using donor eggs, and how there was a shortage of donors. She found it disturbing that so many people who wanted children so badly would be unable to have them without help. Amy didn't plan on having any children herself, so she figured that she might as well give her eggs to somebody who would truly appreciate them.

She contacted an infertility clinic, and quickly qualified to donate. Her egg donation process was smooth, and when she woke up in the hospital room after the doctors retrieved forty eggs, she was greeted by the sight of six massive bouquets of flowers—a gift from the intended parents, a futile attempt to express how much Amy's own gift of her eggs meant to them. As she left the hospital a little while later, she felt incredibly proud of herself. She knew she had made a huge difference in someone's life. Even if she didn't know them, she knew that what she had done mattered.

Almost two weeks later, Amy was at work. Her boss, an older woman who resembled Amy to such an extent that more than once they had been asked if they were sisters, was on the phone. She was crying. She said she was pregnant. Amy realized that her boss had had rather erratic attendance at work during the same period that she herself was frequently absent to attend medical appointments for the egg donation cycle. And she remembered seeing her boss's husband at the infertility clinic during that time, too. And she thought, with delight: "Imagine if it was them!"

### Introduction

In 2012, over 8,666 babies were born as a result of donor egg IVF cycles. In the ten years between 2003, the year the Society for Assisted Reproductive Technology (SART) began making its data available online, and 2012, the most recent year for which data are available, well over 67,835 babies conceived using donor eggs have been born in the

United States, in increasing numbers each year.<sup>2</sup> These numbers significantly understate the incidence of donor egg birth, as they count multiple births as single births, and they do not include donor egg births from IVF cycles performed at non-member clinics or births from cycles performed before 2003 and from 2013 to the present.<sup>3</sup> Overall, the 91,260 fresh (non-frozen) donor egg cycles comprise about ten percent of all fresh IVF cycles.<sup>4</sup>

In vitro fertilization (IVF) allows human eggs to be retrieved from one woman, fertilized outside the uterus, and transferred into the uterus of another woman, a

<sup>&</sup>lt;sup>2</sup> Society for Assisted Reproductive Technology (SART), Clinic Summary Reports 2003-2012, All Member Clinics, available from www.cdc.gov/art/; Internet; Accessed 14 September 2014. Data is collected from member clinics in collaboration with the Centers for Disease Control. SART is an affiliate of the American Society for Reproductive Medicine (ASRM). SART has collected data since 1985, and the CDC became involved in 1992 with the Fertility Clinic Success Rate and Certification Act, which requires the CDC to collect data from clinics and submit an annual report to Congress on clinic success rates. In 2012, 83.6% of fertility clinics in the U.S. were members of SART, similar to the 85% SART membership in 2008. (See CDC website, www.cdc.gov/art/, link to "Preliminary 2012 Data—Clinic Tables and Data Dictionary.") SART (in conjunction with the CDC) is the only national body that collects data on fertility clinics at present, and has gained legitimacy both through its association with the CDC, and by establishing itself as the source for (supposedly) unbiased success rates, accessible to fertility clinics' potential clients. Total egg donor births at SART member clinics in order from 2003-2012: 5180; 5474; 5989; 6489; 6898; 7187, 7124, 7334, 7494, 8666.

<sup>&</sup>lt;sup>3</sup> Though there have been no large, long-term studies on the health of children born through egg donation, a few long term studies on the risks to children born through IVF indicate that children conceived through IVF are at a very small increased risk of autism and mental retardation if they were part of a set of twins or triplets (Sven Sandin, M.Sc. et al., "Autism and Mental Retardation Among Offspring Born After In Vitro Fertilization," *Journal of the American Medical Association* 310, no. 1 (2013): 75-84); that children conceived through the use of ICSI (in which a sperm is injected into an egg to achieve fertilization) have a twofold risk of birth defects (Michèle Hansen, M.P.H. et al., "The Risk of Major Birth Defects after Intracytoplasmic Sperm Injection and In Vitro Fertilization," *New England Journal of Medicine* 346, no. 10 (Mar. 2002): 725-730); and that children conceived through IVF are not at an increased risk of childhood cancers (Carrie L. Williams, M.B., B.Ch. et al., "Cancer Risk Among Children Born after Assisted Conception," *New England Journal of Medicine* 369, no. 19 (Nov. 2013): 1819-1827). While there are no studies on children of egg donation specifically, children born through IVF generally appear overall to be healthy.

<sup>&</sup>lt;sup>4</sup> SART, Clinic Summary Reports 2003-2012.

process commonly referred to as "egg donation."<sup>5</sup> Would-be parents make use of this technology by obtaining healthy eggs from young women, either as a substitute for a recipient woman's eggs when she has no viable eggs, or as a necessary part of the creation of an embryo for homosexual couples or single fathers-to-be.<sup>6</sup>

The practice of egg donation has in turn spurred its own commercialization by creating demand for organizations that function as brokerage houses, matching intended parents who need eggs with women who are willing to give them for an attempt to create a baby.<sup>7</sup> At present, these "egg donor agencies" function without regulation directed at the substance of their business. As business entities, they are subject to state and federal business law, but because they are non-medical in nature, they are not subject to the different levels of regulation that are imposed on medical practitioners and fertility clinics.

<sup>&</sup>lt;sup>5</sup> "Egg Donation. An egg from a fertile woman that is donated to an infertile woman to be used in an assisted reproductive technology procedure such as IVF. The woman receiving the egg will not be biologically related to the child but will be the birth mother on record." American Society for Reproductive Medicine, "Egg Donation," *ReproductiveFacts.org*, www.reproductivefacts.org/topics/detail.aspx?id=418; Internet; Accessed 30 August 2014. And a more sociologically-aware definition: "Surprisingly early on fertility medicine proved able to deliver a compromise solution: sort of like adoption, and sort of like having your own biological offspring.... The chance to—well, to adopt half a baby, in a sense, and gestate that baby and experience childbirth and breast-feeding, and control one's diet and alcohol intake and cigarette smoking and all the other things that cannot be controlled, or not so easily, if the child is being gestated by another. Fertility medicine offered the woman who cannot conceive using her own eggs the opportunity to conceive using the eggs of another." Liza Mundy, *Everything Conceivable: How Assisted Reproduction is Changing the World* (New York: Anchor Books, 2008), 47.

<sup>&</sup>lt;sup>6</sup> There is no real evidence of a link between ovarian stimulation for egg donors and future risk of cancer or infertility, though there has been no systematic follow-up of egg donor health. A few retrospective studies have hinted that there may be some association between egg donation and cancer, but their results did not achieve statistical significance. Some people are calling for long term follow up of a large cohort of egg donors—in order to determine whether there are in fact unidentified medical risks from donating one's eggs—which would enable true informed consent. Molly Woodriff, M.P.H., Mark V. Sauer, M.D., and Robert Klitzman, M.D., "Advocating for Long-Term Follow-Up of the Health and Welfare of Egg Donors," *Fertility and Sterility* 102, no. 3 (Sept. 2014): 662; Jennifer Schneider, M.D., Ph.D., "Fatal Colon Cancer in a Young Egg Donor: A Physician Mother's Call for Follow-Up and Research on the Long-Term Risks of Ovarian Stimulation," *Fertility and Sterility* 90, no. 5 (Nov. 2008): 2016.e.1; Dominic Stoop, M.D. et al., "Effect of Ovarian Stimulation and Oocyte Retrieval on Reproductive Outcome in Oocyte Donors," *Fertility and Sterility* 97, no. 6 (June 2012): 1328.

<sup>&</sup>lt;sup>7</sup> See Debora Spar, *The Baby Business: How Money, Science, and Politics Drive the Commerce of Conception* (Boston: Harvard Business School Press, 2006); Rene Almeling, *Sex Cells: The Medical Market for Eggs and Sperm* (Berkeley, Los Angeles, and London: University of California Press, 2011).

My primary research question is this: In the absence of law, how do egg donor agencies make decisions and what normative regulations and meanings, moral and otherwise, do those decisions create?

In order to answer this question, I asked the opinions and solicited the observations and experiences of the people who make decisions in egg donor agencies about how day-today decisions are made, how they ought to be made, how they ought *not* to be made, and about the potential problems presented by the work they do. I also asked about the origins and implementation of any formal policies they have created for their own agencies' internal guidance.<sup>8</sup>

The practice of egg donation raises important legal, moral, and ethical questions, including but not limited to issues of commodification of genetic and reproductive material, markets in women's reproductive labor, exploitation of women, and the moral worth of human eggs. The law has not kept pace with the technology, so the people working in the field of egg donation do so essentially without legal guidance. This dissertation examines how the day-to-day decision-making in egg donor agencies, and the creation of their formal and informal policies as well, imparts moral meaning and normative regulation to the practice of egg donation.

I chose to focus on egg donation, as opposed to surrogacy or sperm donation, because while each of these practices raises some of the same ethical issues, egg donation is unique in the way in which it implicates the "specter of eugenics," a gruesome piece of United States history that reached its height in the early twentieth century.<sup>9</sup> The belief that the human race should be improved by the selective breeding of "desirable" genetic elements (intelligence and whiteness being two major such elements), and the forced sterilization of "undesirables" (including the mentally disabled, mentally ill, and the physically disabled and deformed), eugenics and its supporters were responsible for the forced sterilization of an estimated more than 60,000 people, sometimes without their knowledge.<sup>10</sup> The belief system was even embodied by the highest court in the land in the case *Buck v. Bell*, in which Justice Oliver Wendell Holmes, writing for the 8-1 majority, argued that the science of eugenics supported the forced sterilization of Carrie

<sup>&</sup>lt;sup>8</sup> See "Research Methodology," in this chapter.

<sup>&</sup>lt;sup>9</sup> "By the end of the nineteen-twenties, sterilization laws were on the books of twenty-four states ... by the mid-thirties, some twenty thousand sterilizations had been legally performed in the United States." Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Cambridge and London: Harvard University Press, 1985, 1995), 111.

<sup>&</sup>lt;sup>10</sup> Paul A. Lombardo, *Three Generations, No Imbeciles: Eugenics, The Supreme Court, and* Buck v. Bell (Baltimore: The Johns Hopkins University Press, 2008), x.

Buck as a means of protecting the public welfare: "Three generations of imbeciles are enough."<sup>11</sup>

While the eugenics movement in the early twentieth century largely utilized "negative eugenics"—the prevention of reproduction of "undesirables"—as a means of administration, some of the practice of egg donation can be seen as "positive eugenics," the promotion of the reproduction of "desirables," people with traits that are considered genetically superior.<sup>12</sup> An example of this is advertisements touting extreme compensation, sometimes on the order of \$50,000, or even \$100,000, for donors who attend Ivy League colleges, or who are blonde and blue-eyed, or especially tall or athletic.<sup>13</sup> The media often calls this cherry-picking of egg donor traits making a "designer baby,"<sup>14</sup> and therein lies the risk: that people in medical need of donors will, through their donor choice, attempt to "improve" their genetic line, or, more dangerously, that people *not* in medical need of an egg donor will seek to do the same. Widespread use of egg donation in this manner could have an extensive and unpredictable effect on race relations in the United States and society's valuation of each

<sup>&</sup>lt;sup>11</sup> Buck v. Bell, 274 U.S. 200 (1927). Carrie Buck was a poor girl who fell pregnant outside of wedlock when she was sixteen. Because of her pregnancy (evidence that she was morally degenerate), she was sent to a state institution—The Virginia Colony for Epileptics and Feeble-Minded—just after Virginia enacted a sterilization law. The law was based on the theory that "defects—criminality, poverty, illegitimacy, and the like—were passed down from people like Carrie to their children." Lombardo, *Three Generations, No Imbeciles,* x. *Buck v. Bell* confirmed the theory of hereditary defect, but it did so on patently weak evidence; as Paul Lombardo argues, the case was a "legal sham … Carrie Buck was the victim of an elaborate campaign to win judicial approval for state sterilization laws." Lombardo, *Three Generations, No Imbeciles,* xi.

<sup>&</sup>lt;sup>12</sup> "'Positive eugenics' ... aimed to foster more prolific breeding among the socially meritorious, and 'negative eugenics' ... [was] intended to encourage the socially disadvantaged to breed less—or better yet, not at all." Kevles, *In the Name of Eugenics*, 85.

<sup>&</sup>lt;sup>13</sup> See, e.g., Gina Kolata, "\$50,000 Offered to Tall, Smart Egg Donor," *The New York Times*, 3 March 1999, available from www.nytimes.com/1999/03/03/us/50000-offered-to-tall-smart-egg-donor.html; Internet; Accessed 4 September 2014; Annie M. Lowrey, "Will You Be My Baby's Mama? The Egg Donor Market Wants You, Harvard Women, and It'll Pay," *The Harvard Crimson Magazine*, 29 April 2004, available from www.thecrimson.com/article/2004/4/29/will-you-be-my-babys-mama/; Internet; Accessed 4 September 2014; Kevin Su, "Not By the Dozen," *The Yale Herald*, 24 February 2014, available from yaleherald.com/ news-and-features/not-by-the-dozen/; Internet; Accessed 4 September 2014.

<sup>&</sup>lt;sup>14</sup> See, e.g., Aaron Saenz, "Paying More for Egghead Donors—A Sign of Designer Babies to Come," *Singularity Hub*, 8 April 2010, available from singularityhub.com/2010/04/08/paying-more-for-eggheadegg-donors-a-sign-of-designer-babies-to-come/; Internet; Accessed 4 September 2014; David Jones, "The Designer Baby Factory: Eggs from Beautiful Eastern Europeans, Sperm from Wealthy Westerners and Embryos Implanted in Desperate Women," *U.K. Daily Mail Online*, 4 May 2012, available from www.dailymail.co.uk/news/article-2139708/The-designer-baby-factory-Eggs-beautiful-Eastern-Europeans-Sperm-wealthy-Westerners-And-embryos-implanted-desperate-women.html; Internet; Accessed 4 September 2014.

individual human, regardless of race, ethnicity, physical attributes, intelligence, or athleticism.<sup>15</sup>

The compensation issue cuts both ways, however, as some minority ethnicities can command high compensation on the basis of the rarity of their participation in egg donation.<sup>16</sup> Renee Almeling finds that this phenomenon applies to Asian women and African-American women alike, though at least one agency reports that "Asian females out-earn white women by 13%, black women by 31% and Latinas by 52%."<sup>17</sup> Consequently, the phenomenon of the market rewarding historically subordinate groups is limited to the less subordinated minorities, such as Asian and Jewish women. Black and Hispanic women are both more likely to donate their eggs than Asian and Jewish women (for cultural reasons), and less likely to be in search of an egg donor (for complex social and economic reasons), so they do not benefit from the elevated compensation earned by some minorities.

In theory, the same risk of eugenics exists in sperm donation, and in fact, so-called "genius sperm banks" have periodically existed.<sup>18</sup> And while the risk of eugenics through sperm donation is very real—and perhaps more likely than that through egg donation, given the lower financial costs involved and the possibility of performing turkey-baster artificial insemination at home—I focus on egg donation specifically

<sup>&</sup>lt;sup>15</sup> "In [the donor gamete] market, race and ethnicity are are biologized, as in references to Asian eggs or Jewish sperm, and these are some of the primary sorting mechanisms in donor catalogs, along with hair and eye color. This routinized reinscription of race at the genetic and cellular level in donation programs, which as medicalized organizations offer a veneer of scientific credibility to such claims, is worrisome given our eugenic history." Almeling, *Sex Cells*, 173.

<sup>&</sup>lt;sup>16</sup> "Due to the difficulty of maintaining a diverse pool of donors, [Rene Almeling's respondent] egg agencies often increase the fee for donors of color, especially Asian Americans and African Americans. This results in a situation where they are often more highly valued than white women, which is unexpected, given that the reverse is often true in other contexts, including the labor market and in adoption agencies. But in this market, race is seen as a biologically based characteristic, and sex cells from women of color are perceived as scarce, which contributes to their increased value." Almeling, *Sex Cells*, 69.

<sup>&</sup>lt;sup>17</sup> Shan Li, "Asian Women Command Premium Prices for Egg Donation in the U.S.," *Los Angeles Times*, 3 May 2012, available from www.geneticsandsociety.org/article.php?id=6199; Internet; Accessed 4 September 2014.

<sup>&</sup>lt;sup>18</sup> Perhaps the most famous "genius sperm bank" was millionaire Robert K. Graham's eugenics project, the Repository for Germinal Choice. The Southern California bank was publicized by the *Los Angeles Times* in 1980, and Graham was briefly condemned by the public for his eugenics aims. The bank supposedly began with the sperm of three (or five) Nobel Prize winners. Graham died in 1997, and the Repository closed in 1999. David Plotz, "The 'Genius Babies,' and How They Grew," *Slate.com*, 8 February 2001, available from www.slate.com/articles/life/seed/2001/02/ the\_genius\_babies\_and\_how\_they\_grew.html; Internet; Accessed 4 September 2014.

because egg retrieval involves a much more physically invasive and medically risky process than sperm donation and, consequently, egg donors command much greater compensation than sperm donors.<sup>19</sup> And, in the same vein, I focus on egg donation rather than surrogacy because while surrogacy raises issues of the commodification of women's reproductive labor, along with a host of emotional and social concerns, it is not a direct part of the process of selecting the genes of future generations.<sup>20</sup> The specter of eugenics marks the ethical importance of egg donation, and that specter tends to be much less obvious than the conflicts that arise in surrogacy—which not infrequently

<sup>&</sup>lt;sup>19</sup> Society's concepts of "caring motherhood and distant fatherhood" also come into play here, increasing the value of eggs over sperm because "it is not just that individual women have fewer eggs than individual men have sperm, or that eggs are more difficult to extract, that results in both high prices and constant gift-talk in egg donation, but the close connection between women's reproductive bodies and cultural norms of caring motherhood." Rene Almeling, "Selling Genes, Selling Gender: Egg Agencies, Sperm Banks, and the Medical Market in Genetic Material," *American Sociological Review* 72 (2007): 337; Almeling, *Sex Cells*, 84. According to the California Cryobank website, sperm donors are compensated "up to \$125 per donation." California Cryobank, "Sperm Donor Compensation: Cryobank Sperm Donor Pay and Benefits," available from www.spermbank.com; Internet; Accessed 4 September 2014. Rene Almeling found in 2011 that sperm donors are paid around \$74 per donation. Almeling, *Sex Cells*, 68.

<sup>&</sup>lt;sup>20</sup> Among the issues that surrogacy raises are whether women should be able to sell their reproductive labor, whether it is "baby-selling" at worst, or a violation of public policy at best, to create agreements in which parental rights are assigned to the intended parents prior to the child's birth, and whether it is socially and ethically acceptable for people of greater financial means to hire people of lesser financial means—which sometimes involves intended parents from developed nations hiring surrogates from developing nations—to carry their babies. See Margaret Jane Radin, "Market-Inalienability," *Harvard Law Review* 100, no. 8 (June 1987): 1849; Mundy, *Everything Conceivable*; Spar, *The Baby Business*; Lisa C. Ikemoto, "Reproductive Tourism: Equality Concerns in the Global Market for Fertility Services," *Law and Inequality: A Journal of Theory and Practice* 27 (Aug. 2009): 277-309; Carmel Shalev, "International Surrogacy, Global Consumerism, Harms to Women and Children," *Biopolitical Times*, 15 September 2014, available from www.biopoliticaltimes.org/article.php?id=8061; Internet; Accessed 18 September 2014.

make headlines<sup>21</sup>—and thus more sinister in its ability to manifest without general recognition of its perils. Many of my interviewees' agencies are both egg donor *and* surrogacy agencies, but I questioned them about their decision-making with regard to the egg donation side of their business.

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This dissertation is theoretically grounded in two core literatures: institutional change in sociology and feminist legal theory, to be bridged by an "inhabited institutions" approach. Theories of institutional change commonly address the circumstances in which an established organization in an established field undergoes systemic change.<sup>22</sup> Some donor egg agencies may be established organizations, but their field is emergent, and they have different characteristics than the institutions addressed by current institutional theory (e.g., they are small organizations, largely run by women, dealing with an ethically ambiguous business). Thus I hope to extend the theories of

<sup>&</sup>lt;sup>21</sup> The first major surrogacy scandal was the *Baby M* case in New Jersey, in which a traditional surrogate (who was the genetic mother of the baby) changed her mind after the child's birth, resulting in a state court decision that commercial surrogacy was against public policy. In re Baby M, 537 A.2d 1227, 109 N.J. 396 (N.J. 1988). More recently, the Baby Gammy scandal has painted intended parents as evildoers in the midst of a military government "crackdown" on commercial surrogacy in Thailand: an Australian couple hired a Thai surrogate, who bore twins, one of whom was diagnosed with Down Syndrome. Allegedly, the intended parents retrieved the healthy child and abandoned the child with Down Syndrome. To make matters even worse, the intended father is a convicted sex offender. See, e.g., Sonia Allan, "Baby Gammy Case Reveals Murky Side of Commercial Surrogacy," *MercatorNet*, 5 August 2014, available from www.mercatornet.com/articles/view/

baby\_gammy\_case\_reveals\_murky\_side\_of\_commercial\_surrogacy; Internet; Accessed 18 September 2014; Thomas Fuller, "Thailand's Business in Paid Surrogates May Be Foundering in a Moral Quagmire," *The New York Times*, 26 August 2014, available from www.nytimes.com/2014/08/27/world/asia/in-thailands-surrogacy-industry-profit-and-a-moral-quagmire.html?smid=nytcore-iphone-share&smprod=nytcore-iphone&\_r=3; Internet; Accessed 18 September 2014; James Hookway, "Thailand Targets Surrogacy Practices Amid Scandals," *The Wall Street Journal*, 27 August 2014, available from online.wsj.com/articles/thailand-targets-surrogacy-practices-1409146050; Internet; Accessed 18 September 2014; Angela Pownall, "New Twist in Surrogacy Scandal," *The West Australian*, 19 September 2014 (AU time), available from au.news.yahoo.com/thewest/a/25052362/new-twist-in-surrogacy-scandal/; Internet; Accessed 18 September 2014 (US time); Reuters, "Thai Surrogate Baby Gammy: Australian Parents Contacted," *BBC News Asia*, 7 August 2014, available from www.bbc.com/news/world-asia-28686114; Internet; Accessed 18 September 2014; Reuters, "Thailand to Ban Commercial Surrogacy in Wake of Gammy Scandal," *The Guardian*, 13 August 2014, available from www.theguardian.com/lifeandstyle/2014/aug/13/thailand-ban-surrogacy-gammy; Internet; Accessed 18 September 2014.

<sup>&</sup>lt;sup>22</sup> See, e.g., Paul J. DiMaggio and Walter W. Powell, "The Iron Cage Revisited: Institutional Isomorphism and Collective Rationality in Organizational Fields," in *The New Institutionalism in Organizational Analysis*, eds. Walter W. Powell and Paul J. DiMaggio (Chicago and London: The University of Chicago Press, 1991).

institutional change to explain how organizations in a new field create their initial internal regulatory structure.

The most potentially relevant theories of institutional change are diffusion models.<sup>23</sup> Diffusion models explain how institutional change occurs across a field, at the interorganizational level, in such a way that organizations come to look like each other.<sup>24</sup> I observed that egg donor agencies' responses to uncertainty and to pressure from outside the field, as well as their nascent attempt to professionalize, led to some amount of convergence of norms within the field. Surprisingly, very few egg donor agency decision-makers appeared to look outside their field to analogous fields, like organ donation, tissue sales, foster/adoption, or even surrogacy, in order to shape their internal structure according to the rules they find in other organizations. The origins of agency norms lay primarily with agency decision-makers' personal sense of morality, which itself is necessarily embedded in a common industry and social context.

That socially embedded personal morality was especially apparent in my interviewees' responses to questions about the ethical issues raised by the practice of egg donation. Feminist legal theory addresses in depth the concerns of commodification of reproductive tissue and the exploitation of women's reproductive labor<sup>25</sup>—these are also the two largest and most obvious (to the layperson) ethical issues with egg donation. Where theories of institutional change address organizational behavior, feminist theory focuses on people—in particular, women, and their role in society. The relatively recent theory on "inhabited institutions" helps to bridge the gap between the organizational focus of institutional change theory and the focus of feminist theory on individual agency and on the impact of social and economic paradigms on a particular

<sup>&</sup>lt;sup>23</sup> DiMaggio and Powell, "The Iron Cage Revisited," 66-75.

<sup>&</sup>lt;sup>24</sup> See, e.g., DiMaggio and Powell, "The Iron Cage Revisited."

<sup>&</sup>lt;sup>25</sup> See, e.g., Donna Dickenson, *Property in the Body* (Cambridge: Cambridge University Press, 2007); Margaret Jane Radin, *Contested Commodities: The Trouble with Trade in Sex, Children, Body Parts, and Other Things* (Harvard University Press, 1996); idem, "Market-Inalienability," 1849; Debra Satz, "Markets in Women's Reproductive Labor," *Philosophy and Public Affairs* 21, no. 2 (Spring 1992): 107-131; Josephine Johnston, "Paying Egg Donors: Exploring the Arguments," *Hastings Center Report* 36, no. 1 (2006): 28-31; Marjorie M. Shultz, "Questioning Commodification," review of *Contested Commodities: The Trouble with Trade in Sex, Children, Body Parts, and Other Things*, by Margaret Jane Radin, *California Law Review* 85 (1997): 1841; Joan Williams, *Unbending Gender: Why Family and Work Conflict and What to Do about It* (United States: Oxford University Press, 2000).

group of people.<sup>26</sup> In this case, my interviewees' personal morality, originating from an industry and social context, is actualized via their organizations, and converges with the actualized morality of other decision-makers (through their own agencies) into something like norms addressing the trickiest ethical questions in the field.

An inhabited institutions approach to organizational theory is an attempt to make visible the individuals who comprise an organization.<sup>27</sup> It asks not only how an organization constrains its constituents' behavior, but also how the behavior and social interactions of organizational members shape the organization's structure and policies.<sup>28</sup> In this dissertation, I utilize an inhabited institutions approach to incorporate feminist legal theory with the theories of institutional change in order to establish a vision of institutional change at the crossroads of the emergence of a new field and moral concerns in feminist legal theory. Ultimately, my goal is to inform scholarship and policymaking about and regulation of egg donor agencies in a socially and morally conscientious way.

My primary theoretical interest is in the behavior of organizations, and individuals within those organizations, in unregulated markets. After making a map of agencies nationwide, and conducting my interviews, three different forms of "regulation" have emerged: medical regulation/professional norms (visible in particular in in-house egg

<sup>&</sup>lt;sup>26</sup> For an account of the "inhabited institutions" approach, see the following paragraphs, and Tim Hallett and Marc J. Ventresca, "Inhabited Institutions: Social Interactions and Organizational Forms in Gouldner's 'Patterns of Industrial Bureaucracy,'" *Theory and Society* 35, no. 2 (Apr. 2006): 213-236. See also Amy Binder, "For Love and Money: Organizations' Creative Responses to Multiple Environmental Logics," *Theory and Society* 36 (2007): 547-571; Patricia H. Thornton, William Ocasio, and Michael Lounsbury, *The Institutional Logics Perspective: A New Approach to Culture, Structure, and Process* (Oxford and New York: Oxford University Press, 2012).

<sup>&</sup>lt;sup>27</sup> See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Michael Smets, Tim Morris, and Royston Greenwood, "From Practice to Field: A Multi-Level Model of Practice-Driven Institutional Change," *Academy of Management Journal* 55, no. 4 (Aug. 2012): 877-904; and P. Hirsch and M. Lounsbury, "Ending the Family Quarrel: Toward a Reconciliation of 'Old' and 'New' Institutionalisms," *American Behavioral Scientist* 40, no. 4 (Feb. 1997): 406-418.

<sup>&</sup>lt;sup>28</sup> Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Smets, Morris, and Greenwood, "From Practice to Field;" Hirsch and Lounsbury, "Ending the Family Quarrel." For accounts of how individuals manage conflicting institutional logics, see Anne-Claire Pache and Filipe Santos, "Inside the Hybrid Organization: Selective Coupling as a Response to Conflicting Institutional Logics," *Academy of Management Journal* 56, no. 4 (Aug. 2013): 972-1001; Julie Battilana and Silvia Dorado, "Building Sustainable Hybrid Organizations: The Case of Commercial Microfinance Organizations," *Academy of Management Journal* 53, no. 6 (Dec. 2010): 1419-1440; and Royston Greenwood et al., "Institutional Complexity and Organizational Responses," *The Academy of Management Annals* 5, no. 1 (July 2011): 317-371.

donor programs), legal regulation (such as the prohibition of surrogacy in New York), and the pure market. This dissertation is about the pure market, and how people create ethical standards in unregulated markets, that is, in the absence of legal regulation or professional norms.

After speaking with decision-makers in agencies primarily in California, but also across the country, I found that in the absence of law, these women fall back on ethics. When making decisions for their agencies, they refer to their own personal morality and to industry- and society-wide ethical views. These morality- and ethics-based decisions coalesce into a shared morality and emergence of ethically grounded new field norms. I conclude that at least a subgroup of egg donor agency decision-makers are thinking about the ethical issues raised by their business, forming standards within their own agencies, and interested in creating field-wide norms.

### The Long Road<sup>29</sup>

The practical aspects of egg donation through egg donor agencies take place in the context of multiple organizations and medical practitioners. The following is a typical pattern of progression through the infertility field, though of course there are as many variations as there are patients.

A typical infertile woman with a male partner will try to become pregnant via sexual intercourse for some time before seeking medical assistance from her gynecologist. Once she approaches her physician, the infertile woman will undergo some testing, often a few cycles on an ovulation-inducing drug, and perhaps a few attempts at intrauterine insemination. If the woman continues to be unable to become pregnant or to sustain a pregnancy, she is referred (or chooses herself to go) to a reproduction specialist physician, typically a reproductive endocrinologist. Some reproductive endocrinologists practice in infertility clinics housed in research hospitals or other large medical organizations such as Kaiser Permanente. Other reproductive endocrinologists own their own independent medical clinics. Patients may seek infertility treatment at any of these types of clinics. At most infertility clinics, the patient does not need a referral from a primary care physician.

<sup>&</sup>lt;sup>29</sup> The following accounts of the structure of the infertility field are a composite of the organizations and procedures described by my interviewees, as well as information gleaned from multiple egg donor agency websites.

Once established as a patient of a reproductive endocrinologist, the infertile woman will undergo more in depth testing. Sometimes a cause of the infertility is found, and sometimes it is not ("unexplained infertility"). Treatment may be through intrauterine insemination or in vitro fertilization. Patients who ultimately need egg donation often undergo several in vitro fertilization treatment cycles with their own eggs before "moving on" to donor egg in vitro fertilization. "Failed" cycles include those in which the woman does not become pregnant at all, suffers a "chemical pregnancy," in which the embryo implants briefly before expiring, and miscarriages. Only a small portion of all infertility patients must engage an egg donor in order to become pregnant; of these, some patients will, of course, decide that egg donation is not an option they want to pursue, and choose either to remain child free or to adopt instead.

Reasons for requiring egg donation include poor egg quality (often because of "advanced" maternal age; such patients are often over forty years old), genetic problems the mother does not wish to pass on to her child, and previous treatment for cancer that has rendered her infertile. When a reproductive endocrinologist recommends that a patient engage an egg donor in order to improve her chances of becoming pregnant, she may seek that donor either in a clinic "in-house" program, or with an independent agency (the subject of this dissertation). In-house programs tend to host a small number of donors relative to their independent counterparts, because inhouse programs don't recruit donors as actively as independent agencies; their business focus leans more heavily to the medical side of the industry. In-house programs are usually overseen by the reproductive endocrinologists, but sometimes have their own staff. In-house programs offer the advantage of working with a single organization during what is a very complex medical procedure involving two patients (the infertile woman and the donor) over the course of several weeks.

If a patient chooses to work with an independent egg donor agency, she must choose the agency (often with recommendations from her clinic), and then, once the patient chooses a donor, the agency will coordinate with the patient's medical clinic to ensure that the donor attends all of her medical appointments. Patients who know they will need an egg donor from the start, such as women who have had their ovaries removed or been diagnosed with premature ovarian failure (early menopause), single intended fathers, and homosexual fathers, may start with an egg donor agency rather than with a physician or clinic. Egg donor agencies are often more customer service oriented than in-house programs.

Egg donors come to an agency via a different route. They are recruited by agencies, typically through ads in a college newspaper, or via social media. Potential donors responding to ads are informed about the egg donation process, and if, once educated,

they decide to become a donor, they undergo preliminary screening and are listed in the agency's database. This is the point at which the paths of the intended parent and the donor converge.

When a patient comes to an egg donor agency, whether from her physician's office/ clinic or not, the patient is transformed into an "intended parent," and the agency will support the intended parent's desires for the qualities she is looking for in an egg donors. Intended parents choose a donor from the agency database, and then the donor undergoes in depth screening, including a psychological evaluation, medical screening at the intended parent's clinic, and infectious disease testing. From then on, both the intended mother and the donor are seen for their medical appointments at the intended parent's medical clinic.

In the following paragraphs, I refer to the "intended mother" as the patient, though the same process applies if the intended parents have engaged a gestational surrogate, in which case the surrogate will be taking medications and attending medical appointments.

Assuming the donor clears all of her screening hurdles, a "cycle" is scheduled, and the intended mother and the egg donor take hormonal medication, often birth control pills or the drug lupron, in order to "sync" their menstrual cycles. Once their bodies are working on the same time frame, at the start of their next menstrual cycle, both the intended mother and the donor begin to take daily hormone injections on a very strict schedule. The donor's medications stimulate her ovaries to produce multiple eggs, and the intended mother's medications prepare her uterine lining for embryo implantation. These injections can last anywhere from two to six weeks, depending on what medical protocol the clinic is using. Additionally, both intended mother and donor must attend several appointments to get vaginal ultrasounds, during which the physician checks the uterine lining of the intended mother and the follicle development of the donor. When the intended mother and the donor have been taking their injections long enough (approximately two weeks into the menstrual cycle), the intended mother's uterine lining appears to be the proper thickness, and the donor's follicles have grown enough to indicate they contain mature eggs, the donor will take a different injection to "trigger" ovulation.

The donor's eggs are retrieved under anesthesia via ultrasound-guided needle aspiration the day after the trigger shot, before the eggs have a chance to ovulate out of the follicles. After the retrieval, the donor's part in the cycle is complete, though she should be watched for complications from the injections or the retrieval for the next two weeks until her next menses. A donor can often participate in another egg donation IVF cycle after a month or two of her natural menstrual cycle.

After the egg retrieval, the clinic's laboratory, typically staffed by embryologists, will attempt to fertilize the eggs with the intended father's (or donor) sperm. Fertilization can take place by simply placing the sperm in the same petri dish as the eggs, or it can happen via intracytoplasmic sperm injection (ICSI), in which a single sperm, chosen by the embryologist, is injected into each egg. Then everyone waits.

The third day after the egg retrieval, the embryologist checks on the embryos. They should have eight cells at that point. If there are many eight-celled embryos, most reproductive endocrinologists recommend waiting to do the embryo transfer into the intended mother's uterus until the fifth day after egg retrieval, as that allows for the embryos to develop further, and for the "bad" embryos to weed themselves out more thoroughly than if the transfer is performed on day three. But if there are only a few embryos, the transfer will take place on day three.

The transfer of the embryos into the intended mother's (or surrogate's) uterus involves the reproductive endocrinologist inserting an ultrasound-guided catheter into the woman's uterus and injecting the embryos. Many reproductive endocrinologists recommend transferring only a single embryo in order to reduce the number of multiple births (twins, triplets, and other high order multiple births). After the transfer, the intended mother must wait for ten days to two weeks to find out whether they cycle has succeeded and she has become pregnant. The pregnancy test is a quantitative beta hCG blood draw, which measures the actual level of pregnancy hormone in the woman's system.

If there is no pregnancy, the intended mother has a follow up appointment with the reproductive endocrinologist to discuss the possible reasons for the failure and the next steps to take. If the intended mother has become pregnant, she will receive a series of beta hCG tests to ensure that the pregnancy is progressing as it should (that her hCG level is rising appropriately), and is not problematic. Women who undergo IVF are more at risk for complications such as ectopic pregnancy, so reproductive endocrinologists watch for such complications. At six to eight weeks pregnancy, the intended mother undergoes a vaginal ultrasound to confirm that the pregnancy is intrauterine; often she is able to see and/or hear a tiny heartbeat at that appointment. And that appointment is a milestone in another way as well: if all looks good, she will "graduate" to the care of her obstetrician or midwife. After that, the reproductive endocrinologist is no longer involved.

IVF is an expensive medical procedure; it is rarely covered by insurance, and it costs intended parents approximately \$12,000 to \$16,000 out of pocket. And that is just for the medical expenses: physician appointments, medications, testing, medical procedures, and lab expenses. The medical costs for an egg donor IVF cycle are slightly higher because between the two patients (intended mother and donor), they need more medications and more ultrasound appointments.

Egg donor agency (or in-house program) costs are separate from the clinic/medical costs; whether they find a donor in an in-house program or at an independent egg donor agency, patients must pay an administration fee to the program or agency that recruited the donor and coordinated her screening and medical appointments. For agencies, that fee is often between \$4000 and \$7500. The egg donor's compensation is separate as well; in California, a typical donor receives between \$5000 and \$10,000. Additionally, there can be a number of separate expenses in an egg donation arrangement, such as the fees for screening the donor, genetic testing of the donor, an insurance policy for the donor, the donor's legal fees, and the intended parent's legal fees. When combined, the medical costs and the non-medical egg donation costs, on their very lowest end, total approximately \$22,000 to \$25,000. More realistically, an egg donation cycle in California can easily cost \$42,000 or more.

#### **Chapter Overview**

This dissertation asks what happens when organizations operate in an ethically complex field without any guidance from the law. Egg donor agencies are a relatively new type of organization, developed in response to a market need for their services accompanying the breakthroughs in reproductive technology that enabled in vitro fertilization.<sup>30</sup> Whereas the physicians and clinics performing the medical procedures are subject to their profession's guidelines and longstanding professional norms, egg donor agencies are not directly beholden to any such professional organization. I ask how individual agency decision-makers come to their decisions in the running of egg donor agencies, and how those decisions, actualized within the organization, become part of the process of developing norms and shared moral meaning in the new field of egg donor agencies.

The following chapters detail the many ethical issues that arise for egg donor agencies, and how agency decision-makers address those issues on a problem-by-problem basis

<sup>&</sup>lt;sup>30</sup> The oldest egg donor agency in the country was founded in 1991 by Shelley Smith. See Spar, *The Baby Business*, 44-45.

and as an overall gestalt. I show how, in making decisions for their agencies, agency decision-makers seek to build a foundation for their own agency's ethical standards, as well as to direct the appearance of the egg donation industry from outside in an effort to establish the legitimacy of egg donor agencies as a group. Furthermore, agency decision-makers are faced with ethical quandaries on topics varying as widely as how to manage the inappropriate behavior of an individual client, to how to justify their fundamental business purpose in the face of lengthy criticism from feminist academic sources, in addition to the popular media. In the following chapters, I argue that my interviewees think a lot about the ethical issues their business raises, but that, in contrast to what the literature may suggest about looking across the field for sources for organizational norms, agency decision-makers' primary point of reference is their own personal morality. That personal morality, however, is embedded in a common social and infertility industry context, and the many individual decisions made according to agency decision-makers' personal morality, which are then implemented through their organizations, coalesce into an overlapping group of norms and a shared moral meaning: caretaking of the individuals involved in egg donation.

The next section develops a multi-disciplinary theoretical framework appropriate for analyzing the complex interactions at the nexus of the development of field norms in a new industry and specific ethical issues addressed by feminist legal theory. Existing literature on diffusion models of the spread of organizational norms propose several means of the transfer of norms among organizations: modeling behavior on similar organizations, responses to outside pressures exerted on the organizations, and a deliberate effort to normalize a field (professionalization).<sup>31</sup> I refine these theories by examining how my interviewees' agencies' reported behavior illustrates them, and filling in the gaps with an inhabited institutions approach, which credits individual actors within an organization with personal agency—in this case, it makes visible the personal morality of agency decision-makers, the critical source of their organizations' individual and group norms and shared meaning.<sup>32</sup> I then look to the two primary concerns of feminist legal theory with egg donation, commodification and exploitation, as a means of further elucidation of the ways in which agency decision-makers'

<sup>&</sup>lt;sup>31</sup> DiMaggio and Powell, "The Iron Cage Revisited;" John W. Meyer and Brian Rowan, "Institutionalized Organizations: Formal Structure as Myth and Ceremony," in *The New Institutionalism in Organizational Analysis*, eds. Walter W. Powell and Paul J. DiMaggio (Chicago and London: The University of Chicago Press, 1991).

<sup>&</sup>lt;sup>32</sup> See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field;" Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" Greenwood et al., "Institutional Complexity."

personal morality serves as the foundation for a functioning ethics among egg donor agencies.<sup>33</sup>

Chapter Two gives a brief history of egg donation and egg donor agencies, and a description of the current state of egg donation technology, including the infertility industry's newfound ability to freeze eggs (and not just embryos).<sup>34</sup> The chapter also provides an overview of the current state of the law on egg donation and related topics, almost none of which applies directly to the organizations at issue in this dissertation, egg donor agencies.

Chapter Three examines the uncertainty in the relatively new field of egg donation and demonstrates agency decision-makers' responses to that uncertainty. I found that they primarily respond to uncertainty in individual ways; they came the field for a variety of reasons—from personal experience with the industry to previous work in a peripheral field such as mental health, to the general desire to help people to build their families and they sometimes look to other agencies not as models to emulate, but as an example of what not to do (something I term "reverse modeling"). Occasionally, agency decisionmakers model their decisions on the actions of other agencies, or come to a decision in consultation with other egg donor industry professionals, but this consensus-seeking behavior is the exception to the rule. I then show that, counterintuitively, all of this personal, "divergent" behavior leads to a convergence of values. I argue that because agency decision-makers' personal morality is embedded in a larger social and infertility industry context, personal values are in fact shared values, as evidenced by the overlapping standards that agency decision-makers establish for their own agencies. Furthermore, I argue that agency decision-makers' personal morality is also the source of a universally shared moral meaning among my interviewees: that their primary directive in running their businesses is to take care of their intended parent clients and egg donors in the process of helping intended parents to build their families.

While Chapter Three analyzed, in part, the standards that agency decision-makers set within their agencies, in an attempt to better their own, individual agencies, Chapter Four addresses how agency decision-makers would like their industry to be viewed

<sup>&</sup>lt;sup>33</sup> Dickenson, *Property in the Body*; Radin, *Contested Commodities*; Satz, "Markets in Women's Reproductive Labor," 107-131; Shultz, "Questioning Commodification," 1841.

<sup>&</sup>lt;sup>34</sup> Z.P. Nagy et al., "Clinical Evaluation of the First One Hundred Recipient Cycles Using Vitrified / Warmed Oocytes from a Cryo-Egg Bank and Comparison of Outcomes with Fresh Oocyte Donations," *Fertility and Sterility* 92, no. 3 (Sept. 2009): S70; The Practice Committee of the American Society for Reproductive Medicine and the Practice Committee of the Society for Assisted Reproductive Technology, "Mature Oocyte Cryopreservation: A Guideline," *Fertility and Sterility* 99, no. 1 (Jan. 2013): 37-43; Spar, *The Baby Business*, 61.

from the outside—their efforts at legitimacy. I first show the pressure brought to bear on the egg donor agency industry from the outside: by the media, by the market (represented by intended parents), and, indirectly, by other agencies that behave in an unethical (or even criminal) manner. I then look at the ways in which agency decision-makers respond to these pressures, primarily by diverting some of the medical profession's considerable legitimacy for themselves through deferral to clinic standards, criticism of clinics they deem to be behaving unethically, and maintaining close working relationships with reputable clinics. Agency decision-makers also attempt to establish legitimacy among their organizations as a group by trying to subvert the shame surrounding egg donation by encouraging disclosure to donor-conceived children and contact between egg donors and intended parents. I then argue that the strongest attempt to establish legitimacy for the field is the nascent professionalization effort currently underway in the form of the Society for Ethics in Egg Donation and Surrogacy (SEEDS), which is creating a set of best practices standards specific to egg donor agencies, and trying to build a consensus on those standards.<sup>35</sup>

In Chapter Five, I turn to feminist theory's first major issue with egg donation: commodification.<sup>36</sup> I show that the extreme market demand for egg donors raises some serious ethical concerns, and that agency decision-makers, for the most part, remain ambivalent about this aspect of their business. I argue that this ambivalence, which is, again, with reference to their personal morality, impacts the ways in which agency decision-makers structure their businesses. They try to ensure that donor compensation is for a donor's time and services, rather than for her eggs. Some agency decisionmakers structure their compensation such that egg donors with the same amount of experience receive the same compensation, rather than compensating based on genetic or other individual traits. They do their best to respect egg donor choices during the process of egg donation, thus according the egg donor full individual autonomy. Agency decision-makers also frame egg donation as a gift, which embeds the experience of commodification for both donor and intended parent into a more socially acceptable framework and makes the process feel more positive for everyone concerned. And finally, agency decision-makers go to some effort to humanize the parties to each other, and to create sympathy for egg donors from intended parents and vice versa. I conclude that agency decision-makers are ambivalent about the

<sup>&</sup>lt;sup>35</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>36</sup> Almeling, *Sex Cells*; Donna Dickenson, "Commodification of Human Tissue: Implications for Feminist and Development Ethics," *Developing World Bioethics* 2, no. 1 (2002): 55-63; Dickenson, *Property in the Body*; Lisa C. Ikemoto, "Eggs as Capital: Human Egg Procurement in the Fertility Industry and the Stem Cell Research Enterprise," *Signs* 34, no. 4 (2009): 763-781; Johnston, "Paying Egg Donors," 28-31; Radin, *Contested Commodities*; idem, "Market-Inalienability," 1849; Satz, "Markets in Women's Reproductive Labor," 107-131; Shultz, "Questioning Commodification," 1841.

commodification aspect of egg donation because first, payment for genetic traits implicates eugenics, and second, that the creation of a family via egg donation threatens traditional concepts of family and definitions of motherhood.<sup>37</sup> Ultimately, however, agency decision-makers proceed to run their agencies in good faith because despite the tricky ethical waters in which they swim, in their eyes, the end of building families more than justifies the uncertainties of the means.

Chapter Six examines the other major issue that feminist theory raises with egg donation: the possibility of exploitation of egg donors.<sup>38</sup> I show that a minority of my interviewees believe simply that exploitation is not an issue for egg donors; that in fact, it is an opportunity for empowerment through participation in the market. In that view, means of "protecting" egg donors, such as placing caps on compensation, are nothing more than patronizing. I then show that the majority of my interviewees believe that exploitation is a possibility, though not one they are especially concerned about. They take various steps to avoid it, such as ensuring donor maturity, using responsible recruiting methods, fully educating donors, protecting donor privacy, and seeing that donors receive competent medical treatment and legal representation. Some agency decision-makers also place caps on donor compensation to avoid the primary pitfall of exploitation: that a young woman would be so dazzled by a seemingly high compensation, agency decision-makers look to their own sense of morality in determining what protections, if any, to put in place for their egg donors.

In Chapter Seven, I recap my conclusion that in their relatively new organizations, practicing in a new field that implicates complex ethical issues, agency decision-makers look first to their personal morality when making decisions for their agencies. Because that personal morality is embedded in a larger infertility industry and social context, each person's idea of what's right greatly overlaps with the next, and in this way, individual agency decision-makers' moral decisions, actualized through their agencies, coalesce into a set of ethical group norms and a shared moral meaning. These shared

<sup>&</sup>lt;sup>37</sup> Eugenics is the idea that "the physical, mental, and behavioral qualities of the human race could be improved by suitable management and manipulation of its hereditary essence." Kevles, *In the Name of Eugenics*, ix. Egg donation threatens ideas of motherhood in a way that is completely new: "Never before in history has it been possible for a woman to give birth to an infant who is genetically unrelated to her. Never before has it been possible for a woman to be the genetic parent of living children to whom she has not given birth." Mundy, *Everything Conceivable*. Also, see discussion of the centrality of mothering to some feminist theorists in Naomi Cahn, "Birthing Relationships," *Wisconsin Women's Law Journal* 17 (2002): 163-198.

<sup>&</sup>lt;sup>38</sup> Radin, Contested Commodities; Mundy, Everything Conceivable; Shultz, "Questioning Commodification," 1841.

values suggest a new regulatory direction based on a mixed methods approach of minimal state oversight combined with heavy self-regulation. I conclude by sharing the many avenues of research on which I was unable to travel due to the particular constraints of this dissertation.

### **Definition of Terms**

The following is a set of brief definitions of terms which should clarify my use of these terms in the context of this dissertation. These definitions are not meant to be exhaustive, but rather to serve as guidance in interpreting my arguments.

### **Organizations**

*AAARTA/American Academy of Assisted Reproductive Technology Attorneys*:<sup>39</sup> The national professional organization for family formation attorneys. Membership requires conformity with AAARTA's ethical standards and significant practical experience.

*ABA/American Bar Association*: The national professional organization for attorneys. Parent organization for Family Law Section and Assisted Reproductive Technologies Committee.

*ASRM/American Society for Reproductive Medicine*:<sup>40</sup> The national professional organization of reproductive endocrinologists and other medical practitioners who treat infertility.

*Agency/Egg Donor Agency/Independent Egg Donor Agency*: An organization, not run by a medical clinic, that, for a fee paid by intended parents, 1) recruits and screens egg donors and 2) serves as a broker between egg donors and intended parents, facilitating matches between the two and overseeing the process of an egg donation IVF cycle.

*Clinic/Infertility Clinic*: A medical establishment in which people suffering from infertility seek treatment, typically from physicians with a specialty in reproductive endocrinology. I choose to use the term "infertility clinic," rather than "fertility clinic," because I believe it is more descriptive of the conditions the clinic treats.

<sup>&</sup>lt;sup>39</sup> American Academy of Assisted Reproductive Technology Attorneys (AAARTA), www.aaarta.org.

<sup>&</sup>lt;sup>40</sup> American Society for Reproductive Medicine (ASRM), www.asrm.org.

*Frozen Egg Bank*: An organization that performs donor egg retrievals and stores the cryopreserved eggs for sale to intended parents. Such organizations are typically affiliated with a clinic and often owned by physicians. Many of them recruit their own donors.

*In-House Programs/Clinic Programs*: An organization or program, housed within a medical infertility clinic (either affiliated with a clinic or run by a clinic), which recruits egg donors and matches them with intended parents for a fee in addition to the intended parents' / patients' medical costs.

*Search Service*: An organization, not an agency, that, for a fee, searches for an egg donor on behalf of an intended parent across many agencies' donor databases. May also provide other services, such as coordinating all the moving pieces of a donor egg IVF cycle (including appointments, medications, legal agreements, etc.) with the multiple organizations involved.

*SEEDS/The Society for Ethics in Egg Donation and Surrogacy*:<sup>41</sup> A nonprofit organization created by several egg donor agencies, whose mission is to establish best practices standards for agencies through consensus.

# <u>People</u>

*Agency Decision-Maker/Decision-Maker*: My agency interviewees; people who have decision-making authority at the agency in which they work (and which they often founded and/or run).

*Children/Donor-Conceived Children/Future Children/Created Children/Donor-Conceived Offspring*: A child created by means of a donor egg IVF cycle.

*Egg Donor*: A young woman who, typically for compensation, participates in an IVF cycle to have her ovaries stimulated with hormones and her eggs retrieved with the intention of giving those eggs to an intended parent (or to a frozen egg bank).

*Family Formation Attorney*: An attorney who, among other things, drafts agreements and other documents for people participating in collaborative ART arrangements. Such agreements can be between intended parents and a donor, between a donor and an

<sup>&</sup>lt;sup>41</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

agency, or between an agency and intended parents. They may also include specific agreements about, for example, the disposition of any leftover embryos.

*Genetic Counselor*: A person trained to help intended parents "understand and adapt to the medical psychological, and familial implications of genetic contributions to disease."<sup>42</sup> Genetic counselors utilize "interpretation of family and medical histories to assess the chance of disease occurrence of recurrence; education about inheritance, testing, management, prevention, resources and research; and counseling to promote informed choices and adaptation to the risk or condition."<sup>43</sup>

*Intended Parent / Recipient (Intended Mother, Intended Father)*: A person or partnered couple (married, domestic partners, or otherwise), who would like to have biological children but cannot do so via sexual intercourse. Reasons for the inability can include medical infertility, homosexuality, danger posed to the intended mother by pregnancy, and the desire not to pass on heritable genetic diseases. I typically use the term "intended parent," though some of my interviewees prefer "recipient."

*Mental Health Professional*: A person licensed to counsel others on mental health issues, typically a psychologist, social worker, or psychiatrist. Such counseling for egg donation can include evaluation of egg donors for qualifications to donate and counseling of egg donors and intended parents to ensure that they are aware of and have been prompted to think through all of the social and emotional implications of egg donation.

*Surrogate*: A woman who, typically for compensation, gestates a baby with the intention of giving the baby to an intended parent at birth. In *traditional surrogacy*, rarely practiced today, the surrogate is artificially inseminated and becomes pregnant with a baby genetically related to her. Most surrogacy arrangements today are *gestational surrogacy* arrangements, in which an embryo is created using eggs from the intended mother or an egg donor, and thus the resulting baby is not genetically related to the surrogate.

<sup>&</sup>lt;sup>42</sup> Amy Vance, M.S., CCC, "Do You Need Genetic Counseling?" *Resolve: For the Journey and Beyond* (Spring 2011), available from www.resolve.org/family-building-options/donor-options/do-you-need-genetic-counseling.html; Internet; Accessed 15 August 2014.

<sup>43</sup> Ibid.

# <u>Medical</u>

*ART/Assisted Reproductive Technology*: All medical means of helping people to conceive children, including, but not limited to: artificial insemination and intrauterine insemination, IVF, egg donation, and surrogacy.

*Collaborative ART/Third Party ART*: ART in which a person other than the intended parent(s) provides either gametes or a functional uterus to help bring a desired baby into being.

*Donor Egg IVF*: An IVF procedure in which eggs are retrieved from one woman's body (the donor), fertilized, and placed into another woman's uterus (the intended mother or a surrogate).

*Egg Donation*: The process by which an egg donor undergoes ovarian stimulation and egg retrieval and then gives the eggs to an intended parent. A clinic fertilizes the eggs and then transfers them into the uterus of the intended mother or a surrogate. The result, if successful, is a child not genetically related to the woman who gives birth (e.g., an intended mother may become pregnant with a child not genetically related to her; a surrogate may become pregnant with a child genetically related to the intended mother, but not the surrogate; or a surrogate may become pregnant with a child not genetically related to either the intended mother or the surrogate). I have chosen to follow the industry standard of using the term "donation," even though egg donors are typically compensated, because it is significant to the way in which decision-makers help to frame the industry, and to how the experience of egg donors and intended parents are contextualized to make them more positive.

*Egg/Oocyte*: Human eggs, also referred to as oocytes.

*Egg Retrieval*: The medical procedure in which mature eggs are, after ovarian stimulation, aspirated from ovarian follicles using a needle, typically through the vaginal walls.

*Embryo*: A fertilized egg, typically allowed to develop for three to five days before being transferred to a woman's uterus or frozen for future use.

*Fresh IVF Cycle*: An IVF cycle in which the transfer of an embryo to a woman's uterus happens three to five days after the egg retrieval, and in which the embryo is never frozen.

*Frozen Eggs*: Eggs that are frozen after retrieval and before in vitro fertilization using the relatively new technology of vitrification, or rapid cryopreservation. Eggs can then be thawed and fertilized, and transferred into a woman's uterus as in a regular IVF cycle.

*Frozen Egg IVF Cycle*: An IVF cycle performed with eggs that have been frozen after retrieval. Note the distinction from a "frozen embryo transfer," which involves a frozen embryo, not a frozen egg.

*Frozen Embryo Transfer*: An IVF cycle in which there is no ovarian stimulation; a previously frozen embryo is thawed and transferred to a woman's uterus.

*Gametes*: Sex cells: human eggs and sperm.

*Infertility*: The inability to conceive a child when desired, for medical reasons or functional reasons such as having a same-sex partner.

*IVF/In Vitro Fertilization*: The medical procedure in which eggs are retrieved from a woman and combined with sperm outside the body, left three to five days to fertilize and develop into embryos, and then placed into a woman's uterus in the hopes that they will implant in the uterine lining and she will become pregnant.

*IVF Cycle/Cycle*: One round of treatment with IVF, involving ovarian stimulation, egg retrieval, in vitro fertilization, and transfer of embryos to a woman's uterus. Typically takes about one to two months of active medical treatment.

*Ovarian Stimulation*: The medical process by which a woman takes prescription hormones to stimulate the development of ovarian follicles and the maturation of many eggs in preparation for egg retrieval.

# <u>Other</u>

*Donor Database*: A database, typically digital, compiled by an egg donor agency, listing their (typically available) egg donors, along with the donors' physical characteristics and any other "non-identifying" information collected by the agency. Usually protected by some sort of password system, intended parents are granted access to the database in order to choose a donor.

*Family Building*: In this dissertation, attempts by intended parents to have children.

*Geographic Classifications*: I categorized agency locations by primary United States Census geographic regions, namely West, Midwest, Northeast, and South.<sup>44</sup> I sometimes refer to the Northeast region as "East Coast."

#### **Research Methodology**

This dissertation draws on over six years of research on collaborative reproductive technology, including studies of bioethics, moral philosophy, feminist theory, and institutional change theory. As a lawyer and social scientist, my work combines legal analysis with qualitative research to reveal how egg donor agencies, organizations that are part of a field with significant bioethical implications and which function in an unregulated legal environment, create their own norms and moral meanings in the process of their everyday interactions with intended parents, egg donors, and other professionals in the infertility industry.

I chose to interview my informants because interviewing gives us access to the observations of others and the ability to learn about people's interior experiences.<sup>45</sup> It also gives us the ability to learn about settings that would otherwise be closed to us. I employed a semi-structured format to ask open-ended questions and sacrificed uniformity of questioning to achieve fuller development of information.<sup>46</sup> Semi-structured interviews are suitable for developing descriptions of process: how events occur, such as the daily decision-making that goes on in egg donor agencies.<sup>47</sup> They are also useful for getting "accurate accounts of the kinds of mental maps that people carry

<sup>&</sup>lt;sup>44</sup> United States Census Bureau, "Regions and Divisions," www.census.gov/history/www/programs/ geography/regions\_and\_divisions.html; Internet; Accessed 6 September 2014.

<sup>&</sup>lt;sup>45</sup> Robert S. Weiss, *Learning from Strangers: The Art and Method of Qualitative Interview Studies* (New York: The Free Press, 1994). According to Weiss, "If we have the right informants, we can learn … how organizations set their goals. Interviewing can inform us about the nature of social life." Ibid., 1.

<sup>&</sup>lt;sup>46</sup> See John Lofland et al., *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis* (Canada: Wadsworth, 2006). Semi-structured interviewing can "direct conversation without forcing the interviewee … to select reestablished responses.... [T]he goal is to elicit from the interviewee rich, detailed materials that can be used in qualitative analysis." Ibid., 17.

<sup>&</sup>lt;sup>47</sup> Weiss, *Learning from Strangers*, 9. We interview because we "want from our informants the fullest, most detailed description possible" and "qualitative interviews can elicit the processes antecedent to an outcome of interest."

around inside their heads."<sup>48</sup> These mental maps are important for the process of refining existing theory; as reviewed in the final section of this chapter, institutional change theory has given us insight into the ways in which organizations may develop norms, but it has little to tell us about how organizations behave in the absence of law, and even more so, how individuals create meaning for themselves within the context of organizations functioning in a thorny ethical field and simultaneously unregulated by law. Since my goal is to fill the gaps in our knowledge and refine existing theory to address such circumstances,<sup>49</sup> a qualitative approach is appropriate since it remains open to nuance that might be overlooked in the context of "canonical sociological research,"<sup>50</sup> which, rather than generating theory, proceeds from existing theoretical concepts and is therefore confined by their preexisting constructs and presumptions.

My field research consists of semi-structured telephone interviews conducted with people in positions of authority in independent egg donor agencies, primarily in California, in addition to several interviews with professionals in the field, including lawyers, reproductive endocrinologists, genetic counselors, and mental health professionals. My interviews were conducted in January through March of 2014. I obtained verbal consent both to interview the informant and to record our conversation. I recorded each interview, and after completing the interviews, I transcribed some of them myself and had the remainder transcribed by the company CS Administrative Services.<sup>51</sup> Each transcriber signed a nondisclosure agreement and agreed to destroy all audio, digital, and hard copy files after the completion of the transcription.<sup>52</sup> I then proofread all of the transcriptions, and edited them to compensate for the choppiness of spoken language. I eliminated most of the "um's," "you know's," "OK's," and "like's" typically found as gap fillers in conversations, without altering the speaker's substantive meaning. Similarly, in exchanges between the interviewee and myself, I omitted my own interjections of "OK," "yeah," "uh-huh," and "right," which I frequently used to indicate to the interviewee that I was listening. Finally, I edited the

<sup>&</sup>lt;sup>48</sup> Kristin Luker, *Salsa Dancing into the Social Sciences* (Cambridge and London: Harvard University Press, 2008), 167. Luker notes that we are not necessarily concerned with the absolute truth of what interviewees may tell us, but rather with why they choose to tell us what they do.

<sup>&</sup>lt;sup>49</sup> This refinement of theory is one aspect of Glaser and Strauss's grounded theory method, in which theory is discovered from the data, rather than vice versa. Barney G. Glaser and Anselm L. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (New Brunswick and London: Aldine Transaction, 1967).

<sup>&</sup>lt;sup>50</sup> Luker, Salsa Dancing.

<sup>&</sup>lt;sup>51</sup> CS Administrative Services, www.csadminservices.net/; Internet; Accessed 13 October 2014.

<sup>&</sup>lt;sup>52</sup> See Appendix V for copies of non-disclosure agreements.

interviews to eliminate real names or references to amounts of money or other practices that might lead to identification of the interviewee.

Due to the sensitive nature of many interviewees' comments, interviews were conducted on condition of confidentiality, in accordance with the requirements of my University of California, Berkeley Committee for the Protection of Human Subjects research protocol approval.<sup>53</sup> Quotes are attributed to the role of the interviewee as an egg donor agency decision-maker, unless noted otherwise, and reflect answers to questions regarding personal opinions about the ethical issues raised in their business, the best ways to address those issues, the manner in which their own agency functions and creates norms and meaning for itself, and the role the interviewee sees legal, professional, or market regulation playing in their business. For reasons of confidentiality, I refer to interviewees who hold the topmost position in their agencies (or, in larger agencies, one of the top executive positions) as "Director," though some in fact hold titles such as "President" or "CEO," and to interviewees who do not hold an executive position as "Case Manager." Quotations in the following chapters are drawn from twenty-three thirty-minute to two-plus-hour interviews with agency decisionmakers and infertility industry professionals. See the following section for a demographic overview of my interviewees and their agencies; I withhold further details about the nature of the specific people I interviewed for reasons of confidentiality, due to my relatively small sample size and the small world of the egg donor agency community. References to percentages or fractions of "my interviewees" comprise calculations based only on agency decision-maker respondents, and do not include responses from other professionals in the field.

My semi-structured interviews consisted of seven main topical themes. I typically began by asking for a narrative of how the interviewee came to work in the field, and moved on to questions about the agency and its charges from there:

1) *Decision-maker's background*: how they came to be in the field, how they set up their agency, whether it was difficult, and how long they've been in the field.

2) *Agency structure*: how the agency works, how it's changed, key organizations with which it interacts, whether it's incorporated or affiliated with a clinic, whether it gives or gets referrals from clinics, how much it charges for its services, how it maintains client privacy, whether it carries liability insurance, and whether the agency has any professional or ethical guidelines.

<sup>&</sup>lt;sup>53</sup> UC Berkeley Committee for the Protection of Human Subjects, cphs.berkeley.edu/ (protocol #2013-07-5498, effective Sept. 21, 2013 to September 20, 2016).

3) *Intended parent issues*: how intended parents discover the agency, what concerns the agency has about its clients, how clients treat donors, whether clients are screened in any way, whether the clients' age, marital status, sexual orientation, or financial situation matters, and what opinion interviewee holds on contact between clients and donors.

4) *Donor issues*: how donors are recruited and screened, how screening has changed since the agency started, how donors are educated about the donation process, how much they get paid, and whether the donors' motivations matter.

5) *Created children*: whether the agency is concerned about children created through donor egg IVF, whether they should be told their origins, whether they should be made aware of any half-siblings they might have, and whether it is good for children to have an open relationship with their donor.

6) *Narrative*: I asked for stories about situations that made the employee uncomfortable, stories about what they dread happening, stories about what makes them feel good doing what they do, what stories circulate at the office, and what practices they consider to be "bad."

7) *Decision-maker's general beliefs*: the source of their beliefs about ART, what they think about the donors and the intended parents, what they think are the key ethical and moral issues they confront, how it feels to be working in the field with very little social or moral guidance, whether the advent of technology to freeze eggs will change their role within the industry, whether they've ever been threatened with or heard about a lawsuit, whether and how professional guidelines affect their decisions, what the state of their knowledge is regarding the law on reproductive technology, and what regulations they'd like to see implemented or avoided, if any.

I concluded by asking whether I asked the right questions and whether there was anything that I had missed. In interviews with other field professionals, I used a version of this interview protocol modified appropriately for the particular interviewee; for example, I asked mental health professionals about donor screening, but did not ask them about agency fees.

I began by soliciting interviews in the San Francisco Bay Area. I reached out to the contact person on Bay Area egg donor agency websites, and then employed snowball sampling to identify additional interview candidates in Southern California and other parts of the country. In total I contacted thirty-eight independent agencies, three donor search services, and sixteen in-house egg donor programs. Two-thirds of my agency interviews took place with California agencies. Often referred to as the "wild west" of

the infertility industry, California is the birthplace of egg donor agencies, is governed by law friendly to collaborative reproduction arrangements, and boasts the highest concentration of agencies in the world.<sup>54</sup> As such, California agencies presumably have great freedom within which to establish their norms and greater potential to consult with one another in the development of those norms. The interview data I collected is not intended to be representative of all actors in egg donor agencies within California or in other parts of the country. Rather, I sought to solicit information reflecting different agency decision makers' concepts of the field and the role of legal, professional, and market regulation in the field in general and their business in particular.

After reaching a stage of theoretical saturation within California, at which point I was hearing similar comments repeatedly, I solicited further interviews in other parts of the country to ensure that what I had found in California was not at odds with the rest of the nation. These "confirmation interviews," conducted in locations with the greatest density of agencies (including Illinois, Texas, and Florida), proved to be in accordance with my findings in California in all parts of the country except the Northeast, and in fact many of my interviewees mentioned the differences between egg donation practices in the West and those of agencies in the Northeast. Therefore, I make no claims about regions other than California, but I found my coding schema developed using grounded theory method,<sup>55</sup> based on California agencies, to be adequate to describe my findings nationwide.

The vast majority of my interviewees hold the topmost business position in their agency, and more than two-thirds of them are the original founder of their agency. Those interviewees who do not hold the top position in their agency are still in a position to make independent decisions during the course of their day and to influence the trajectory of the overall business.

My sampling was limited by the nature of the interviewees who were willing to speak with me; I gave an overview of my areas of interest when soliciting interviews, and I suspect that only people who had given some thought to the issues I presented were responsive to my solicitation. Therefore, my study sample presumably reflects the "best" of the field—those agencies which have a lengthy and/or positive reputation

<sup>&</sup>lt;sup>54</sup> See Chapter Two, "State Statutes and Case Law on Egg Donation and Collaborative ART: California," for a discussion of the current state of the law on ART in California. See Appendix I for a visual representation of the state-by-state concentration of egg donor agencies.

<sup>&</sup>lt;sup>55</sup> Glaser and Strauss, *The Discovery of Grounded Theory*. Grounded theory is the process of discovering theory from data; Glaser and Strauss argue that the adequacy of a theory cannot be divorced from the process of producing it. I examined my data for its own merits, discovered categories that emerged organically, and organized this dissertation accordingly.

among their peers and which take responsibility for the potential ethical and legal pitfalls of their business. Agencies which have perpetrated fraud on their clients or engaged in other objectively unethical practices are not, I think, represented in my sample, nor were they likely to accede to a request to be interviewed about the role of regulation in their field.

I conducted a single brief interview with a representative of an in-house program. My solicitations to such programs were uniformly rejected, even when requested with reference to a prior (agency) interviewee. After speaking with interviewees at independent agencies, I sense that my lack of success with in-house programs may be in part because reproductive endocrinologists are typically in control of those programs, and physicians tend to be wary of sharing potentially prejudicial information with researchers, particularly when the researcher also happens to be an attorney. Tellingly, the few in-house program representatives who gave reasons for not acceding to my request for an interview cited the relevance of my research and their inability to speak openly about the issues I was investigating. They spoke to the importance of my research and its relationship with sensitive internal matters, saying things like:

I'm in a tight spot: I love what you're studying, but we're currently dealing with the issues that you've mentioned and I simply can't speak with you as a representative of my agency. (Director, Northern California In-House Program)

Finally, my research draws on content analysis of legal and other documents provided by my interviewees and of the websites of my interviewees' agencies, within the context of a thorough internet search to compile a comprehensive list of all agencies and inhouse programs with a web presence currently functioning in the United States.<sup>56</sup> My internet search for agencies and in-house programs consisted of searching for the term "egg donor" through thirty pages of Google search results. The last six pages yielded no new agencies or in-house programs. To double check, I also searched the first two pages of each of the following terms: "egg donation," "oocyte donor," "oocyte donation," "egg donor agency," and "oocyte donor agency." No new agencies or in-house programs were yielded through these additional searches. Comparison of my interviewees' agency websites gives insight into to what extent they are modeling their practices on one another, and into their public representations of their ideals.

<sup>&</sup>lt;sup>56</sup> See Appendix II for the compiled list of agencies and in-house programs.

## A Glimpse of the Interviewees and their Agencies

The single most striking characteristic of my agency decision-maker interviewees is that they are all women. The vast majority of egg donor agencies across the country are founded and run by women, with a few exceptions (and those exceptions tend to be larger, traditionally corporate organizations). Almost seventy percent of my interviewees founded their agencies, and almost ninety percent currently hold the topmost position in their organization. Twenty-five percent of my interviewees had personal experience in the industry as intended parents, and just over thirty percent had served as egg donors or surrogates prior to starting their agencies; over forty percent of my interviewees became involved in the industry with no personal experience of it. Fifty-six percent of my interviewees have some sort of professional credentials; their ranks include attorneys, nurses, and mental health professionals. Half of them are individual members of the American Society for Reproductive Medicine (ASRM).<sup>57</sup>

My interviewees' agency staff are also mostly women; I confirmed male staff members at twenty percent of the agencies. Ninety percent of my interviewees' agencies had ten or fewer staff members; half of those had five of fewer staff members. Sixty-two percent of my interviewees' agencies either had on staff or listed on their websites affiliations with specific mental health professionals; similarly, forty-four percent had nurses, thirty percent had attorneys, and thirteen percent had genetic counselors on staff or specific affiliations listed on their websites.

Only one of my interviewees' agencies has been in existence less than five years. Almost forty percent have been in existence between six and ten years; and another forty percent have been in existence for eleven to twenty-five years.<sup>58</sup> They charge between \$4500 and \$7500 for their services, with more charging at the middle and lower end of that spectrum. Most of them, though not all, have some sort of formal business structure: fifty-six percent of them are incorporated, while thirty-one percent are LLCs. While a few operate only locally, most of them work with intended parents and egg donors in other states, and even other countries.

<sup>&</sup>lt;sup>57</sup> The professional organization for health professionals in ART is the American Society for Reproductive Medicine (ASRM), www.asrm.org.

<sup>&</sup>lt;sup>58</sup> I did not discover the age of approximately twenty-five percent of the agencies at which I interviewed.

Less than twenty percent of my interviewees' agencies run or are affiliated with a frozen egg bank; however, eighty-five percent of them also serve as surrogacy agencies.<sup>59</sup> Some agencies run the two different services under one business roof; other agencies separate them into two sister businesses.

My interviewees do *not* include representatives of in-house programs (aside from the single interview mentioned previously, which I did not include in my data analysis in order to preserve the interviewee's confidentiality). Nor do they include representatives of the "run-out-of-the-garage" variety of egg donor agency mentioned by a number of my interviewees; I surmise that such people may be more likely to be engaging in unethical practices, and were therefore less likely to respond to my solicitations for an interview.

The women who did respond, and whom I interviewed, run and make decisions in agencies that are generally reputable, and often well known among their agency compatriots, even if they don't always agree with one another's practices. Therefore, while they are not necessarily representative of all agencies in California, much less in the United States, they provide a satisfactory illustration of the best the industry has to offer—a collection of organizations and individual decision-makers who are thinking well beyond the fastest way to make a buck.

#### **Theoretical Frame**

To the best of my knowledge, there are no studies on the self-regulation and decisionmaking processes of egg donor agencies. My effort to discover how the process of dayto-day decision-making occurs in the new and ethically uncertain field of egg donor agencies is embedded in two core literatures. Theories of institutional change in sociology provide a framework for understanding how decisions are made and how agencies may come to look like each other over time. Feminist legal theory provides an understanding of the central ethical issues involved in egg donation, including commodification of genetic material and women's reproductive labor, and the exploitation and empowerment of women. I use an "inhabited institutions" approach to fill a gap in the literature at the juncture of these fields: how individual decision-making is happening in egg donor agencies, and how the resulting organizational decisions and normative regulations are both affected by ethical issues and creating moral meaning in the process.

<sup>&</sup>lt;sup>59</sup> For combined egg donor/surrogacy agencies, I directed my questions with my focus on egg donation in mind.

#### Institutional Change

Egg donor agencies are a new kind of organization. They have sprung up as part of the vast and lucrative infertility industry, and like the rest of the industry, have gone essentially unregulated thus far. They are subject to standard business law, but as yet, they are not subject to any laws aimed at ensuring ethical and safe practices, or protection of the donors and the intended parents. Because of the sensitive nature of the agencies' business and the large amount of bad press the fertility industry has received, it is only a matter of time until regulation emerges.<sup>60</sup> What remains to be seen is the process by which that happens. Three diffusion model theories of institutional change—mimetic, coercive, and normative isomorphism—posit that regulation may emerge from above or laterally across the field.

#### **Diffusion Models**

Diffusion models explain how institutional change occurs across a field, at the interorganizational level, in such a way that organizations come to look like each other. Paul DiMaggio defines this isomorphism as "a constraining process that forces one unit in a population to resemble other units that face the same set of environmental

<sup>&</sup>lt;sup>60</sup> For examples of negative media coverage, see Ruha Benjamin, Ph.D., "Which Comes First: The Woman or Her Eggs?" Huffington Post Science, 17 April 2013, available from www.huffingtonpost.com/ruhabenjamin-phd/which-comes-first-the-woman-or-her-eggs\_b\_3018415.html; Internet; Accessed 8 September 2014; Marcy Darnovsky, Ph.D. and Susan Berke Fogel, J.D., "California Controversy: Let's Not Expand the Market in Women's Eggs," Huffington Post Los Angeles, 3 September 2013, available from www.huffingtonpost.com/marcy-darnovsky-phd/california-controversy-le\_b\_3861808.html; Internet; Accessed 8 September 2014; Jen Dziura, "Bullish Life: The Truth About Egg Donation," The Gloss, 3 January 2014, available from www.thegloss.com/2014/01/02/career/bullish-life-truth-egg-donation/; Internet; Accessed 8 September 2014; Justine Griffin, "The Cost of Life: My Experience as a First-Time Egg Donor," Huffington Post Women, 5 June 2014, available from www.huffingtonpost.com/justine-griffin/thecost-of-life-my-experience-as-a-first-time-egg-donor\_b\_5413036.html; Internet; Accessed 8 September 2014; Martha Irvine, Associated Press, "Increase in Egg Donors Raises Concerns," The Washington Post, 19 February 2007, available from www.washingtonpost.com/wp-dyn/content/article/2007/02/18/ AR2007021800536.html; Internet; Accessed 7 September 2014; "Inside the Lucrative Life of an Egg Donor," ABC News, 4 November 2013, available from abcnews.go.com/blogs/health/2013/11/04/inside-thelucrative-life-of-an-egg-donor/; Internet; Accessed 8 September 2014; Jenna Johnson, "Egg Prices at Top Universities," The Washington Post, 25 March 2010, available from voices.washingtonpost.com/campusoverload/2010/03/egg\_prices\_at\_top\_universities.html?wprss=campus-overload; Internet; Accessed 8 September 2014; Roni Caryn Rabin, "As Demand for Donor Eggs Soars, High Prices Stir Ethical Concerns," The New York Times, 15 May 2007, available from www.nytimes.com/2007/05/15/health/ 15cons.html; Internet; Accessed 8 September 2014; David Tuller, "Payment Offers to Egg Donors Prompt Scrutiny," The New York Times, 10 May 2010, available from www.nytimes.com/2010/05/11/health/ 11eggs.html; Internet; Accessed 8 September 2014.

conditions."<sup>61</sup> Institutional isomorphism, in particular, occurs where organizations compete not just for resources and customers, but also for political power and institutional legitimacy, for social as well as economic fitness.<sup>62</sup> In fact, the formal structures of many organizations reflect the "myths of their institutional environments instead of the demands of their work services."<sup>63</sup> Thus, institutional isomorphism is interinstitutional change—change that originates at the level of the organization.

DiMaggio and Powell describe three mechanisms by which isomorphic change may take place. *Mimetic isomorphism* is the result of standard responses to uncertainty.<sup>64</sup> Organizations model themselves on other organizations when their goals are ambiguous or "when the environment creates symbolic uncertainty"—and both the legal and ethical environments of egg donor agencies are far from certain.<sup>65</sup> Diffusion of ideas according to mimetic isomorphism may take place unintentionally, indirectly, or explicitly, and isomorphism results in part because there is relatively little variation in models throughout society.<sup>66</sup> This is certainly true of egg donor agency websites, many of which resemble each other in both structure and appearance. Mimetic isomorphism predicts that change is more likely to occur with greater uncertainty between means and ends, and with greater ambiguity of goals. In both cases, the organization will model itself after organizations it perceives as successful.<sup>67</sup> While it seems that egg donor agencies might take as their role models other agencies, or perhaps surrogacy or adoption agencies, in reality they rarely do so, preferring to look to agency decisionmakers' personal morality as a model. Still, mimetic isomorphism is perhaps the best theoretical fit for organizations that are "starting from scratch" in a new field with novel legal and ethical dilemmas; it seems likely that they would look outside their field to analogous organizations to model. I found that when functioning within a mimetic isomorphic framework, the agency decision-maker is focused inward, looking to the benefit of her individual agency.

<sup>&</sup>lt;sup>61</sup> DiMaggio and Powell, "The Iron Cage Revisited," 66.

<sup>62</sup> Ibid.

<sup>&</sup>lt;sup>63</sup> Meyer and Rowan, "Institutionalized Organizations," 41.

<sup>&</sup>lt;sup>64</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-70.

<sup>&</sup>lt;sup>65</sup> Ibid., 69. As already discussed, there is no law directly governing egg donor agencies, and more generally, there is a great deal of controversy over whether egg donation is an ethical practice at all, and if so, within what parameters it can ethically function.

<sup>&</sup>lt;sup>66</sup> DiMaggio and Powell, "The Iron Cage Revisited," 70.

<sup>67</sup> Ibid., 75.

The second mechanism of change is *coercive isomorphism*, which stems from political influence and the problem of legitimacy; organizations change in response to pressures that are exerted on them by other organizations on which they are dependent, and by the cultural expectations of society, including a common legal environment.<sup>68</sup> Egg donor agencies may tend toward isomorphism as a result of pressures from (largely negative) media attention or as a result of their dependence on fertility clinics to work with them in order to keep business going. It may be that a process of coercive isomorphism is occurring multidirectionally across the field of reproductive technology, and that egg donor agencies, clinics, lawyers, doctors, and psychologists are all shaping each other's practices. In contrast to the inward focus of the individual under mimetic isomorphism, when functioning within a coercive isomorphism framework, the agency decisionmaker is focused outward, on the perception of the agency by its intended audience (clients, donors, the media, the public, etc.).

Finally, normative isomorphism is associated with professionalization.<sup>69</sup>

Professionalization is the collective struggle of the members of an occupation "to define the conditions and methods of their work, to control 'the production of producers,' and to establish a cognitive base and legitimation for their occupational autonomy."<sup>70</sup> Isomorphism occurs as a result of professionalization because it spurs the growth of professional networks that "span organizations and across which new models diffuse more rapidly."<sup>71</sup> Normative isomorphism, like coercive isomorphism, is part of the attempt to control the field, and is also about a collective concern of the perception of the field to outsiders.

There is a nascent attempt at professionalization among the people who run egg donor agencies, though agency decision-makers do not so name it. The existence of professional associations for the larger infertility industry, however, as well as the interest of more general professional associations like the American Bar Association

<sup>&</sup>lt;sup>68</sup> Ibid., 67. Coercive isomorphism allows an explicit role for power; the people who are in a position to effect such pressures on organizations can, to some extent, guide isomorphic change. Coercive isomorphism also predicts that change is more likely to occur where an organization is heavily dependent on another organization, and where an organization's resource supply is centralized. Ibid., 74.

<sup>&</sup>lt;sup>69</sup> Ibid., 70; Magali Sarfatti Larson, *The Rise of Professionalism: A Sociological Analysis* (Berkeley, Los Angeles, and London: University of California Press, 1977), 49-52.

<sup>&</sup>lt;sup>70</sup> DiMaggio and Powell, "The Iron Cage Revisited," 70, quoting Larson, The Rise of Professionalism, 49-52.

<sup>&</sup>lt;sup>71</sup> DiMaggio and Powell, "The Iron Cage Revisited," 71. Additionally, organizational fields that employ a large professionally trained labor force will tend toward homogeneity as the organizations compete on the basis of status and offer the same benefits and services as their competitors (e.g., biglaw salaries). Ibid., 73. Filtering of personnel is critical for normative isomorphic change, including hiring within the industry, common promotion practices, and required academic credentials. Ibid., 71.

(ABA),<sup>72</sup> may be part of the push for egg donor agencies to adopt greater professionalization, thus encouraging normative isomorphism. In particular, professional guidelines issued by the ASRM and the ABA's Draft Model Act Governing Assisted Reproductive Technology Agencies may foster normative isomorphism.<sup>73</sup> On the other hand, normative isomorphism predicts that change is more likely the greater the reliance on academic credentials in choosing managerial personnel, and the greater the participation of managers in professional associations.<sup>74</sup> This would perhaps argue against isomorphism among egg donor agencies, or at least make change more likely as a result of coercive or mimetic, rather than normative, isomorphism.

DiMaggio and Powell posit that ideas move across fields, through pressures exerted on organizations by other organizations or by society at large, through modeling of other organizations in times of uncertainty, and through the filtering of personnel.<sup>75</sup> Conflict is not especially visible in any of these processes, which are imagined as smooth transitions from one organizational form to another.

<sup>74</sup> DiMaggio and Powell, "The Iron Cage Revisited," 75.

75 Ibid., 66-75.

<sup>&</sup>lt;sup>72</sup> The professional association for attorneys, which has sections and committees devoted to different areas of law, including ART. American Bar Association (ABA), www.americanbar.org.

<sup>&</sup>lt;sup>73</sup> For ASRM guidelines, see: The Practice Committee of the American Society for Reproductive Medicine and the Practice Committee of the Society for Assisted Reproductive Technology, "Recommendations for Gamete and Embryo Donation: A Committee Opinion," Fertility and Sterility 99, no. 1 (Jan. 2013): 47-62 (Replaces: The Practice Committee of the American Society for Reproductive Medicine and the Practice Committee of the Society for Assisted Reproductive Technology, "2008 Guidelines for Gamete and Embryo Donation: A Practice Committee Report," Fertility and Sterility 90, suppl. 3 (Nov. 2008): S30-S44) [general guidelines]; The Ethics Committee of the American Society for Reproductive Medicine, "Financial Compensation of Oocyte Donors," Fertility and Sterility 88, no. 2 (Aug. 2007): 305-309 [caps on donor compensation]; The Practice Committee of the American Society for Reproductive Medicine, "Repetitive Oocyte Donation," Fertility and Sterility 90, suppl. 3 (Nov. 2008): S194-S195 [limits on number of cycles per donor]; The Ethics Committee of the American Society for Reproductive Medicine, "Misconduct in Third-Party Assisted Reproduction: A Committee Opinion," Fertility and Sterility 101, no. 1 (Jan. 2014): 38 [on misconduct by donors or intended parents]; The Ethics Committee of the American Society for Reproductive Medicine, "Interests, Obligations, and Rights in Gamete Donation: A Committee Opinion," Fertility and Sterility 102, no. 3 (Sept. 2014): 675-681 (Replaces: Ethics Committee of the ASRM, "Interests, Obligations, and Rights of the Donor in Gamete Donation," Fertility and Sterility 91, no. 1 (Jan. 2009): 22-27) [on interests and rights of egg donors]; The Ethics Committee of the American Society for Reproductive Medicine, "Oocyte or Embryo Donation to Women of Advanced Age: A Committee Opinion," Fertility and Sterility 100, no. 2 (Aug. 2013): 337 [on older donor egg recipients]; and The Ethics Committee of the American Society for Reproductive Medicine, "Informing Offspring of Their Conception by Gamete or Embryo Donation: A Committee Opinion," Fertility and Sterility 100, no. 1 (July 2013): 45-49 [on disclosure to children]. See Appendix IV for the full text of the American Bar Association Model Act Governing Assisted Reproductive Technology Agencies (DRAFT October 2013). For normative isomorphism, see DiMaggio and Powell, "The Iron Cage Revisited," 75.

Other theorists argue that institutional change can result from contradictions with other organizations.<sup>76</sup> Institutions constrain the ends to which their own behavior is directed, and by virtue of their central logic, they also constrain the means by which those ends are achieved.<sup>77</sup> Institutional change occurs when there is a contradiction between institutions, and the outcome depends in part on "the nature of power and the institutionally specific rules by which resources are produced [or reproduced], allocated, and controlled."<sup>78</sup> This model allows for diffusion of ideas at the organizational level, but also takes into account the likelihood of conflict among organizations as part of that diffusion of ideas. In egg donor agencies, such a contradiction can occur in the manner in which donors are compensated; e.g., a flat rate for all donors versus a hierarchical pay scale based on genetic "merit." If one method is more lucrative, or on the other hand, comes to be seen as unethical and therefore normatively forbidden, egg donor agencies throughout the field might change their rules accordingly.

The idea of conflicting institutional logics can be applied to multiple levels as well—not simply conflict among egg donor agencies, or even among egg donor agencies and infertility clinics, but among these organizational institutions, medical professional bodies, and conceptual institutions such as the market and social moral belief systems. Egg donor agencies encounter these concrete and conceptional institutions, and must manage their conflicting logics, on a daily basis. Royston Greenwood et al posit that managing multiple institutional logics results in "institutional complexity."<sup>79</sup> Julie Battilana and Sylvia Dorado argue that such institutional complexity results in "hybrid organizations," which are organizations that "combine institutional logics in

<sup>&</sup>lt;sup>76</sup> Ronald L. Jepperson defines an institution in part as "a social pattern that reveals a particular reproduction process ... [institutions] owe their survival to relatively self-activating social processes." Ronald L. Jepperson, "Institutions, Institutional Effects, and Institutionalism," in *The New Institutionalism in Organizational Analysis*, eds. Walter W. Powell and Paul J. DiMaggio (Chicago and London: The University of Chicago Press, 1991), 145. Change is thus forced by blocking the activation of reproductive procedures or by thwarting the successful completion of reproductive procedures, thus modifying or destroying the institution. Roger Friedland and Robert R. Alford, in contrast, conceptualize society as comprised by several different institutional orders, each with a "central logic—a set of material practices and symbolic construction—which constitutes its organizing principles and which is available to organizations and individuals to elaborate." Roger Friedland and Robert R. Alford, "Bringing Society Back In: Symbols, Practices, and Institutional Contradictions," in *The New Institutionalism in Organizational Analysis*, eds. Walter W. Powell and Paul J. DiMaggio (Chicago and London: The University of Chicago Press, 1991), 248.

<sup>&</sup>lt;sup>77</sup> Friedland and Alford, "Bringing Society Back In," 251.

<sup>78</sup> Ibid., 253-254.

<sup>&</sup>lt;sup>79</sup> Greenwood et al., "Institutional Complexity," 317-371.

unprecedented ways."<sup>80</sup> In order to manage conflicting institutional logics, hybrid organizations must find a "common organizational identity" that balances the tension between their combined logics.<sup>81</sup> In their study on microfinance organizations, Battilana and Dorado find that organizations manage conflicting institutional logics by means of hiring and socializations policies. Management of conflicting institutional logics in egg donor agencies can manifest via policies for recruiting and protecting egg donors, as well as agency treatment of intended parents.

Anne-Claire Pache and Filipe Santos further develop the idea of the common organizational identity in hybrid organizations. They argue that, rather than decoupling institutional logics, or compromising, organizations "selectively couple intact elements prescribed by each logic."<sup>82</sup> This cherry-picking approach to managing conflicting institutional logics allows the organization to project legitimacy to outsiders without deception or negotiation. Particularly relevant to the case of egg donor agencies, Pache and Santos describe a "trojan horse" hybridization pattern, in which "organizations that entered the field with low legitimacy because of their embeddedness in the market logic strategically incorporated elements from the social logic in an attempt to gain legitimacy and acceptance."<sup>83</sup> Egg donor agencies would appear to fit this description well; they came into being in large part because their entrepreneurs spotted a market niche for egg donor brokers. In order to gain legitimacy, agency decision-makers employ many strategies, including framing egg donation as a gift—a socially acceptable transaction pulled from the social logic. Pache and Santos see this as manipulation of the templates provided by different logics in an attempt to gain acceptance.<sup>84</sup>

Given that regulation does not currently exist for egg donor agencies, a diffusion model seems an appropriate theory for explaining the emergence of regulation. Agencies would seem to be likely to look to each other for governance and ethical models, and so undergo isomorphic change. Agencies will be subject to coercive isomorphism as a result of the controversial nature of their business and the resulting social pressures from negative media coverage. This is already happening, as Rene Almeling points out in the context of how the transaction of egg donation is framed in the larger society: "Calling egg donation a gift and sperm donation a job is more than mere rhetoric; it

<sup>&</sup>lt;sup>80</sup> Battilana and Dorado, "Building Sustainable Hybrid Organizations," 1419-1440.

<sup>&</sup>lt;sup>81</sup> Ibid., 1420.

<sup>&</sup>lt;sup>82</sup> Pache and Santos, "Inside the Hybrid Organization," 972-1001.

<sup>&</sup>lt;sup>83</sup> Ibid., 972.

<sup>&</sup>lt;sup>84</sup> Ibid.

shapes organizational practices in multiple and varied ways."<sup>85</sup> Agencies will also likely be subject to mimetic isomorphism, as both their organizational technologies and their legal status are uncertain. Finally, the reproductive industry is a small world, and to the extent it is governed, that guidance comes from professional associations like ASRM and SART.<sup>86</sup> The existence of professional organizations, which members include physicians, psychologists, and lawyers, among others, might serve to filter the personnel hired in management positions in agencies, encouraging normative isomorphic change. Ultimately, diffusion models provide a very useful way to think about how egg donor agencies are functioning today, and how self-regulation will emerge.

This understanding of how agencies might come to look like one another, and how regulation might emerge, is enhanced by the concept of conflicting institutional logics, and its application to how egg donor agencies manage the conflicts between institutional logics such as those of agencies, infertility clinics, the economic market, and social moral values by picking and choosing elements of each logic in order to create a complete hybrid organization. All of these theories, however, focus on the organization without recognizing the contribution of individuals to organizational behavior and institutional logics.

### Inhabited Institutions

A major criticism of DiMaggio and Powell's diffusion models is that the only model they propose that allows a place for individual agency is coercive isomorphism. This lack is an effect of the historical dichotomy between structural constraints and individual agency; theorists have tended to focus either on organizational behavior, treating organizations as actors in themselves, or individual action.<sup>87</sup> Criticism of these theories of organizational behavior calls for a reconciliation between the theoretical old and new institutionalizes that would "provide a more balanced approach to the actionstructure duality."<sup>88</sup> Instead, according to Patricia Thornton, William Ocasio, and

<sup>&</sup>lt;sup>85</sup> Rene Almeling, "Gender and the Value of Bodily Goods: Commodification in Egg and Sperm Donation," *Law and Contemporary Problems* 72 (2009): 58. See also idem, *Sex Cells*.

<sup>&</sup>lt;sup>86</sup> American Society for Reproductive Medicine (ASRM), www.asrm.org; Society for Assisted Reproductive Technology, www.sart.org.

<sup>&</sup>lt;sup>87</sup> Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*, 18.

<sup>&</sup>lt;sup>88</sup> Hirsch and Lounsbury, "Ending the Family Quarrel," 406-418.

Michael Lounsbury, we must look at organizations on multiple levels of analysis, including "individual, organizational, field, and societal."<sup>89</sup>

A pioneering way of examining the effect of individual agency on organizations and vice versa is the "inhabited institutions" approach to theories of organizational behavior, as described by Tim Hallet and Marc J. Ventresca. This approach brings individual agency back into organizational sociology, which has been "decoupled" from its foundations in social interaction.<sup>90</sup> Institutions are made up of individuals, and thus, of social interactions. They are "composed of people who act, at times in concert and at times in conflict, within the confines of an immediate working context, and within a larger environment."<sup>91</sup> Institutions guide social interactions, but institutional meanings are constructed and moved forward by social interactions; institutions are "populated with people whose social interactions suffuse institutions with local force and significance."<sup>92</sup>

An inhabited institutions approach can be recognized by three "signposts": embeddedness of institutions and interaction; meanings local and immediate, broad and public; and a skeptical, inquiring attitude.<sup>93</sup> First, an institution cannot be removed from its social context. Recognizing the interaction of the institution with both the local context of the community and an extra-local context (perhaps in this case the popular conception of infertility treatment) links institutional and interactionist concerns.<sup>94</sup> Second, an inhabited institutions approach acknowledges that institutions do not exist apart from their constituent people, and that the interactions of those people give the institution its meaning.<sup>95</sup> Simultaneously, however, there are wider systems of meanings that "provide, authorize, and organize the elements of an on-going activity."<sup>96</sup> Individual people are both the "carriers" of institutional forces and the shapers of those forces. Finally, an inhabited institutions approach is skeptical of abstract, deductive

<sup>&</sup>lt;sup>89</sup> Thornton, Ocasio, and Lounsbury, Institutional Logics Perspective, 18.

<sup>&</sup>lt;sup>90</sup> The decoupling of institutions from social interactions is problematic because institutions become "reified abstractions," separate from the process of interpretation and modification through the very social interactions that makes institutions tick, and because social interaction creates meaning: "Institutions are not inert containers of meaning; rather they are 'inhabited' by people and their doings." Hallett and Ventresca, "Inhabited Institutions," 215.

<sup>&</sup>lt;sup>91</sup> Ibid., 213.

<sup>92</sup> Ibid.

<sup>93</sup> Ibid., 226.

<sup>&</sup>lt;sup>94</sup> Ibid.

<sup>95</sup> Ibid.

<sup>&</sup>lt;sup>96</sup> Ibid., 227.

models of institutional operations that may or may not reflect empirical reality. "It is an approach that observes how people act, in situ, in the real world."<sup>97</sup>

Amy Binder defines organizations in terms of the people by whom they are constituted: organizations are "places where people and groups make sense of, and interpret, institutional vocabularies of motive."<sup>98</sup> Binder found, in her case study of a transitional housing organization, that individual department members creatively used local meanings based on their personal interests and interactional, on-the-ground decision-making in order to avoid increasing bureaucracy in their organization.<sup>99</sup> In many ways, the case of egg donor agencies is the opposite of Binder's case study; where her organization was funded and regulated by the government, eggs donor agencies are neither. Yet the organizations are both shaped by their individual members' personal interests and on-the-ground decision-making. Binder's concept of organizations as comprised of people provides a map for "how human agency is integrated into organizational dynamics."<sup>100</sup>

Binder shares other theorists' criticism of new institutionalism, which theory emphasizes "organizations' ceremonial adherence to scripts as they stake claims for legitimacy," arguing that the theory falls short in accounting for "the human creativity that goes into determining what, precisely, the environment actually does demand, and how people go about squaring those demands with their own local meaning systems, personal commitments, and professional obligations."<sup>101</sup> Binder calls for an inhabited institutional scripts, but rather strategically adopt and create practices that satisfy multiple institutional demands, and do so in interaction with other individuals.<sup>102</sup> Or, as Binder puts it, "Logics are not purely top-down: real people, in real contexts, with consequential past experiences of their own, play with them, question them, combine them with institutional logics from other domains, take what they can use from them, and make them fit their needs."<sup>103</sup>

<sup>103</sup> Ibid.

<sup>97</sup> Ibid., 229.

<sup>&</sup>lt;sup>98</sup> Binder, "For Love and Money," 547. In Binder's case study of a transitional housing organization, the external environment is federal funding; new institutionalism would predict that increasing federal funding would similarly increase bureaucracy, but in fact, Binder found that individual department members employed creative uses of institutional logics to avoid bureaucracy.

<sup>99</sup> Ibid.

<sup>100</sup> Ibid.

<sup>&</sup>lt;sup>101</sup> Ibid.

<sup>&</sup>lt;sup>102</sup> Ibid.

Similarly, Thornton, Ocasio, and Lounsbury propose an institutional logics perspective to explain the relationship between structure and agency.<sup>104</sup> They claim that the first institutional logics perspective was described by Friedland and Alford at the same time as DiMaggio and Powell's institutional change theory. Thornton, Ocasio, and Lounsbury argue that an institutional logics perspective transforms institutional theory and is distinct from neoinstitutional theory. Instead, institutional logics perspective is "a metatheoretical framework for analyzing the interrelationships among institutions, imdividuals, and organizations in social systems."<sup>105</sup> Thornton, Ocasio, and Lounsbury claim that both individuals and organizations are aware of different institutional logics at work, including cultural norms, symbols, and institutional practices, and incorporate those logics into their thoughts, beliefs, and decision-making. The core premise of an institutional logics perspective, according to Thornton, Ocasio, and Lounsbury, is that "the interests, identities, values, and assumptions of individuals and organizations are embedded within prevailing institutional logics."<sup>106</sup>

Many institutional logics perspective theorists focus on how daily on-the-ground decision-making can result in organizational change. Michael Smets, Tim Morris, and Royston Greenwood describe practice-driven institutional change, or "change that originates in the everyday work of individuals, but results in a shift in field-level logic."<sup>107</sup> They find mechanisms by which change emerges from everyday work, becomes justified, and diffuses within the organization and field, thus providing a space for individual agency within institutional theory. Similarly, M. Scully and A. Segal find that the individual actions of activist employees in a high tech firm can cause "piecemeal change" in the organization: "Forces of disruption exist alongside forces of reproduction [Jepperson's definition of an insitution] and may come unexpectedly from surprising quarters in ways that cannot be predicted."<sup>108</sup>

Two other theorists address institutional logics relevant to egg donor agencies. W. Richard Scott finds that professions "have leading roles in the creating and tending of institutions."<sup>109</sup> Professions can work on institutions in variable ways, including

<sup>&</sup>lt;sup>104</sup> Thornton, Ocasio, and Lounsbury, Institutional Logics Perspective, 18.

<sup>&</sup>lt;sup>105</sup> Ibid., 2.

<sup>&</sup>lt;sup>106</sup> Ibid.

<sup>&</sup>lt;sup>107</sup> Smets, Morris, and Greenwood, "From Practice to Field," 877.

<sup>&</sup>lt;sup>108</sup> M. Scully and A. Segal, "Passion with an Umbrella: Grassroots Activists in the Workplace," in *Social Structure and Organizations Revisited*, eds. M. Lounsbury and M.J. Ventresca (Oxford: Elsevier, 2002), 19: 161.

<sup>&</sup>lt;sup>109</sup> W. Richard Scott, "Lords of the Dance: Professionals as Institutional Agents," *Organization Studies* 29, no. 2 (Feb. 2008): 219.

devising "normative prescriptions to guide behavior."<sup>110</sup> While egg donor agencies do not have their own profession as yet, such a body is in the works, and its purpose is explicit: to create normative prescriptions to guide behavior. And Cheris Shun-ching Chan looks at two conceptions of culture—as shared meaning and as a repertoire of strategies—to understand the emergence of the market for life insurance in China in the face of "incompatible shared values and ideas acting as cultural barriers."<sup>111</sup> Culture, a powerful institutional logic, shapes the development of the market for Chinese life insurance. Similarly, culture dramatically affects the development of the market for egg donor agencies; agency decision-makers are influenced by social conceptions of the morality of egg donation, as I will show.

I use an inhabited institutions approach to bridge the divide between the macro organization-level focus of theories of institutional change and the micro focus on the individual agent and subject of feminist legal theory. "Institutions are not inert cultural logics or representations; they are populated by people whose social interactions suffuse institutions with force and local meaning."112 Similarly, an institutional logics perspective helps to combine the diffusion models of organizational change with an inhabited institutions approach to seeing the individual agency within organizations. These theories are important for examining the behavior of egg donor agencies because the individuals who run them, all women, are—for the most part—embedded in the same social world, the same culture, and the same field. These common institutional logics drive the decision-making of agency directors, and, in turn, shapes the field of egg donor agencies. Yet cultural differences, such as are found on the East Coast, result in differing agency practices and structures. Thus it is in the context of these theories that acknowledge the role of the individual in organizational behavior that I examine how the interactions and behavior of egg donor agency workers suffuse their organizations with meaning, moral meaning in particular.

#### Feminist Legal Theory

Feminist legal theory addresses the ethical concerns of egg donation: commodification of genetic material and women's reproductive labor; exploitation and the empowerment of women; and the implications of egg donation for what it means to be human. Egg donor agencies typically facilitate an arrangement between an egg donor

<sup>&</sup>lt;sup>110</sup> Ibid.

<sup>&</sup>lt;sup>111</sup> Cheris Shun-ching Chan, "Creating a Market in the Presence of Cultural Resistance: The Case of Life Insurance in China," *Theory and Society* 38, no. 3 (May 2009): 271.

<sup>&</sup>lt;sup>112</sup> Hallett and Ventresca, "Inhabited Institutions," 226.

and an intended parent in which the donor provides eggs and the intended parent compensates the young woman, ostensibly for her time, the risks she takes, and her experience of pain and suffering. Whether this is a "donation" or a "sale" is a matter of rhetoric thus far, but the general understanding by the ASRM is that the compensation is for the donor's effort and risks, and not for the eggs themselves.<sup>113</sup> This is to some extent borne out by the fact that donors who complete an egg retrieval cycle are typically compensated regardless of whether any eggs are actually retrieved, whether they fertilize, or whether the recipient becomes pregnant. Either way, however, it is commodification: of genetic material on the one hand, and of reproductive services on the other.

#### Commodification of Genetic Material and Women's Reproductive Labor

Egg donation, and by extension, egg donor agencies, implicates the meaning of our humanity. Baby-selling has long been prohibited in the United States, as well as in most other cultures, and because egg donation via an agency involves the sale of eggs (or at least something that looks like the sale of eggs)—which are intended to develop into a baby—egg donation bears too striking a resemblance to the sale of babies for some theorists.<sup>114</sup>

Feminist theory is concerned with the sanctity of life, though it has two, rather opposite, takes on that illustrious goal. The first is enabling infertile (or single or gay/lesbian) people to have children.<sup>115</sup> This good should not be minimized, as it is a "biological imperative" to reproduce, and the despair that many people feel over the inability to do so, and the extremes to which people are willing to go to have children, is documented across history (e.g., the biblical story of Sarah and Abraham, not to mention the countless American Catholics who ignore the Church's edicts and use IVF or egg

<sup>&</sup>lt;sup>113</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305-309.

<sup>&</sup>lt;sup>114</sup> "By statute or case law, all states decry 'baby-selling' and most prohibit the payment of 'finders fees' to agencies, lawyers, or unlicensed intermediaries." Joan Heifetz Hollinger, "State and Federal Adoption Laws," in *Families by Law: An Adoption Reader*, eds. Naomi R. Cahn and Joan Heifetz Hollinger (New York and London: New York University Press, 2004), 41. For a feminist take on baby-selling, see Radin, "Market-Inalienability," 1927.

<sup>&</sup>lt;sup>115</sup> While there is no dominant feminist view on adoption, "some feminists have made the experience of mothering central to their theories, developing a jurisprudence that could be termed 'biological feminism.... By contrast, other conceptions of feminism focus instead on context and relationship, and on gendered rather than merely biological differences." Naomi R. Cahn and Joan Heifetz Hollinger, eds., *Families by Law: An Adoption Reader* (New York and London: New York University Press, 2004), 257.

donation to conceive their children).<sup>116</sup> Egg donor agencies have served as a medium through which many people otherwise unable to have children enjoy the opportunity to have a child who shares one of the parents' genetic makeup, as well as the opportunity for the mother to experience pregnancy and childbirth. Some feminist theorists sees motherhood as a powerful, important part of the experience of being a woman, and egg donor agencies can play a role in achieving that experience.<sup>117</sup>

The counter to this good is a concern with the commodification of genetic material and of women's reproductive labor. Using technology to assist reproduction places into controversy a number of our most central beliefs about family, parenthood, and the extent to which we ought to intervene in decision-making about things as fundamental as genetic makeup. Many feminist authors believe that ART procedures are bad for women.<sup>118</sup> One of the major complaints against reproductive technology is that it commodifies the cells and biological processes that are involved in reproduction, and that that is unethical in itself.<sup>119</sup>

Feminist theorist Donna Dickenson argues that the distinction between persons and things, which has its origins with Kant, is at the core of the problem of commodification of human tissues.<sup>120</sup> Property law posits that only objects—not persons—can be regulated by property-holding.<sup>121</sup> Consequently, "to the extent that persons' body parts can be regulated by property-holding, those body parts are objects, or things. If we are embodied persons, then to some extent we become objects too. The question is to what extent."<sup>122</sup>

<sup>&</sup>lt;sup>116</sup> As Linda J. Lacey clarifies, "The urge to have children is very complex and not limited to a desire to see one's genetic makeup reflected in a child." Linda J. Lacey, "'O Wind, Remind Him That I Have No Child': Infertility and Feminist Jurisprudence," in *Families by Law: An Adoption Reader*, eds. Naomi R. Cahn and Joan Heifetz Hollinger (New York and London: New York University Press, 2004), 274.

<sup>&</sup>lt;sup>117</sup> For a feminist perspective on the power of motherhood, see Ann Oakley, *Becoming a Mother* (Schocken Books, 1979).

<sup>&</sup>lt;sup>118</sup> Lacey, "'Remind Him That I Have No Child," 274.

<sup>&</sup>lt;sup>119</sup> See, e.g., The Ethics Committee of the American Society for Reproductive Medicine, "Financial Incentives in Recruitment of Oocyte Donors," *Fertility and Sterility* 82, no. 1 (2004): S240-S244.

<sup>&</sup>lt;sup>120</sup> Dickenson, "Commodification of Human Tissue;" idem, *Property in the Body*. For the philosophical basis of the distinction of the moral worth of people versus objects, see Immanual Kant, *Groundwork of the Metaphysics of Morals* (1785) and *The Metaphysics of Morals* (1797).

<sup>&</sup>lt;sup>121</sup> Dickenson, Property in the Body, 4-5.

<sup>122</sup> Ibid.

Traditional doctrine in law is that "tissues and organs, once taken from the body, are res *nullius*, no one's property," and the effect of the California Supreme Court's decision in *Moore v. Regents of the University of California* in 1990 was to confirm this doctrine.<sup>123</sup> Dickenson suggests, however, that the Court's approach in *Moore* was misguided because the court focused on informed consent as a means of transferring property and assumed that property rights are an all or nothing concept.<sup>124</sup> Instead, she looks to the concept of property rights as a "bundle of rights," which can be activated or withheld according to the particular legal situation.<sup>125</sup> Rather than denying Moore all property rights to his tissue, Dickenson argues that a more integrated approach would have been for the court to grant Moore a right to the management of his tissue, a right to security against its being taken by others, and a right to transmit it to others by gift; but to deny a right to the income that can be derived from its use by others, a right to its capital value, and a right to transmit it to others by sale.<sup>126</sup> Such an approach would have the advantage of respect for the dignity and personhood of the patient without concern for the "chilling" effect on research of the patient's total control over his tissues. Along the same lines, Lisa Ikemoto argues that a result of the *Moore* decision was the normative effect of shifting the focus in the biotechnology as well as the fertility industry from property rights to how the transfer occurs.<sup>127</sup> The outcome of *Moore* and subsequent cases means that "the question of whether anyone can own human tissue is no longer regarded as an ethical issue."128

Thus the commodification of the body threatens to reduce persons to the condition of objects; in Dickenson's view, commodification of the parts of our body threatens our very humanity.<sup>129</sup> The commodification of human eggs is even more problematic because it applies only to women, and thus implicates broader gender inequalities.<sup>130</sup>

<sup>&</sup>lt;sup>123</sup> Moore v. Regents of the University of California, 793 P.2d 479 (1990); Dickenson, "Commodification of Human Tissue," 57.

<sup>&</sup>lt;sup>124</sup> Dickenson, Property in the Body, 14.

<sup>&</sup>lt;sup>125</sup> Ibid.

<sup>&</sup>lt;sup>126</sup> Ibid.

<sup>&</sup>lt;sup>127</sup> Ikemoto, "Eggs as Capital," 779.

<sup>&</sup>lt;sup>128</sup> Ibid.

<sup>&</sup>lt;sup>129</sup> Dickenson, Property in the Body, 4-5.

<sup>&</sup>lt;sup>130</sup> Ibid., 9-10.

Margaret Radin is another leading scholar on the commodification of things human.<sup>131</sup> She defines commodification as 1) objectification, or the possibility of being alienated from personhood; 2) fungibility; 3) commensurable valuation, i.e., the worth of a commodity can be scaled in comparison with that of another commodity; and 4) capacity to be valued in monetary terms.<sup>132</sup> Radin argues that persons and community should be central in our world, and that some things simply should not be commodified because they are intricately entwined with personhood or "human flourishing."<sup>133</sup>

Radin argues that in an ideal world, all things related to sexuality would be marketinalienable, which she defines as "nonsalability, a species of inalienability . . . . "<sup>134</sup> Yet we don't live in an ideal world, and some things cannot be made market-inalienable. For example, prostitution is something that cannot be made completely marketinalienable because doing so would harm the personhood of the prostitutes.<sup>135</sup> Her solution is to decriminalize prostitution, but to prohibit an organized market, including brokerage and advertising.<sup>136</sup>

Although prostitution cannot be made completely inalienable, Radin argues that there are elements of sexuality that should be: baby-selling, and, possibly, surrogacy.<sup>137</sup> Baby-selling is the simple case, because "conceiving of any child in market rhetoric wrongs personhood," and that this is something we all intuitively understand.<sup>138</sup> Radin's concern with surrogacy is that it is unclear what is being purchased; if the resulting baby is the commodity, then surrogacy is tantamount to baby-selling and should be prohibited.<sup>139</sup>

If, however, payment is for the "gestational services" of the surrogate (or, presumably, the egg production services of a donor), then it is more in line with prostitution. Like prostitution, surrogacy involves the problem of making available to poor women an

<sup>135</sup> Ibid.

<sup>136</sup> Ibid.

- <sup>138</sup> Ibid., 1927.
- <sup>139</sup> Ibid.

<sup>&</sup>lt;sup>131</sup> See Radin, Contested Commodities; idem, "Market-Inalienability," 1849.

<sup>&</sup>lt;sup>132</sup> Radin, Contested Commodities, 118-120.

<sup>&</sup>lt;sup>133</sup> Radin, "Market-Inalienability," 1851-1852.

<sup>&</sup>lt;sup>134</sup> Ibid., 1850.

<sup>&</sup>lt;sup>137</sup> Ibid., 1935.

option that they might find degrading, yet preferable to other options.<sup>140</sup> Radin suggests that the solution in our nonideal world is to allow only unpaid surrogacy.<sup>141</sup> This would protect us from most of the risks of commodification. Radin also posits that we might allow an incomplete commodification of surrogacy, with rules similar to those of adoption.<sup>142</sup>

The concept of incomplete commodification is more difficult for surrogacy than for prostitution, however; we need to put in place rules that protect the personhood of the child. Additionally, "[t]he potential for commodification of women is deeper, because, as with commissioned adoption, we risk conceiving of all of women's personal attributes in market rhetoric, and because paid surrogacy within current gender structure may symbolize that women are fungible baby-makers for men whose seed must be carried on."<sup>143</sup>

Debra Satz also sees a problem with paid surrogacy within our current gender structure; in fact, she argues that is *the* problem with markets in women's reproductive labor.<sup>144</sup> Unlike Radin, Satz does not see a distinction between women's reproductive labor and human labor generally, and consequently she rejects the "asymmetry thesis"—the belief that markets in women's reproductive labor are more problematic than other currently accepted labor markets.<sup>145</sup> Instead, Satz's argument against surrogacy "centers on the hypothesis that in our society such contracts will turn women's labor into something that is used and controlled by others and will reinforce gender stereotypes that have been used to justify the unequal treatment of women."<sup>146</sup>

Marjorie Shultz, in contrast, does not see an inherent problem with markets in women's reproductive labor and reproductive tissue.<sup>147</sup> As she points out, Radin's view on commodification is polarized: she imagines a directly inverse relationship between commodification and human flourishing. Shultz, in contrast, recognizes the possibility, or even the necessity, for the two to coexist: "A job might provide deep personal

<sup>140</sup> Ibid., 1934.

<sup>141</sup> Ibid.

<sup>&</sup>lt;sup>142</sup> Ibid. For example, a surrogate should be able to keep the baby if she changes her mind after birth and she should be able to choose abortion if she changes her mind before birth.

<sup>&</sup>lt;sup>143</sup> Ibid., 1935.

<sup>&</sup>lt;sup>144</sup> Satz, "Markets in Women's Reproductive Labor," 107-131.

<sup>&</sup>lt;sup>145</sup> Ibid., 110-115.

<sup>146</sup> Ibid., 123-124.

<sup>&</sup>lt;sup>147</sup> Shultz, "Questioning Commodification," 1841.

satisfaction to an individual and still be understood as something that should bring a good salary; can be replaced by some other, roughly similar job; and can be departed from without fundamental damage to the self."<sup>148</sup> Joan Williams takes it a step further (in the context of intimate relationships rather than reproductive labor): she claims that Radin ignores that "women's key problem has been too little commodification, not too much."<sup>149</sup>

Rene Almeling argues for a more nuanced vision of commodification.<sup>150</sup> In her work with egg donor agencies and sperm banks, she has found that the way in which the market for gametes is framed deeply impacts how the gamete donors experience commodification.<sup>151</sup> She found that egg donor agencies treat their donors as altruistic agents giving a "precious" gift to their intended parents. There is a direct link from donor to recipient—the donor knows that she is undergoing an IVF cycle in order to produce eggs for a particular person or couple, who often send gifts or thank-you notes to the donor at the conclusion of the cycle—and donors are paid regardless of the outcome of the cycle.<sup>152</sup> At sperm banks, in contrast, sperm donors are treated as though they are doing a job. There is no rhetoric about the gift the donor is providing to intended parents, and donations are banked for future use by people of whom the sperm donor has no knowledge.<sup>153</sup> Sperm donors are paid only for viable samples, for getting the job done. "[I]n the market for sex cells... a woman's donation is considered a precious gift and a man's donation a job well done."<sup>154</sup> Almeling argues that this gendered framing of the market for gametes affects women's and men's experiences of paid donation.<sup>155</sup> Although both men and women are typically attracted to the market by the financial incentives, during the process egg donors reframe their participation as an altruistic and valuable gift to the intended parents, which feels morally good. Men, in contrast, feel that they are simply "assets" or "resources" for the sperm bank, which often leads to feelings of discontent. In the market for gametes, the way the market is

<sup>153</sup> Ibid., 10-11.

154 Ibid., 166.

155 Ibid., 15.

<sup>148</sup> Ibid., 1850.

<sup>&</sup>lt;sup>149</sup> Viviana Zelizer, *The Purchase of Intimacy* (Princeton: Princeton University Press, 2005), 18.

<sup>&</sup>lt;sup>150</sup> Almeling, *Sex Cells*; idem, "Gender and the Value of Bodily Goods," 37-58; idem, "Selling Genes, Selling Gender," 319-340.

<sup>&</sup>lt;sup>151</sup> Almeling, *Sex Cells*; idem, "Gender and the Value of Bodily Goods," 37-58; idem, "Selling Genes, Selling Gender," 319-340.

<sup>&</sup>lt;sup>152</sup> "Women who complete a cycle are paid regardless of how many eggs they produce." Almeling, *Sex Cells*, 68.

framed makes the experience of commodification a largely positive one for women and a negative one for men. Almeling argues that although scholarship on commodification has focused solely on the monetary exchange, it is in fact the "underlying activity," and all the other factors that go into making a market—who is doing the buying and selling, what is being bought and sold, how the exchange is organized, and how the participants experience it— ...[that] *do* matter."<sup>156</sup>

Because Dickenson and Radin see any commodification of our bodies as an inherent "bad," and Satz sees markets in women's reproductive labor as intractably problematic, they would likely recommend that egg donation, and thus, presumably, egg donor agencies, be outlawed altogether.<sup>157</sup> A compromise position that takes into account the realities of the world might mirror Radin's suggestion for prostitution: allow egg donation, but prohibit an organized market, which would again outlaw egg donor agencies. The feminist anti-commodification position leaves little room for egg donor agencies to exist at all. But Shultz's and Williams' arguments, that women can sell their reproductive and intimate labor without damaging their personhood, and in fact that such a practice may lead to greater equality with men, leaves a role for egg donor agencies.<sup>158</sup> Almeling takes this opening a step further, with the concept that the experience of commodification is entirely dependent on the organization of the market and other underlying activity, rather than the fact of a monetary exchange.<sup>159</sup> With concerns about commodification in mind, agencies might be regulated such that they promote the payment of women for their services, rather than payment for their eggs or genetic makeup, to the extent that is possible. The goal is to diminish the "bad" of commodification and maximize the "good" of empowering women in the marketplace and enabling infertile (and other) people to have children.

#### Exploitation and Empowerment of Women

When it comes to the question of what reproductive technologies do for gender equality, once again feminists have two very different takes. The basic disagreement is over whether practices like egg donation empower women to participate in the market

<sup>&</sup>lt;sup>156</sup> Ibid., 168.

<sup>&</sup>lt;sup>157</sup> Dickenson, *Property in the Body*; Radin, *Contested Commodities*; Satz, "Markets in Women's Reproductive Labor," 107-131.

<sup>&</sup>lt;sup>158</sup> Johnston, "Paying Egg Donors," 28-31; Shultz, "Questioning Commodification," 1841; Williams, *Unbending Gender*.

<sup>&</sup>lt;sup>159</sup> Almeling, Sex Cells, 168.

and take advantage of their reproductive capacity in the same way that they use their other attributes in life, or whether egg donation is too exploitative to be permitted.

Marjorie Shultz argues that women should be allowed to participate in markets for reproductive tissue and services; the coexistence of commodification and personhood can become particularly important in the context of gender subordination.<sup>160</sup> Women have historically been prohibited from participating in the public/market sphere, and enabling women to use their reproductive capacities may help them to establish market equality with men.<sup>161</sup>

Indeed, Rene Almeling finds that women are at an advantage in the market for reproductive material.<sup>162</sup> She takes commodification as a starting point and asks how the "social process of bodily commodification varies based on sex and gender."<sup>163</sup> She finds, to her surprise, that categories of people who have traditionally been subordinated have a great deal of value in the market for reproductive tissue. Women are paid more for their eggs than men are for their sperm, both because eggs are a scarcer resource *and* because women have more cultural validation for their donation based on "gendered stereotypes about caring motherhood and distant fatherhood."<sup>164</sup> Furthermore, egg donor agencies play a role in increasing the value of donations from women of color, and sperm banks for men of color, because people from these populations are harder to recruit, and therefore can command a higher price.<sup>165</sup> Almeling concludes that abstract distinctions between commodity and gift, and market and family, no longer make sense. "Instead, the commodification of the human body can be expected to vary based on the sex and gender of that body, as economic valuations intertwine with cultural norms in specific structural contexts."<sup>166</sup>

In addition to empowering donors by allowing women to participate more fully in the public sphere, egg donation can empower intended parents as well. Anti-subordination feminists tout egg donation for older women as a tool to make women more like men (who can typically become parents at a later age than women), and therefore a "good

<sup>&</sup>lt;sup>160</sup> Shultz, "Questioning Commodification," 1851.

<sup>&</sup>lt;sup>161</sup> Ibid.

<sup>&</sup>lt;sup>162</sup> Almeling, Sex Cells, 69.

<sup>&</sup>lt;sup>163</sup> Almeling, "Selling Genes, Selling Gender," 319.

<sup>&</sup>lt;sup>164</sup> Ibid., 337. Linda J. Lacey agrees: "Women are socialized to become mothers, while men are rarely socialized to become fathers." Lacey, "Remind Him That I Have No Child," 275.

<sup>&</sup>lt;sup>165</sup> Almeling, Sex Cells, 69.

<sup>&</sup>lt;sup>166</sup> Almeling, "Selling Genes, Selling Gender," 338.

and liberating breakthrough."<sup>167</sup> This has implications for gender equality in the workplace as well, as egg donation may enable women to delay childbearing until their careers are firmly established.

The counter to the argument for women's autonomy in the egg donation market is a concern about exploitation of the women who donate their eggs. The ASRM claims that "[c]ollege students and other women may agree to provide oocytes in response to financial need."<sup>168</sup> Similarly, feminist Judy Norsigian and "others worry that women, especially poorer women, may be attracted by financial compensation to donate eggs without understanding the risks."<sup>169</sup> Feminists are concerned, in other words, that young women will be driven to donate their eggs for the substantial compensation, where if their circumstances were more favorable, they would not donate.

Concerns about exploitation of the donors are entwined with issues of class and race. According to bioethicist John Robertson, the "[p]oor and minorities have greater rates of infertility than middle and upper classes, yet only the latter can afford the high costs of IVF and other assisted reproductive treatments."<sup>170</sup> Similarly, as Dorothy Roberts argues, "policies punish poor black women for bearing children but advanced technologies assist mainly affluent white women not only to have genetically-related children, but to have children with preferred genetic qualities."<sup>171</sup> While this leads to grave social injustice, it is a system-wide problem, not specific to reproductive technology. Our society allows greater access to health care to people who can pay for it —this includes even such life-saving procedures as heart transplants.<sup>172</sup>

Yet women agreeing to donate eggs in response to financial need is not necessarily exploitation; people frequently take jobs they'd rather not do because they need to pay rent or buy food. Concerns about exploitation are derided by some feminists who argue that women, poor or not, can make reasoned decisions for themselves: "We should recall that our society now allows women to make most of the same life-altering

<sup>&</sup>lt;sup>167</sup> Mundy, Everything Conceivable, 50.

<sup>&</sup>lt;sup>168</sup> ASRM Ethics Committee, "Financial Incentives in Recruitment of Oocyte Donors," S240-S244.

<sup>&</sup>lt;sup>169</sup> Mundy, Everything Conceivable, 312.

<sup>&</sup>lt;sup>170</sup> John Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton: Princeton University Press, 1994), 226.

<sup>&</sup>lt;sup>171</sup> Dorothy E. Roberts, "Privatization and Punishment in the New Age of Reprogenetics," *Emory Law Journal* 54 (2005): 1343.

<sup>&</sup>lt;sup>172</sup> Robertson, Children of Choice, 226.

decisions as everyone else."<sup>173</sup> In response to the proposal that egg donation be uncompensated in order to prevent economic exploitation, ART expert Liza Mundy asks, "Why is egg extraction from poor women acceptable as long as they are not paid?"<sup>174</sup> Since donating eggs subjects the donor to risks, both known and unknown, it should perhaps be treated as a risky job. In our society we allow people to undertake risky employment, and often they are paid well in order to compensate them for taking the risk. Loggers, crop dusters, and commercial fisherman all earn higher wages than their non-dangerous counterparts. Rather than prohibiting compensation of egg donors out of a fear that young women will make the decision to donate out of desperation— or, as would be implied by the patronizing tone of such regulation, stupidity—we should pay them appropriately for the risks they are willing to undertake.

But this does not mean that potential donors should enter the market completely unprotected. As with all medical procedures, informed consent should be required of each donor for each donation. Informed consent is a relatively recent doctrine in the medical field.<sup>175</sup> Historically, medicine operated on a paternalistic model: doctor knows best. The physician would choose what he thought was the best treatment option and the patient was expected to comply.<sup>176</sup> But health care rhetoric has shifted to embrace the concept that people should be able to make their own decisions about their bodies.<sup>177</sup> As one court put it, "[t]rue consent to what happens to one's self is the informed exercise of a choice...."<sup>178</sup> Informed consent is not a perfect protection, but it is a good start. While informed consent must take place between the physician and the

<sup>176</sup> Starr, Social Transformation of American Medicine, 389.

<sup>177</sup> See generally Canterbury v. Spence, 464 F.2d 771 (D.C. Cir. 1972) (holding that a patient has a right to be informed of the risks of a proposed medical treatment); Cobbs v. Grant, 8 Cal. 3d 229 (1972) (holding that a physician has a duty to disclose medical treatment choices and risks).

<sup>178</sup> Canterbury, 464 F.2d at 781. Judith Daar argues that true informed consent is not possible in the ART world precisely because of the way in which egg donation is framed by agencies, and because the physician automatically has a conflict of interest. Judith F. Daar, "Regulating the Fiction of Informed Consent in ART Medicine," *The American Journal of Bioethics* 1, no. 4 (2001): 19-20.

<sup>&</sup>lt;sup>173</sup> Johnston, "Paying Egg Donors," 31.

<sup>&</sup>lt;sup>174</sup> Mundy, Everything Conceivable, 313.

<sup>&</sup>lt;sup>175</sup> The idea of rights in health care emerged in the 1970s, mirroring the example of the 1960s Civil Rights struggle. Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry* (United States: BasicBooks, 1982), 388-389. See also Patricia Agre and Bruce Rapkin, "Improving Informed Consent: A Comparison of Four Consent Tools," *IRB: Ethics and Human Research* 25, no. 6 (Nov.-Dec. 2003): 1-7. Marjorie Shultz talks about the development a new protected interest, which had its origins in informed consent. Marjorie M. Shultz, "From Informed Consent to Patient Choice: A New Protected Interest," *The Yale Law Journal* 95, no. 2 (Dec. 1985): 219. Both doctrines are at issue in egg donation.

donor, agencies should double check with the donor to ensure that she has freely given her informed consent.

Another means of protecting egg donors is to require that one of the parties involved in the transaction—probably the intended parents, but it could also be the agency—carry an insurance policy that covers the donor in the event of an injury from the process of donation. In this way, at least the donor would be assured of adequate care things go wrong during her donation.

Although some feminist theory is concerned with the exploitation of egg donors, other theorists see more harm in prohibiting women from donating or prohibiting compensation for donations.<sup>179</sup> These feminists see opportunity in egg donation: opportunity for donors to command high earnings and opportunity for intended parents to act in a more equal way with men. But as with any risky enterprise, some regulation is appropriate: at a minimum, donors should give their informed consent, and they should be covered by a generous health insurance policy purchased by the intended parents or the agency. The agency should be responsible for ensuring that these requirements are met. In this way we can maximize the "good" of empowering women to autonomously participate in the reproductive labor market and earn just compensation, while simultaneously minimizing the "bad" of the risks that participation entails.

This dissertation seeks to discover how day-to-day decision-making in egg donor agencies is shaping the regulation of the field and to what extent that process intersects with feminist legal thought on commodification, markets in women's reproductive labor, and exploitation and empowerment. I examine how egg donor agencies are influenced by the media, looking to other fields for models, and undergoing a process of professionalization. I ask to what extent the ethical concerns of their particular business influence those decisions. I look at how agencies are shaping the field and the ways in which women can participate in it. I ask to what extent the normative structure of the field promotes or inhibits commodification, exploitation, and/or empowerment of women. Finally, I look at how the interactions of egg donor agencies with other organizations are shaping the field. To answer these questions, I spoke with the decision-makers themselves.

<sup>&</sup>lt;sup>179</sup> Radin, *Contested Commodities*; Satz, "Markets in Women's Reproductive Labor," 107-131. Also see Mundy, *Everything Conceivable*, for a discussion of the arguments of feminist Judy Norsigian.

### CHAPTER TWO

### The State of the ART

The practice of egg donation is essentially unregulated in the United States. Some state laws have danced around the borders of egg donation, barely touching on the practice in favor of emphasizing surrogacy or standard IVF (in vitro fertilization using the infertile patient's own eggs). Where egg donation is regulated, it is typically only to the extent of declaring that an egg donor is not a legal parent. Very few laws specifically address egg donor agencies. Some federal agencies and professional organizations have promulgated guidelines about egg donation, but for the most part, these guidelines have either not been adopted, or they lack the teeth of enforcement.

Other countries, in contrast, have directly regulated the practice of egg donation, from prohibiting compensation of egg donors to prohibiting the practice of egg donation altogether.

However, many states and the federal government have regulated practices which may be considered analogous, each in its own way, to egg donation. Perhaps the most analogous law is that of organ and human tissue donation, which focuses on the legal and property status of organs and tissue. Surrogacy has been more widely regulated than egg donation, and adoption, of course, is stringently regulated in the United States and beyond. Both surrogacy and adoption laws tend to focus on the best interests of the child and the nature of the parent-child relationship, as opposed to the property focus of organ and tissue donation statutes.

This chapter begins with a history of egg donation and description of the current status of egg donation technology. It then moves on to survey the state and international laws and guidelines that affect egg donation and, more generally, collaborative assisted reproductive technology (collaborative ART), defined here as conception achieved with donor gametes and reproductive technology. Since legislation appears largely to lump surrogacy and egg donation together, they are included together in the first three parts of the section on current law, with more detailed treatment afforded to laws affecting egg donation.

### The Frontier Field of Egg Donation

### A Brief History

Egg donation in humans has its origins in the invention of in vitro fertilization (IVF), fertilization that takes place outside the body.<sup>180</sup> IVF begins with the retrieval of mature eggs from a woman's body, typically after a course of ovarian stimulation with hormone medications. The eggs are placed with sperm in a petri dish to await fertilization, or, in a more complex procedure called intracytoplasmic sperm injection (ICSI), a single sperm is injected into each egg to facilitate fertilization.<sup>181</sup> After incubating in a growth medium for three to five days, allowing the new embryo to reach either eight cells or blastocyst stage (when the embryo is 200-300 cells large and first begins to differentiate into the structures that will become the embryo and the placenta), the embryo is injected via catheter through a woman's cervix into her uterus, where it is hoped the embryo will implant into the uterine lining and begin to grow into a fetus.<sup>182</sup> Today, egg donation is used to treat infertility in cases where the woman's eggs are compromised, whether due to her age, premature ovarian failure, cancer, or other maladies, and in cases of "functional infertility," such as a single father or a male same-sex couple (in which case a gestational surrogate is also engaged).<sup>183</sup>

Human IVF was developed by Dr. Robert Edwards, and assisted by gynecological surgeon Patrick Steptoe, who made upwards of seventy attempts before the world's first baby conceived through IVF was born in 1978 in England.<sup>184</sup> Three years later, the

<sup>&</sup>lt;sup>180</sup> Patricia A. King, Judith Areen, and Lawrence O. Gostin, *Law, Medicine and Ethics* (New York: Foundation Press, 2006), 576.

<sup>&</sup>lt;sup>181</sup> American Society for Reproductive Medicine, "Intracytoplasmic Egg Donation (ICSI)," *ReproductiveFacts.org*, www.reproductivefacts.org/topics/detail.aspx?id=1276; Internet; Accessed 6 September 2014.

<sup>&</sup>lt;sup>182</sup> The number of days an embryo is allowed to incubate depends on a variety of complex factors, including how many embryos are created in a particular cycle, as well as the quality of their visual appearance at day three past egg retrieval. See King, Areen, and Gostin, *Law, Medicine and Ethics*, 4; American Society for Reproductive Medicine, "Frequently Asked Questions About Infertility: What is IVF?" *Reproductive Facts.org*, www.reproductivefacts.org/awards/index.aspx?id=3012; Internet; Accessed 16 August 2014.

<sup>&</sup>lt;sup>183</sup> American Society for Reproductive Medicine, "Egg Donation," (Fact Sheet), *ReproductiveFacts.org*, www.reproductivefacts.org/FACTSHEET\_Egg\_Donation/; Internet; Accessed 6 September 2014.

<sup>&</sup>lt;sup>184</sup> See Mundy, *Everything Conceivable*, 7. This first "test tube" baby was Louise Brown, born on July 25, 1978. Ms. Brown gave birth to her traditionally-conceived son in December 2006. Ms. Brown's younger sister, also conceived via IVF, was the first woman conceived via IVF to to give birth to a traditionally-conceived child, in May 1999.

United States also had an IVF birth.<sup>185</sup> It was only a few years later that IVF technology was used to transfer one woman's egg into another woman's body, and the first egg donor baby was born in 1983 in Australia.<sup>186</sup> The United States followed the next year, when a woman with premature ovarian failure (early menopause) asked if she could do IVF with her sister's eggs.<sup>187</sup>

In the beginning, egg donation could not be done en masse, because eggs were retrieved via laparoscopic surgery, a highly invasive procedure requiring general anesthesia.<sup>188</sup> But by 1987, doctors were retrieving eggs vaginally using needle aspiration, a much less invasive procedure with a quick recovery time—and it became possible to ask strangers to do this for strangers.<sup>189</sup> A group of physicians headed by Dr. Richard Paulson began to recruit egg donors.<sup>190</sup> At first, because they had no idea what the risks were for either donors or the intended mothers, the physicians only treated women under forty years old who had suffered premature ovarian failure, and only accepted donors who had completed their own childbearing.<sup>191</sup> Notably, these donors were not paid, or at least, not much, for fear of exploiting the donors and entering the realm of baby-selling.<sup>192</sup> Slowly, the physicians began treating older and older women, who became pregnant with donor eggs at the same rate as younger women, and the physicians realized that what mattered most was "not the age of the patient, but the age of the egg."<sup>193</sup>

In response to the growing demand for donor eggs in the 1990s, people outside the medical field realized the potential for a market. In 1990, a few fertility clinics began offering to pay donors \$2500 for their "time and inconvenience."<sup>194</sup> Until then, egg donation was uncompensated and, consequently, the demand far outstripped the supply.<sup>195</sup> In 1991, Shelley Smith, who conceived her own children through egg donor

<sup>&</sup>lt;sup>185</sup> See Mundy, Everything Conceivable, 29.

<sup>&</sup>lt;sup>186</sup> Monash IVF, monashivf.com/treatment/qld/treatments-available/egg-donation/; Internet; Accessed 16 August 2014.

<sup>&</sup>lt;sup>187</sup> See Mundy, Everything Conceivable, 48; Spar, The Baby Business, 42-43.

<sup>&</sup>lt;sup>188</sup> Mundy, Everything Conceivable, 48.

<sup>&</sup>lt;sup>189</sup> See ibid.; King, Areen, and Gostin, Law, Medicine and Ethics, 571.

<sup>&</sup>lt;sup>190</sup> Mundy, Everything Conceivable, 48.

<sup>&</sup>lt;sup>191</sup> Ibid., 49.

<sup>&</sup>lt;sup>192</sup> Ibid.

<sup>&</sup>lt;sup>193</sup> See ibid.

<sup>&</sup>lt;sup>194</sup> Spar, The Baby Business, 44.

<sup>&</sup>lt;sup>195</sup> Ibid.

IVF, decided to serve as a broker between potential egg donors and intended parents in need of eggs.<sup>196</sup> She offered compensation to her donors higher than that offered by fertility clinics, and charged intended parents \$4500 for her services in addition to the donor's compensation.<sup>197</sup> Competition for Smith's services quickly emerged, in the form of large institutions and solo brokers.<sup>198</sup> In the last almost twenty-five years, the role of the agency has grown more complex; agencies provide more detailed donor profiles and more in depth testing and evaluation of donors than previously.<sup>199</sup> Agencies now ask donors such detailed (and, some would argue, irrelevant) questions as what are their favorite foods and movies, and a psychological evaluation is considered a standard part of the screening process. Additionally, donor compensation has risen steadily over the last two decades. Though compensation in big cities is higher than in less metropolitan areas, today egg donors can expect to receive between \$5000 and \$8000 for a single cycle.<sup>200</sup>

The lay of the land among egg donor agencies changes rapidly. In the course of my research for this dissertation, I created a list of egg donor agencies in Northern California in 2010. When I reevaluated that list in early 2014, I was obliged to almost completely revise it; though some agencies had remained in business, far more had become defunct, with new agencies springing up to take their places. One of my interviewees who had established her agency early on said that "the competition is so fierce now … my business isn't as fruitful as it used to be."<sup>201</sup>

Yet another layer to the commercial market for donor eggs began in the mid-2000s, in response to the desire of some intended parents to find the "perfect donor" and to be escorted through the complex process of infertility treatment. Organizations that I term "search services" built networks of agencies to whose donor databases they have access, and they search through multiple agency databases in search of a donor matching the intended parent's particular desired criteria. Intended parents pay a fee for this service

<sup>196</sup> Ibid., 44-45.

<sup>&</sup>lt;sup>197</sup> Ibid.

<sup>&</sup>lt;sup>198</sup> Ibid.

<sup>&</sup>lt;sup>199</sup> Ibid., 45.

<sup>&</sup>lt;sup>200</sup> Based on knowledge gained from my interviewees and extensive perusal of egg donor agency websites across the country.

<sup>&</sup>lt;sup>201</sup> Director, Northern California Agency.

to the search organization, but often get a discount (per an agreement between the search service and the agency) on agency fees.<sup>202</sup>

Advances in IVF technology improved IVF outcomes, and, specifically, egg donor IVF outcomes. Egg donor IVF cycles have higher success rates overall than IVF cycles performed with the infertile woman's own eggs, because egg quality is so important and infertile women are more likely to have poor egg quality than egg donors.<sup>203</sup> The advent of preimplantation genetic diagnosis (PGD) in 1990 enabled even better cycle outcomes, allowing embryos to be tested for a number of genetic abnormalities before being transferred into a woman's uterus.<sup>204</sup>

Vitrification is the most recent advance in egg donor IVF technology.<sup>205</sup> Physicians have been cryopreserving embryos since the same time that egg donation was first practiced; the first baby was born from the transfer of a frozen embryo in 1984.<sup>206</sup> But eggs proved more fragile and prone to destruction during freezing and thawing than embryos; older means of cryopreservation involved slowly lowering the temperature, but in eggs, this

<sup>&</sup>lt;sup>202</sup> There are not many such organizations. I was able to locate four in the United States: Baby Steps Fertility, babystepsfertility.com/; Donor Concierge, www.donorconcierge.com/; Fertility Bridges, www.fertilitybridges.com/; and Lotus Blossom Consulting, lotusblossomconsulting.com/, all of which offer slightly different sets of services.

<sup>&</sup>lt;sup>203</sup> RESOLVE, "The Effect of Egg Quality on Fertility," RESOLVE Website, www.resolve.org/aboutinfertility/medical-conditions/the-effect-of-egg-quality-on-fertility.html; Internet; Accessed 6 September 2014.

<sup>&</sup>lt;sup>204</sup> See King, Areen, and Gostin, Law, Medicine and Ethics, 644; Mundy, Everything Conceivable.

<sup>&</sup>lt;sup>205</sup> Vitrification, cryopreservation, and freezing are all terms for more or less the same thing. Vitrification is the newer form of cryopreservation in which the embryos or eggs are frozen rapidly rather than slowly. "Slow freezing is known as equilibrium freezing due to the exchange of fluids between the extra- and intracellular spaces and results in safe freezing without serious osmotic and deformation effects to cells.... Vitrification is a non-equilibrium method and may be regarded as a radical approach in which ice crystal formation is completely eliminated." Mojtaba Rezazdeh Valojerdi et al., "Vitrification versus Slow Freezing Gives Excellent Survival, Post Warming Embryo Morphology and Pregnancy Outcomes for Human Cleaved Embryos," *Journal of Assisted Reproduction and Genetics* 26, no. 6 (June 2009): 347-354, available from www.ncbi.nlm.nih.gov / pmc / articles / PMC2729856 / ; Internet; Accessed 6 September 2014; Nagy et al., "First One Hundred Recipient Cycles Using Vitrified / Warmed Oocytes;" ASRM Practice Committee and SART Practice Committee, "Mature Oocyte Cryopreservation;" Krinos M. Trokoudes, M.D., Constantinos Pavlides, M.Sc., and Xiao Zhang, M.D., Ph.D., "Comparison Outcome of Fresh and Vitrified Donor Oocytes in an Egg-Sharing Donation Program," *Fertility and Sterility* 95, no. 6 (May 2011): 1996-2000.

<sup>&</sup>lt;sup>206</sup> Associated Press, "First Baby Born of Frozen Embryo," *The New York Times*, 11 April 1984, available from www.nytimes.com/1984/04/11/us/first-baby-born-of-frozen-embryo.html; Internet; Accessed 6 September 2014.

frequently caused ice crystals to form, compromising the cell's structure.<sup>207</sup> Slowfreezing was sometimes successful—the first birth from IVF using an egg frozen in this manner was in 1986.<sup>208</sup> But vitrification, a rapid freezing technology first practiced successfully around 2009, has resulted in greater success rates in thaw and ultimate pregnancy outcomes overall (for eggs, sperm, and embryos), but most notably for eggs.<sup>209</sup> Vitrification allows women to cryopreserve their own eggs at a young age, in anticipation of delaying childbirth, or in advance of fertility-compromising cancer treatment.<sup>210</sup> It also enables egg donors to make their contribution directly to a clinic or a frozen egg bank, where the eggs will be stored until chosen at some later date by an intended parent—much like the sperm donor bank model.

Egg donation is one hundred years younger than sperm donation, the first case of which was performed by Dr. William Pancoast in 1884, when he asked for a semen sample from one of his medical students and, without her consent or her infertile husband's, inseminated a woman who was under anesthesia for what she thought was a routine procedure.<sup>211</sup> Because it did not pose the same technological difficulties as egg donation, sperm donation was practiced by physicians in major cities in the early 1900s, and became widely used in the post-WWII era.<sup>212</sup> Even sperm donation, however, has been subject to rapid advancements in technology, as in the last twenty years, the development of microsurgery has enabled the retrieval of sperm from men previously thought to have no sperm at all.<sup>213</sup> Because of sperm donation's relatively long history as compared to egg donation, it is primarily from the study of sperm donor-conceived

<sup>212</sup> See ibid., 73.

<sup>213</sup> See ibid., 74.

<sup>&</sup>lt;sup>207</sup> Mundy, Everything Conceivable, 324; Spar, The Baby Business, 60.

<sup>&</sup>lt;sup>208</sup> Greg Masler, Esq., Lecture to SEEDS Conference, April 25-26, 2014.

<sup>&</sup>lt;sup>209</sup> Valojerdi et al., "Vitrification versus Slow Freezing;" Nagy et al., "First One Hundred Recipient Cycles Using Vitrified/Warmed Oocytes;" ASRM Practice Committee and SART Practice Committee, "Mature Oocyte Cryopreservation;" Trokoudes, Pavlides, and Zhang, "Fresh and Vitrified Donor Oocytes."

<sup>&</sup>lt;sup>210</sup> Spar, *The Baby Business*, 61.

<sup>&</sup>lt;sup>211</sup> See Mundy, *Everything Conceivable*, 72. The first successful recorded case of artificial insemination (with the woman's husband's sperm, as opposed to artificial insemination with *donor* sperm) was almost one hundred years earlier, performed by Scottish doctor John Hunter in 1790.

children that we glean our knowledge of the emotional experience of donor-conceived people.<sup>214</sup>

The first birth from insemination with *frozen* sperm was in 1953,<sup>215</sup> thirty years before the advent of fresh cycle egg donation. In the early 1970s, twenty years after the first successful use of frozen sperm, the first commercial sperm bank opened.<sup>216</sup> Initially, physicians envisioned using the technology to preserve a man's sperm for his own future use, whether in anticipation of cancer treatment, an imminent departure for war, or simply to provide a backup in case he changed his mind about having children after having a voluntary vasectomy. It soon became clear, however, that there was a demand for frozen *donor* sperm, and because of the AIDS crisis in the mid-1980s, the American Association of Tissue Banks, the American Society for Reproductive Medicine, the Food and Drug Administration, and the Centers for Disease Control all recommended that all donor sperm be frozen and quarantined for six months, so that the donor could be tested for HIV at the end of the quarantine period.<sup>217</sup> Sperm banks created the model of a "catalog" of donors, with their traits listed, for intended parents to browse through and choose from, that frozen egg banks would follow thirty years later.<sup>218</sup>

<sup>&</sup>lt;sup>214</sup> Generally speaking, there is consensus in scholarly circles that disclosure to donor-conceived children is best for the children. See, e.g., L. Blake et al., "'Daddy Ran Out of Tadpoles': How Parents Tell their Children that they are Donor Conceived, and what their 7-Year-Olds Understand," *Human Reproduction* 25, no. 10 (2010): 2527-2534; K.R. Daniels and P. Thorn, "Sharing Information with Donor Insemination Offspring: A Child-Conception versus a Family-Building Approach," *Human Reproduction* 16, no. 9 (2001): 1792-1796; Vasanti Jadva et al., "The Experiences of Adolescents and Adults Conceived by Sperm Donation: Comparisons by Age of Disclosure and Family Type," *Human Reproduction* 24, no. 8 (2009): 1909-1919; Patricia P. Mahlstedt, Ed.D., Kathleen LaBounty, B.A., and William Thomas Kennedy, Ed.D., "The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States," *Fertility and Sterility* 93, no. 7 (May 2010): 2236-2246; Marilyn S. Paul and Roni Berger, "Topic Avoidance and Family Functioning in Families Conceived with Donor Insemination," *Human Reproduction* 22, no. 9 (2007): 2566-2571; J.E. Scheib, M. Riordan, and S. Rubin, "Adolescents with Open-Identity Sperm Donors: Reports from 12-17 Year Olds," *Human Reproduction* 20, no. 1 (2005): 239-252.

<sup>&</sup>lt;sup>215</sup> Willem Ombelet and Johan Van Robays, "History of Human Artificial Insemination," *Facts, Views, and Visions in OBGYN* Monograph (2010): 4; California Cryobank, "Sperm Banking History," available from www.cryobank.com/Learning-Center/Sperm-Banking-101/Sperm-Banking-History/; Internet; Accessed 16 August 2014.

<sup>&</sup>lt;sup>216</sup> Spar, The Baby Business, 36-37; California Cryobank, "Sperm Banking History."

<sup>&</sup>lt;sup>217</sup> California Cryobank, "Sperm Banking History."

<sup>&</sup>lt;sup>218</sup> Egg donor databases used by egg donor agencies to facilitate fresh donor egg cycles use a similar model, but their database listings are supplemented by real time agency interaction with the donor as she undergoes screening, as well as the possibility for intended parents to meet the donor. Neither sperm banks nor frozen egg banks offer the opportunity for intended parent interaction with the donor outside of the donor's profile.

The ability to freeze eggs prompted the emergence of a new set of organizations: frozen egg banks. In 2002, an infertility specialist launched Egg Bank USA, with the express purpose of serving women who wished to preserve their fertility.<sup>219</sup> Soon, the market expanded to those in need of donor eggs, and women were recruited to donate their eggs to the clinic or bank, to be offered to intended parents through donor databases, much like with fresh egg donation. In 2007, the ASRM designated IVF with frozen donor eggs "experimental," but in 2012, that designation was lifted, and frozen egg banks were free to move forward without the stigma of appearing untested.<sup>220</sup>

Frozen egg banking introduced two primary differences from fresh egg donation: first, there was no longer a direct agreement between the egg donor and the intended parent. In fresh egg donation, the intended parent chooses a donor, who does not undergo ovarian stimulation and egg retrieval until she is chosen, and ideally, the intended parent and donor then sign an agreement specifying their preferences for all aspects of the egg donation; e.g., the options for disposition of any leftover embryos.<sup>221</sup> When using frozen donor eggs, the donor has completed her donation prior to being selected by the intended parents, so there is no agreement directly between the donor and the intended parents.<sup>222</sup> Second, while in fresh egg donation, all of the eggs retrieved in a single cycle go to a single intended parent, frozen egg banking enables the clinic or bank to sell the eggs from a single donor's cycle to two or more families, thus greatly increasing the potential number of genetic offspring for a particular donor.<sup>223</sup>

<sup>222</sup> When asked about the legal differences between traditional fresh donor egg IVF cycles and frozen donor egg IVF cycles, one of my family formation attorney interviewees said, "It's a lot like a sperm bank, where the sperm donor has gone to the sperm bank, and deposited samples, which are then used or not used ... A lot of the arrangements have been directly with the clinic. And the donor in that case, the genetic provider, has actually had a contract with the clinic ... you end up having parents contracting directly with the egg bank, or the clinic, in that regard. Instead of [with] the donor."

<sup>223</sup> See the websites of four major frozen egg banks: My Egg Bank, www.myeggbank.com; The World Egg Bank, www.theworldeggbank.com; Donor Egg Bank USA, www.donoreggbankusa.com; and Reproductive Biology Associates, www.rba-online.com. The potential for such genetic consanguinity has always been much greater for sperm donation, where a single man can potentially make weekly (or more) deposits of sperm to a frozen sperm bank over a number of years. The movie *Delivery Man* addresses that possibility, and features a main character who has "fathered" 533 children through donation of his sperm.

<sup>&</sup>lt;sup>219</sup> Spar, *The Baby Business*, 61.

<sup>&</sup>lt;sup>220</sup> ASRM Practice Committee and SART Practice Committee, "Mature Oocyte Cryopreservation."

<sup>&</sup>lt;sup>221</sup> As one of my family formation attorney interviewees said about embryo disposition: "Does the donor consent to any and all future uses, or is she restricting some future uses, like not permitting the remaining embryos to research, or if there are third persons? They [intended parents] do need to know what her wishes are, so that they are complying with those wishes. But because of that it makes it especially important to have legal advice on the issue."

If frozen egg banking ultimately supplants fresh egg donation as the primary means of utilizing donor eggs, agency roles will change. While many of the same services provided by agencies will still be necessary—namely donor recruitment, screening, and maintenance of database websites—the link between the donor and the intended parent will be lost, and with it many of the frames that agencies use to embed the experience of donors and intended parents in a positive way.

For now, however, egg donor agencies maintain their dominance in the world of egg donation. In a thorough search online, I found one hundred and four independent egg donor agencies with a web presence in the United States, along with one hundred and twenty in-house egg donor programs (which typically have a much smaller selection of donors), and four search services.<sup>224</sup> Sixty independent agencies had multiple branches in one state, while another twenty-seven had branches in multiple states. Several also had international branches. Half of the United States host one or more independent egg donor agencies, and California, birthplace of the agency, has the most agencies of any state.<sup>225</sup>

Egg donation can also take place outside the context of an egg donor agency. Some intended parents recruit their own donors and make private arrangements with respondents to personal ads.<sup>226</sup> Most commonly outside of agencies, however, young women donate their eggs through clinic in-house programs, egg donation programs run by an infertility clinic. Sometimes these programs operate under the business umbrella of the clinic, and sometimes they are an affiliated but separate business. Still, they function similarly to egg donor agencies, though agency decision-makers argue that they don't provide the thorough donor screening or emotional support that do agencies.

One clinic in California, California Conceptions, has created a unique program that they term "donated embryos."<sup>227</sup> Traditionally, embryo donation is defined as an intended parent donating leftover embryos that they do not plan to use to another intended parent. California Conceptions recruits egg donors, fertilizes their eggs with frozen

<sup>&</sup>lt;sup>224</sup> My search was completed on March 4, 2014, and primarily consisted of searching for the term "egg donor" through thirty pages of Google search results. See Appendix I for a comprehensive chart and maps of my findings.

<sup>&</sup>lt;sup>225</sup> See Appendix I for a visual representation of state-by-state agency concentration.

<sup>&</sup>lt;sup>226</sup> For example, the website Fertility Nation hosts a plethora of personal ads seeking egg donors and advertising willingness to be an egg donor: Fertility Nation Classifieds, www.fertilitynation.com/fertility-nation-classifieds/classifieds/1/egg-donation/; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>227</sup> California Conceptions, www.californiaconceptions.com/; Internet; Accessed 16 August 2014.

donor sperm, and sells the resulting embryos to intended parents.<sup>228</sup> They have a waiting list of intended parents, and match the not-yet-created embryos with two to three separate intended parents (using very basic race criteria).<sup>229</sup> Embryos are thus designated for specific intended parents, but in theory, the clinic could end up owning embryos from a cycle that fell through. The clinic has received significant backlash; critics argue that it is nothing more than the "sale of nascent human life," and that it is inappropriate for clinicians who will not be the resulting children's parents to choose which gametes to combine.<sup>230</sup> This practice raises the specter of eugenics much more visibly than in regular egg donation; in 2007 "the world's first human embryo bank," the Abraham Center of Life, shut down under the scrutiny of an FDA investigation after only a few months of operation.<sup>231</sup> Its founder, Jenalee Ryan, matched what she considered to be attractive and intelligent egg and sperm donors in a blatant effort to create children that would "look and behave like society's presumed best."<sup>232</sup>

Finally, egg donation can take place in the context of stem cell research. Egg donation for stem cell research is controversial in a different way from California Conceptions's "donated embryos." Out of fear of exploitation of young women, especially minority

<sup>228</sup> Ibid.

<sup>232</sup> Obasogie, "'Wal-Martization' of Embryos," Boston Globe.

<sup>&</sup>lt;sup>229</sup> According to Ernest Zeringue, founder of California Conceptions, "We want to keep the embryos moving ... The goal is not to create a bank." Dawn Davenport, "Creating Embryos Specifically to Donate/ Sell?" *Creating a Family* (blog), 20 November 2012, available from www.creatingafamily.org/blog/ creating-embryos-specifically-donatesell/; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>230</sup> Jessica Cussins, "Embryos for Sale?" *Genetic Crossroads*, by *The Center for Genetics and Society*, 29 November 2012, available from www.psychologytoday.com/blog/genetic-crossroads/201211/embryossale; Internet; Accessed 16 August 2014.

<sup>&</sup>lt;sup>231</sup> Abraham Center of Life founder Jennalee Ryan came under a great deal of criticism for increasing the commodification of human reproductive tissue. She justified her organization by saying "If I do discriminate, it's that I only want healthy, intelligent people ... People will say, 'You're trying to create the perfect human race.' But we've always done gene selection just by who women choose as their husbands and men choose as their wives. This is no different." Rob Stein, "Center Sells Ready-Made Embryos," The Washington Post, 7 January 2007, available from seattletimes.com/html/nationworld/ 2003513223\_embryo07.html; Internet; Accessed 7 September 2014. See also Juju Chang and Deborah Apton, "Designing Babies? Embryos from 'Ph.D. Sperm' and 'Attractive Eggs' for Sale," Nightline, ABC *News*, 22 February 2007, available from abcnews.go.com/Business/LifeStages/story?id=2895615; Internet; Accessed 4 September 2014; Osagie K. Obasogie, "'Wal-Martization' of Embryos," Boston Globe, 1 February 2007, available from www.geneticsandsociety.org/article.php?id=3126; Internet; Accessed 16 August 2014; "Abraham Center of Life No Longer in Embryo Business," eWorldWire, 30 May 2007, available from www.eworldwire.com/pressrelease/17092; Internet; Accessed 16 August 2014; Associated Press, "FDA Investigating Business that Lets Prospective Parents Select Embryos," Fox News, 12 January 2007, available from www.foxnews.com/story/2007/01/12/fda-investigating-business-that-letsprospective-parents-select-embryos/; Internet; Accessed 16 August 2014.

and poor women, the National Academy of Sciences recommends that women donating eggs for stem cell research should not be compensated.<sup>233</sup> In August of 2001, President George W. Bush restricted federally funded stem cell research to a very few stem cell lines that had been created prior to the President's declaration.<sup>234</sup> On November 2, 2004, however, California voters passed Proposition 71, the California Stem Cell Research and Cures Act.<sup>235</sup> Proposition 71 provided for a \$3 billion dollar public bond, to be paid over ten years, to support stem cell research, including the creation of new stem cell lines—for which an egg donor is required.<sup>236</sup> Proposition 71 prohibited research donors from receiving compensation; they could only be reimbursed for expenses.<sup>237</sup> In 2009, President Barack Obama lifted the ban on federally funded stem cell research, allowing federal money—when available—to support stem cell research.<sup>238</sup> And in 2013, the California State Assembly and Senate passed Assembly Bill 926, which would have allowed compensation for egg donors for stem cell research.<sup>239</sup> Governor Jerry Brown vetoed the bill on August 13, 2013, stating, "Not everything in life is for sale nor should

<sup>235</sup> California Secretary of State, Statement of Vote and Supplement to the Statement of Vote, 2004 Presidential General Election (2004), available from www.sos.ca.gov/elections/sov/2004-general/#sov; Internet; Accessed 16 August 2014. Proposition 71 was codified as the California Stem Cell Research and Cures Act in the California Constitution, Article XXV, and in the California Health and Safety Code at sections 125290.10 et seq.

<sup>236</sup> California Stem Cell Research and Cures Act, California Health and Safety Code §§ 125290.10 et seq.

<sup>&</sup>lt;sup>233</sup> Institute of Medicine and National Research Council, 2008 Amendments to the National Academies' Guidelines for Human Embryonic Stem Cell Research (2008).

<sup>&</sup>lt;sup>234</sup> The White House Fact Sheet: Embryonic Stem Cell Research (Aug. 9, 2001), available from georgewbush-whitehouse.archives.gov/news/releases/2001/08/20010809-1.html; Internet; Accessed 16 August 2014. The President restricted stem cell research in large part as a response to pressure brought to bear by the anti-abortion movement. He "risk[ed] alienating a key support base–religious conservatives and other anti-abortion rights groups–by allowing even limited federal funding." Eleni Berger, "Research Avenue Adds Fuel to Stem Cell Controversy," *CNN.com Health*, 18 July 2001, available from cmgm.stanford.edu/biochem158/Stem%20Cell/Stem%20Cell%20Debate%20CNN%20.pdf; Internet; Accessed 16 August 2014.

<sup>&</sup>lt;sup>237</sup> Cal. Health & Safety Code § 125290.35(b)(3).

<sup>&</sup>lt;sup>238</sup> Bernadette Tansey, "Obama Policy a Lift for Stem Cell Researchers," *SFGate*, 29 November 2008, available from www.sfgate.com/news/article/Obama-policy-a-lift-for-stem-cell-researchers-3260053.php; Internet; Accessed 16 August 2014.

<sup>&</sup>lt;sup>239</sup> California AB 926 (2013) (vetoed), available from leginfo.legislature.ca.gov/faces/billNavClient.xhtml? bill\_id=201320140AB926&search\_keywords=; Internet; Accessed 7 September 2014.

it be."<sup>240</sup> Consequently, in California, at least, egg donation for stem cell research remains uncompensated.

Not everyone agrees with Jerry Brown that not everything in life is for sale. Kathy Hudson, a biologist who directs the Genetics and Public Policy Center, thinks that egg donors should be paid, arguing that it's patronizing not to pay donors.<sup>241</sup> Liza Mundy agrees with Hudson's argument: "In my opinion, to not [compensate] women undergoing hormonal stimulation and invasive oocyte retrieval research is just plain unfair."<sup>242</sup> It also leads to a deficit of donors for research.

Egg donation, for any purpose, is a relatively new field. The first birth from an egg donor IVF cycle was only thirty years ago, and the rise of commercial egg donation—including the emergence of egg donor agencies—has taken place within the last twenty-five years. The technology on which egg donor agencies base their business is rapidly evolving, and while some agencies have been stable since the early days of egg donation, many rise and as rapidly as ocean waves. The egg donation industry is subject to very little regulation, and most of that is directed at the medical side of the field. Egg donor agencies are essentially unregulated. The following is a survey of the current state of the law of egg donation and related fields.

# The Current State of the Law

#### State Statutes and Case Law on Egg Donation and Collaborative ART

Given the rising prevalence of collaborative reproduction, there is surprisingly little law addressing it. California has the most extensive case law on the subject, but that state's attempts to pass comprehensive legislation have failed. Furthermore, egg donation is treated differently under California law based on its purpose: reproduction versus stem cell research. Most other state laws on collaborative ART, where they exist at all, address the legality of surrogacy and the parentage of children born via ART. Other countries

<sup>&</sup>lt;sup>240</sup> Edmund G. Brown, Jr., Statement from the Office of the Governor (Aug. 13, 2013), available from gov.ca.gov/docs/AB\_926\_Veto\_Message.pdf; Internet; Accessed 16 August 2014. Jerry Brown wasn't the only one concerned about exploitation of egg donors for stem cell research. See, e.g., Diane Beeson and Abby Lippman, "Egg Harvesting for Stem Cell Research: Medical Risks and Ethical Problems," *Reproductive BioMedicine Online* 13, no. 4 (Oct. 2006).

<sup>&</sup>lt;sup>241</sup> Quoted in Mundy, *Everything Conceivable*, 314.

<sup>&</sup>lt;sup>242</sup> Mundy, Everything Conceivable, 314.

that have passed laws regulating egg donation do everything from limiting compensation of donors to prohibiting the practice altogether.

#### <u>California</u>

California has some of the strongest case law on collaborative ART in the country. In the 1993 seminal case *Johnson V. Calvert*, the California Supreme Court decreed that when two women each have a biological claim to legal motherhood (via gestation or genetics), the woman who intended to be the mother in a reproductive technology arrangement should be declared the legal mother.<sup>243</sup> In that case, a couple had hired a surrogate to carry an embryo made from the woman's own eggs and her husband's sperm, but the court implied that the same would be true if a woman (or couple) hired an egg donor and carried the baby, not genetically related to her, herself.<sup>244</sup> *In re Marriage of Buzzanca* further clarified the status of an egg donor by deeming the egg recipient (the gestational mother) and her husband a child's legal parents by virtue of their procreative intent.<sup>245</sup> Similarly, the California Supreme Court held in two separate cases in 2005 that two women in a long term committed relationship who create a child together are the legal mothers of that child.<sup>246</sup> California's "intent doctrine" still stands, and has been further codified in the Family Code, sections 7960-7962.<sup>247</sup>

<sup>&</sup>lt;sup>243</sup> Johnson v. Calvert, 5 Cal.4th 84 (1993). The Court based its analysis on the framework established by Marjorie M. Shultz in "Reproductive Technology and Intent-Based Parenthood: An Opportunity for Gender Neutrality," *Wisconsin Law Review* 1990 (1990): 297-398.

<sup>&</sup>lt;sup>244</sup> Johnson, 5 Cal.4th 84.

<sup>&</sup>lt;sup>245</sup> Buzzanca v. Buzzanca, 72 Cal. Rptr. 2d 280 (Cal. Ct. App. 1998).

<sup>&</sup>lt;sup>246</sup> K.M. v. E.G., 37 Cal.4th 130 (2005); Kristine H. v. Lisa R., 37 Cal.4th 156 (2005). Note that the Court did not explicitly rely on the intent doctrine in either case, yet the result is the same as if it had.

<sup>&</sup>lt;sup>247</sup> California Family Code §§ 7960-7962 (on surrogacy; codification of "intent doctrine"). Additionally, in October 2013, Governor Jerry Brown signed into law a bill allowing a child to have more than two legal parents—thus the intent doctrine could be applied to all parties involved in the creation of a child, whether genetically or biologically related or not. California SB 274 (chaptered October 4, 2103), codified at California Family Code §§ 3040, 4057, 7601, 7612, 8617, and 4052.5.

Although California stands at the forefront of case law about collaborative reproductive technology, its legislation lags behind.<sup>248</sup> Special interest groups such as the Academy of California Family Formation Attorneys are working to get legislation passed.<sup>249</sup> Most of the legislation that does exist addresses the parentage issues that can arise from collaborative ART arrangements, because a third party is providing gametes and/or giving birth.

The last sections of the California Family Code under Division 12, Parent and Child Relationship, were enacted in 2011 and 2013. These laws primarily address surrogacy arrangements, and speak to the handling of client funds (must be with an attorney or in escrow) and the establishment of the parentage of children born via surrogacy (according to the "intent doctrine").<sup>250</sup> The former provisions were effective in 2011 and the latter in 2013.

The bill that established the law governing surrogacy arrangements, AB 1217, was at its inception in February of 2011 a thirty-four page comprehensive overhaul of ART law in California.<sup>251</sup> It addressed topics as far ranging as parentage of children born from ART (included in the final bill), informed consent of all participants in ART (including the disclosure of any relevant professional guidelines), insurance coverage for infertility treatment, options for disposition of frozen embryos, confidentiality of the medical and psychological information of donors and gestational surrogates, and mental health counseling for all participants. It also created a new definition of infertility, to include "the desire to achieve pregnancy by means other than sexual intercourse," which was intended to guarantee insurance coverage for single people and gay/lesbian people attempting to become parents.<sup>252</sup> The bill required the inspection of facilities and particular qualifications for medical providers of infertility treatment, and provided for the possibility of the state establishing a "donor and collaborative reproduction

<sup>&</sup>lt;sup>248</sup> I do not discuss all California ART law here, as much of it is peripheral to the issues raised by egg donation. Some laws not included here: California Family Code § 7620 (on legal jurisdiction when ART occurs in California); California Family Code § 7612(c) (allows more than two legal parents in California when recognizing only two legal parents would be detrimental to the child); and California AB 1951 (passed by the legislature in August and approved by Governor Brown on September 15, 2014) (providing for gender neutral parent entries on birth certificates in California Health and Safety Code § 102425.1), available from leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=201320140AB1951; Internet; Accessed 29 September 2014.

<sup>&</sup>lt;sup>249</sup> Academy of California Family Formation Attorneys, www.acal.org/.

<sup>&</sup>lt;sup>250</sup> California Family Code §§ 7960-7962.

 <sup>&</sup>lt;sup>251</sup> California AB 1217 (2012), as introduced, and compared to final version, available from legislature.ca.gov/faces/billHistoryClient.xhtml; Internet; Accessed 7 September 2014.
 <sup>252</sup> Ibid.

registry" to maintain contact and updated medical information for participants in collaborative reproduction arrangements.<sup>253</sup>

During its journey through the legislative process, however, AB 1217 was gutted down to a two-page bill that in part codified the intent doctrine.<sup>254</sup> Section 7962 created explicit requirements for surrogacy agreements, including date of execution of the agreement, source of the gametes used, independent legal counsel for the surrogate and the intended parents, and execution of the agreement before commencement of any medical procedures relating to the surrogacy.<sup>255</sup> The law establishes that intended parents may file an action to establish the parent-child relationship during the surrogate's pregnancy, that a surrogacy agreement, if properly notarized and filed with a court, rebuts the presumptions of parentage in other parts of the code (namely, that a woman who gives birth is the legal mother, and her spouse the legal father), and that a court must issue an order of parental rights of the intended parents, and termination of the parental rights of the surrogate (and her spouse) pursuant to the petition of any of the parties to such a surrogacy agreement.<sup>256</sup> The law also establishes that surrogacy agreements filed with the court are private and not to be released to anyone other than the parties and their representatives.<sup>257</sup> No part of the new statutes explicitly address egg donation.

Another assembly bill, AB 2344, the "Modern Family Act," which addresses parentage issues in ART, was passed by the California legislature in August approved by Governor Brown on September 15, 2014.<sup>258</sup> The bill provides a form, among others, that satisfies the "writing requirement" of section 7613, and is used to demonstrate intent to parent when using donor sperm or donor eggs.<sup>259</sup> Essentially, the bill would change the law to make parentage law regarding egg donation equivalent to that already existing regarding sperm donation—when completed properly, the form is an enforceable legal

<sup>253</sup> Ibid.

<sup>&</sup>lt;sup>254</sup> California Family Code §§ 7960-7962.

<sup>&</sup>lt;sup>255</sup> California Family Code § 7962(a)-(d).

<sup>&</sup>lt;sup>256</sup> California Family Code § 7962(e)-(f).

<sup>&</sup>lt;sup>257</sup> California Family Code § 7962(g)-(h).

<sup>&</sup>lt;sup>258</sup> AB 2344 will be added to the California Family Code as sections 7613.5, 7962(a)(4), and 9000.5, and small amendments to sections 9001, 9002, 9006, and 9007. California AB 2344 (2014) (parentage in ART), available from leginfo.legislature.ca.gov/faces/billHistoryClient.xhtml; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>259</sup> California AB 2344.

document giving intended parents legal parentage rights and denying gamete donors parental rights.<sup>260</sup>

More specific to egg donation, in 2010, a small section of the Health and Safety Code was enacted in response to solicitations for egg donors promising as much as \$50,000 per cycle.<sup>261</sup> Section 125325 provides that anyone advertising in search of egg donors for ART must include the following notice in "a clear and conspicuous manner:"

Egg donation involves a screening process. Not all potential egg donors are selected. Not all selected egg donors receive the monetary amounts or compensation advertised. As with any medical procedure, there may be risks associated with human egg donation. Before an egg donor agrees to begin the egg donation process, and signs a legally binding contract, she is required to receive specific information on the known risks of egg donation. Consultation with your doctor prior to entering into a donor contract is advised.<sup>262</sup>

The statute also requires that all egg donors be provided with information about the process of egg donation as part of their informed consent before they sign a legally binding contract.<sup>263</sup> It provides, however, for an exemption from the notification requirements for people or entities that certify compliance with the American Society for Reproductive Medicine (ASRM, the fertility industry's leading professional organization) guidelines by registering with the Society for Assisted Reproductive Technology (SART, a branch of the ASRM).<sup>264</sup> This statute is intended to provide a

<sup>&</sup>lt;sup>260</sup> The latter part of the bill, which would be California Family Code section 9000.5, would streamline stepparent adoptions in ART matters.

<sup>&</sup>lt;sup>261</sup> A study by the Hastings Center found that nearly half of advertisements for egg donors promised over \$10,000, and advertised amounts reached \$50,000. Aaron D. Levine, "Self-Regulation, Compensation, and the Ethical Recruitment of Oocyte Donors," *The Hastings Center Report* 40, no. 2 (2010), 25-36.

<sup>&</sup>lt;sup>262</sup> California Health and Safety Code § 125325 (restrictions on advertising for egg donors).

<sup>&</sup>lt;sup>263</sup> "A summary pertaining to oocyte donation procedures, shall be provided, as required pursuant to Section 125335, to all potential egg donors before signing a legally binding contract to become an egg donor, or beginning any egg donation procedures, as part of compliance with the informed consent requirements." California Health and Safety Code § 125325(b).

<sup>&</sup>lt;sup>264</sup> "Persons or entities that certify compliance with the American Society for Reproductive Medicine (ASRM) guidelines by registering with ASRM are exempt from the notice requirements set forth in subdivision (a). Use of the exemption when the guidelines are violated shall constitute false advertising." California Health and Safety Code § 125325(c).

measure of protection against exploitation of egg donors by ensuring their informed consent.

In another arena, stem cell research, California has promulgated laws about egg donation (the equivalent of which are completely lacking for egg donation for ART), effective in 2007.<sup>265</sup> The California Health and Safety Code, sections 125330-125355 addresses the procuring of human eggs for research.<sup>266</sup> This statute requires that researchers obtain informed consent from donors and track the demographics of donors and the outcomes of their cycles.<sup>267</sup> It expressly prohibits the compensation of donors, except for reimbursement of direct expenses incurred as a result of the donation, stating that women should not be paid for their eggs.<sup>268</sup> All of these provisions are dramatically different from egg donation for ART: there is no tracking of donors in ART and, of course, donors may be compensated well above their direct expenses.

In 2013, AB 926, sponsored by the ASRM, proposed repealing the sections of the California Health and Safety Code which prohibited compensation for egg donation for research purposes and allowing compensation at the same rate as egg donations for ART, the specific amount to be determined on a case by case basis by institutional review boards.<sup>269</sup> California Governor Jerry Brown vetoed the bill in August of 2013, citing concerns about exploitation: "In medical procedures of this kind, genuinely informed consent is difficult because the long-term risks are not adequately known. Putting thousands of dollars on the table only compounds the problem."<sup>270</sup> On the other side, organizations like California NOW and Planned Parenthood claimed that restrictions against compensation for egg donation for research only serve to demean women's decision-making authority, especially given that women donation for ART are

<sup>&</sup>lt;sup>265</sup> California Health and Safety Code §§ 125330-125355 (stem cell research initiative), full text of Proposition 71 available from www.cirm.ca.gov/about-cirm/our-history; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>266</sup> Ibid.

<sup>&</sup>lt;sup>267</sup> "Prior to providing AOP or any alternative method of ovarian retrieval to a subject for the purposes of medical research or development of medical therapies, a physician and surgeon shall obtain written and oral informed consent for the procedure from the subject." California Health and Safety Code § 125340(a).

<sup>&</sup>lt;sup>268</sup> "No payment in excess of the amount of reimbursement of direct expenses incurred as a result of the procedure shall be made to any subject to encourage her to produce human oocytes for the purposes of medical research." California Health and Safety Code § 125355.

<sup>&</sup>lt;sup>269</sup> The full text of AB 926 is available from leginfo.legislature.ca.gov/faces/billNavClient.xhtml? bill\_id=201320140AB926&search\_keywords=; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>270</sup> Edmund G. Brown, Jr., Statement from the Office of the Governor (Aug. 13, 2013).

compensated.<sup>271</sup> There is no law that explicitly allows compensation for egg donors for ART in California—but there is no law that prohibits it, either.

### Federal Law and the Law of Other States

#### Federal Law

Federal law does not regulate the sale of gametes (eggs and sperm), and most states allow it. The Food and Drug Administration (FDA) classifies human gametes as human tissue, which is alienable under federal law.<sup>272</sup> Laws that do regulate gamete donation in the fertility industry are mostly limited to disease transmission. The FDA has a number of laws applicable to fertility clinics across the country requiring infectious disease testing of gamete donors and intended parents undergoing ART procedures.<sup>273</sup>

In April 2011, a class action lawsuit was filed in the United States District Court for the Northern District of California by an egg donor who alleged that the ASRM and several infertility clinics had violated antitrust laws by recommending and/or following guidelines for a maximum cap on compensation for egg donors.<sup>274</sup> The plaintiff alleged that but for the actions of the ASRM, the market would function to determine the fee that egg donors receive.<sup>275</sup> In court filings, the ASRM has defended its recommended caps on egg donor compensation on the basis that they strike a balance between avoiding exploitation of donors while still compensating them fairly for the risks they take in donating.<sup>276</sup> The case is still pending, so it remains to be seen what effect it might have on legislation of egg donor compensation in the United States.

<sup>&</sup>lt;sup>271</sup> Francine Coeytaux and Diane Tober, Ph.D., "Eggs for Cash: Pitting Choice Against Risk," *RH Reality Check*, 4 September 2013, available from rhrealitycheck.org/article/2013/09/04/eggs-for-cash-pitting-choice-against-risk/; Internet; Accessed 1 December 2013.

<sup>&</sup>lt;sup>272</sup> 21 C.F.R. §§ 1270 et seq. (FDA classifying gametes as human tissue).

<sup>&</sup>lt;sup>273</sup> See, e.g., 21 C.F.R. § 1271.1 (purpose of regulation is "to establish donor-eligibility, current good tissue practice, and other procedures to prevent the introduction, transmission, and spread of communicable diseases by [human cells, tissues, or cellular- or tissue-based products]").

<sup>&</sup>lt;sup>274</sup> Kamakahi v. American Society for Reproductive Medicine, Case No. 3:11-cv-01781-JCS, United States District Court Northern District of California, complaint filed April 12, 2011.

<sup>&</sup>lt;sup>275</sup> Ibid.

<sup>&</sup>lt;sup>276</sup> Ibid.

#### State Law on Egg Donation and Surrogacy

Aside from statutes on the legal parentage of children born via collaborative ART, addressed below in the Uniform Parentage Act section, only a handful of states have laws that specifically speak to donor ART. California has the most comprehensive regulation, which is still very limited and patchwork in nature.<sup>277</sup> Louisiana is the only state to ban the sale of human eggs;<sup>278</sup> Virginia specifically exempts eggs from its prohibition on the sale of body parts.<sup>279</sup> New Hampshire requires that egg donors be medically screened prior to donation, and that both recipient parents must be medically evaluated and counseled.<sup>280</sup> The bulk of statutory and case law touching on egg donation has to do with the legal parentage of the resulting children.

Similarly, surrogacy laws are a patchwork across the states, though more states have addressed surrogacy than egg donation in their laws. The District of Columbia is the only area to have a complete ban on surrogacy arrangements, and a bill that would legalize surrogacy, The Surrogacy Parenting Agreement Act of 2013, B20-0032, after a public hearing in June 2013, is currently under council review.<sup>281</sup> New York law allows only uncompensated surrogacy arrangements; contracts for which compensation is exchanged are unenforceable and criminal.<sup>282</sup> On the other end of the spectrum, a few states have enacted statutes permitting surrogacy and providing some legislative structure (California, Illinois, New Hampshire, and Nevada).<sup>283</sup> In between, states do everything including refusing to enforce surrogacy arrangements but not criminalizing them, requiring parents to formally adopt a child after birth, criminalizing surrogacy arrangements, allowing surrogacy within certain legislative restrictions, allowing case law to support surrogacy, and in states where there is neither statutory nor case law, routinely unpredictably, or never granting pre-birth orders for parentage.

<sup>281</sup> District of Columbia Surrogacy Parenting Agreement Act of 2013, B20-0032, available from the District of Columbia Legislative Information Management System, lims.dccouncil.us/SearchResults/? Category=0&Keyword=B20-0032; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>277</sup> See previous section, "California."

<sup>&</sup>lt;sup>278</sup> Louisiana Revised Statutes § 9:122.

<sup>&</sup>lt;sup>279</sup> President's Council on Bioethics, *Reproduction and Responsibility: The Regulation of New Biotechnologies* (2004): 151-152.

<sup>&</sup>lt;sup>280</sup> New Hampshire Revised Statutes Annotated §§ 168-5:14, 168-B:13, 166-B:13(IV).

<sup>&</sup>lt;sup>282</sup> New York Domestic Relations Law §§ 122-123.

<sup>&</sup>lt;sup>283</sup> California Family Code §§ 7960-7962; 750 Illinois Compiled Statutes § 47; New Hampshire Public Safety and Welfare § 168; Nevada Revised Statutes §§ 126.500-26.810.

# Pending and Recently Vetoed or Withdrawn Legislation

In addition to the surrogacy legalization bill pending in DC, five states have recent pending or recently vetoed legislation on collaborative ART, which mostly concern surrogacy: Maryland, Minnesota, New York, New Jersey, and Kansas.

The Maryland Collaborative Reproduction Act, SB0208, spells out the legal rights of the gestational surrogate and intended parents, ensuring that the surrogate (or the egg donor) is not the legal mother of the child(ren) and that the intended parents have full parental rights and obligations.<sup>284</sup> It also provides for standard inheritance and other protections for children born from such arrangements.<sup>285</sup> The bill has passed the Judicial Proceedings Committee and as of March 2014, was awaiting reading in the House Rules and Executive Nominations Committee.<sup>286</sup>

In Minnesota, two bills, HF 291 and SF 2627, would add a presumption of parentage to the current paternity/maternity statute for intended parents who use donor gametes and/or a surrogate, and would give infertile women who don't have functional eggs or uterus the same rights as infertile men without sperm under Minnesota Statutes section 257.56.<sup>287</sup>

In New York, the Child-Parent Security Act, A6701/S4617, would dramatically change the legal landscape by allowing compensated gestational surrogacy arrangements.<sup>288</sup> The Act establishes the legal parentage of children born of collaborative ART arrangements and sets forth a legislative structure for commercial gestational surrogacy arrangements.<sup>289</sup> New York's bill also includes a provision about compensation of gamete donors and surrogates, which largely follows the ASRMs guidelines, detailed

<sup>285</sup> Ibid.

<sup>286</sup> Ibid.

<sup>288</sup> New York Child-Parent Security Act, A6701/S4617, available from assembly.state.ny.us/leg/? bn=A06701&term=2013; Internet; Accessed 7 September 2014.

<sup>289</sup> Ibid.

<sup>&</sup>lt;sup>284</sup> Maryland Collaborative Reproduction Act, SB0208, available from mgaleg.maryland.gov/webmga/ frmMain.aspx?pid=billpage&stab=02&id=sb0208&tab=subject3&ys=2014RS; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>287</sup> Minnesota HF 291 (legal parentage of children of ART), available from www.house.leg.state.mn.us/ bills/billnum.asp?Billnumber=HF291&ls\_year=88&session\_year=2013&session\_number=0; Internet; Accessed 7 September 2014; Minnesota SF 2627 (legal parentage of children of ART), available from www.house.leg.state.mn.us/bills/billnum.asp?billnumber=SF+2627; Internet; Accessed 7 September 2014; 2013 Minnesota Statutes § 257.56 provides parental rights to the intended father of a child created through sperm donation, and denies parental rights to the sperm donor.

below.<sup>290</sup> The bill specifies that compensation to donors must not be "to purchase gametes or embryos or to pay for the relinquishment of a parental interest in a child," thus establishing the bill's intent to distinguish payment for a donor's services versus payment for her eggs.<sup>291</sup> The bill is currently awaiting review by the Judiciary Committee in the Assembly and by the Children and Families Committee in the Senate.<sup>292</sup>

In New Jersey, site of the infamous 1988 *Baby M* case in which a traditional surrogate (a surrogate who conceives using her own eggs and the intended father's sperm via artificial insemination) changed her mind after the baby was born and the Court declared traditional surrogacy arrangements against public policy, The New Jersey Gestational Carrier Agreement Act, S1599, would have legalized gestational surrogacy arrangements.<sup>293</sup> The Act recognized gestational surrogacy agreements as within public policy, provided for establishment of legal parentage by the intended parents immediately upon birth, legally protected the best interests of the child, and gave the right to use a surrogacy arrangement to gay and lesbian couples in civil unions and domestic partnerships.<sup>294</sup> New Jersey Governor Chris Christie vetoed the bill in August 2012, so New Jersey will retain its current status quo of regular practice of gestational surrogacy arrangements with no legislative structure.<sup>295</sup>

In Kansas, SB 302 would have made entering into a surrogacy agreement illegal and punishable by up to a \$10,000 fine and/or jail time.<sup>296</sup> The bill was introduced in January 2014, but after a hearing in the Senate Committee on Public Health and Welfare, the bill's sponsor withdrew it from consideration.<sup>297</sup>

<sup>290</sup> Ibid.

<sup>291</sup> Ibid.

<sup>292</sup> Ibid.

<sup>294</sup> New Jersey Gestational Carrier Agreement Act, S1599 (vetoed Aug. 20, 2012).

<sup>295</sup> Ibid.

<sup>297</sup> Ibid.

<sup>&</sup>lt;sup>293</sup> In re Baby M, 537 A.2d 1227, 109 N.J. 396 (N.J. 1988); New Jersey Gestational Carrier Agreement Act, S1599 (vetoed Aug. 20, 2012), available from www.njleg.state.nj.us/bills/BillView.asp; Internet; Accessed 7 September 2014; veto letter available from votesmart.org/static/vetotext/41597.pdf; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>296</sup> Kansas SB 302 (bill died), available from www.kslegislature.org/li/b2013\_14/measures/sb302/; Internet; Accessed 7 September 2014.

#### International Law

Many countries outside the United States have done a more thorough job of regulating egg donation. Some countries, such as Germany, Austria, and Switzerland, prohibit the practice altogether.<sup>298</sup> Others place restrictions on egg donation: the United Kingdom, Denmark, and Canada all limit the use of egg donation via policy enforced by regulatory bodies. Yet other countries both allow and encourage egg donation as a lucrative business.

The United Kingdom, under the Human Fertilisation and Embryology Act of 1990, allows egg donors to receive reimbursement for expenses as well as a small fee, for total compensation up to £750 (about US \$1220).<sup>299</sup> The compensation structure was changed in October 2011, when the total reimbursement was raised from £250.<sup>300</sup> The Act also established the regulatory body The Human Fertilisation and Embryology Authority, which promotes altruistic donation and discourages clinics from working with donors they suspect have been compensated outside the law.<sup>301</sup>

Denmark used to prohibit egg donation, but as of June 2011, anonymous egg donation is permitted and donors are reimbursed by the government.<sup>302</sup> Danish compensation for egg donors, however, is very low at DKK 500 (less than US \$100), and consequently, the

<sup>&</sup>lt;sup>298</sup> See S. Bergmann, "Reproductive Agency and Projects: Germans Searching for Egg Donation in Spain and the Czech Republic," *Reproductive Biomedicine Online* 23, no. 5 (Nov. 2011): 600-608, available from www.rbmojournal.com/article/S1472-6483%2811%2900358-0/abstract; Internet; Accessed 23 September 2014; Jessica Ware, "European Court of Human Rights Upholds Austria's Ban on Egg or Sperm Donation for IVF," *BioNews*, 14 November 2011, available from www.bionews.org.uk/page\_111556.asp; Internet; Accessed 23 September 2014; Swiss Law on Medically Assisted Reproduction, summary available at www.artregi.com/pages/information-on-data-collection/laws-policies.php; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>299</sup> Human Fertilisation and Embryology Act, available from www.legislation.gov.uk/ukpga/2008/22/ contents; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>300</sup> Human Fertilisation and Embryology Act; Human Fertilisation and Embryology Authority, "HFEA Agrees New Policies to Improve Sperm and Egg Donation Services," *HFEA Website*, 19 October 2011, available from www.hfea.gov.uk/6700.html; Internet; Accessed 23 September 2014; Denis Campbell, "Egg and Sperm Donors May get Thousands of Pounds in Fertility Plan," *The Guardian*, 22 August 2010, available from www.theguardian.com/lifeandstyle/2010/aug/22/fertility-eggs-sperm-donors; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>301</sup> Human Fertilisation and Embryology Act, Part 1.4.

<sup>&</sup>lt;sup>302</sup> P.S., "Calls for Increased Compensation for Egg Donors," *The Copenhagen Post*, 3 December 2012, available from www.geneticsandsociety.org/article.php?id=6541; Internet; Accessed 23 September 2014.

country's demand for egg donors far outstrips its supply.<sup>303</sup> Denmark has imposed further restrictions on egg donation, such as embryos from donated eggs and donated sperm may not be created (only a husband's sperm may be used to fertilize donated eggs), so that the child always knows one of his genetic parents.<sup>304</sup> As a result, many Danish fertility clinics work with egg donors in other countries, like Greece, Ukraine, and Spain.<sup>305</sup> More recently, Italy's Constitutional Court overturned its own ban on egg donation in 2014, declaring that the ban violated intended parents' right to have children, right to self determination, and right to health.<sup>306</sup>

Canada prohibits the compensation of egg donors above and beyond reimbursement for expenses.<sup>307</sup> The Assisted Human Reproduction Act was passed in 2004, and the Minister of Health has the authority to enforce it.<sup>308</sup> Australia allows egg donation, but has guidelines that require that donors reveal identifying information once the resulting child reaches the age of eighteen.<sup>309</sup> Payment to donors is prohibited.<sup>310</sup>

In Israel, the harvesting of human eggs was not allowed, by default prohibiting egg donation, until June 2010, when the Knesset approved a bill allowing young women to donate their eggs to infertile couples.<sup>311</sup> The women's medical expenses are covered by the government and they are also compensated by the government, originally in an

<sup>308</sup> Assisted Human Reproduction Act, S.C. 2004, c. 2.

<sup>&</sup>lt;sup>303</sup> Ibid.; "Wanted: Eggs. For Sale: Sperm," *The Copenhagen Post*, 21 May 2012, available from cphpost.dk/ news/wanted-eggs-for-sale-sperm.1674.html; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>304</sup> Copenhagen Fertility Center, "Egg Donation," CFC Website, available from www.copenhagenfertilitycenter.com/uk/behandlingen/gdonation.htm; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>305</sup> "Wanted: Eggs. For Sale: Sperm," *The Copenhagen Post.* 

<sup>&</sup>lt;sup>306</sup> "Italy Drops Ban on Infertile Couples Using Donated Eggs or Sperm," *British Medical Journal* 348 (April 2014): g2722; Giuseppe Banagiano et al., "Italian Constitutional Court Removes the Prohibition on Gamete Donation in Italy," *Reproductive Biomedicine Online* [in press] (September 2014), available from www.rbmojournal.com/article/S1472-6483%2814%2900489-1/fulltext; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>307</sup> Assisted Human Reproduction Act, S.C. 2004, c. 2, available from laws-lois.justice.gc.ca/eng/acts/A-13.4/; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>309</sup> Australian Government, *National Health and Medical Research Council, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*, Part 6.1 (2004, rev. June 2007), available from www.nhmrc.gov.au/\_files\_nhmrc/publications/attachments/e78.pdf; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>310</sup> Ibid., Part 6.5.

<sup>&</sup>lt;sup>311</sup> B.F. Gruenbaum et al., "Ovum Donation: Examining the New Israeli Law," *European Journal of Obstetrics and Gynecology* 159, no. 1 (Nov. 2011): 40-42.

amount of approximately \$2800, but due to a shortage of donors, the compensation was increased in mid-2013 to approximately \$5200 per cycle.<sup>312</sup> The government maintains a database which people of majority age can check to see if they were conceived with collaborative ART, without revealing the donor's identity.<sup>313</sup> The bill prohibits Israeli women from traveling abroad to donate their eggs.<sup>314</sup>

Countries with very liberal egg donation policies attract patients and donors from other parts of the world. Typically in these countries donor fees are paid by the intended parents. Spain, Cyprus, Ukraine, and the Czech Republic have become egg donation destinations for people who can't afford treatment in the United States or live in a country where it is prohibited. Donors in Spain are anonymous and receive compensation of around US \$1500; intended parents are not allowed to choose their donors.<sup>315</sup> Cyprus has more fertility clinics per capita than any other country.<sup>316</sup> Ukraine has an open-door policy for egg donation, in which anonymous donors are paid on the order of a few hundred dollars and foreign patients do not need a visa if they are traveling for the purpose of receiving treatment with donor eggs.<sup>317</sup> The Czech Republic is another egg donation and low donor fees.<sup>318</sup> Other countries that allow and

<sup>&</sup>lt;sup>312</sup> Judy Siegel-Itzkovich, "Ministry Increases Sum Paid to Women for Donating Ova," *The Jerusalem Post*, 16 July 2013, available from www.jpost.com/Health-and-Science/Ministry-increases-sum-paid-to-women-for-donating-ova-319937; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>313</sup> State of Israel, Ministry of Health, "Egg Donation," *Ministry of Health Website*, available from www.health.gov.il/English/Topics/fertility/Pages/ovum\_donation.aspx; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>314</sup> Gruenbaum et al., "Ovum Donation: Examining the New Israeli Law," *European Journal of Obstetrics and Gynecology* 159, no. 1 (Nov. 2011): 40-42.

<sup>&</sup>lt;sup>315</sup> Denis Campbell, "Destination Spain: The Rise and Rise of Fertility Tourism," *The Guardian*, 22 August 2010, available from www.theguardian.com/lifeandstyle/2010/aug/22/spain-fertility-tourism; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>316</sup> Scott Carney, "Unpacking the Global Human Egg Trade," *Fast Company*, Issue 148, 1 September 2010, available from www.fastcompany.com/1676895/unpacking-global-human-egg-trade; Internet; Accessed 5 December 2013.

<sup>&</sup>lt;sup>317</sup> Ministry of Health of Ukraine, "About Approval of the Order to Apply Assisted Reproductive Technologies," Order #787, 9 September 2013; Successful Parents, "Why Ukraine?" available from www.successful-parents.com/main/ukraine/; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>318</sup> M. Susan Wilson, "U.S. Women Crossing Globe for Fertility Help," *NBC News*, 13 June 2014, available from www.nbcnews.com/id/19100571/ns/health-pregnancy/t/us-women-crossing-globe-fertility-help/ #.VCKArefAXTw; Internet; Accessed 23 September 2014.

encourage egg donation include Greece, Russia, South Africa, and Argentina, where harvested eggs are shared among two or more sets of intended parents.<sup>319</sup>

## Professional Organization Guidelines and Model Acts

Professional organizations in the fertility industry have created model laws and ethical guidelines intended to direct lawmakers toward a more standardized policy, and in turn, the legal protection of participants in a largely unregulated practice. For the most part, these guidelines have not been adopted by lawmakers, and when they have, they lack provisions for enforcement.

### SART/ASRM Ethics and Practice Committee Guidelines

Some infertility clinics have agreed to abide by the ethical guidelines of the Society for Assisted Reproductive Technology (SART), a professional organization whose stated mission is to "promote and advance the standards for the practice of assisted reproductive technology to the benefit of our patients, members, and society at large."<sup>320</sup>

SART maintains a list of ART fertility clinics that perform IVF (some of which house their own donor egg programs and some of which do not) that have paid a fee to SART for their listing and agreed to abide by the American Society for Reproductive Medicine (ASRM) Ethics and Practice Committees' guidelines governing repetitive egg donation, financial compensation of egg donors, and the 2012 Recommendations for Gamete and Embryo Donation.<sup>321</sup> According to the Centers for Disease control, which collects data on almost all fertility clinics in the country, the SART membership list for 2012, the most recent year for which data are publicly available, includes a total of 368 active clinics in

<sup>&</sup>lt;sup>319</sup> Pam Madsen, "The Wacky World of International Egg Donation," *The Fertility Advocate*, 19 July 2010, available from www.thefertilityadvocate.com/cross-border-fertility-treatment/the-wacky-world-of-international-egg-donation/; Internet; Accessed 23 September 2014.

<sup>&</sup>lt;sup>320</sup> Society for Assisted Reproductive Technology (SART), www.sart.org. SART is an affiliate of ASRM, which is "a multidisciplinary organization dedicated to the advancement of the art, science, and practice of reproductive medicine." ASRM website, www.asrm.org/mission; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>321</sup> Society for Assisted Reproductive Technology (SART), www.sart.org; ASRM Practice Committee and SART Practice Committee, "Recommendations for Gamete and Embryo Donation."

a total of forty-six states plus Puerto Rico and the District of Columbia.<sup>322</sup> An additional 72 clinics are not SART members.<sup>323</sup> Maine, Rhode Island, and Wyoming have no active fertility clinics, and Alaska's only clinic is not a SART member. 409 total clinics, including 57 non-SART member clinics, perform donor egg cycles (but don't necessarily recruit egg donors themselves).<sup>324</sup>

Notably, SART used to publish a list of egg donor *agencies* that had paid a fee to SART for their listing and, like the clinics on the SART list, had agreed to abide by the ASRM Ethics and Practice committees' guidelines governing repetitive egg donation, financial compensation of egg donors, and the 2008 Guidelines for Gamete and Embryo Donation. That list for 2010 included a total of seventy-two agencies, including two agencies that had branches in multiple states, in a total of twenty-three states.<sup>325</sup> Seven of those agencies were located in the greater San Francisco Bay Area. An online search in 2010 revealed at least nine additional egg donor agencies in the Bay Area, three of which were affiliated with major medical centers. Interestingly, the 2009 SART list of egg donor agencies included several agencies that do not appear on the 2010 list—some because they had become defunct, but most of them still had functioning websites and claimed to provide egg donor agencies.

Another source for listings of egg donor agencies used to be RESOLVE, a national nonprofit support organization for infertile people whose mission is "to promote reproductive health and to ensure equal access to all family building options for men and women experiencing infertility or other reproductive disorders."<sup>327</sup> Like SART, RESOLVE no longer published a list of agencies as of 2013.

The disappearance of the publicly available SART and RESOLVE lists of reputable egg donor agencies may simply be a matter of logistics—perhaps those organizations found that egg donor agencies open and shut down so quickly that it was impossible to keep up with them, much less evaluate them with due diligence. Regardless, the lack of a

<sup>&</sup>lt;sup>322</sup> CDC, www.cdc.gov/art/; Internet; Accessed 7 September 2014. See link to "2012 Data—Clinic Tables and Data Dictionary."

<sup>&</sup>lt;sup>323</sup> Ibid.

<sup>&</sup>lt;sup>324</sup> Ibid.

<sup>&</sup>lt;sup>325</sup> List is no longer available online; a copy is on file with author.

<sup>&</sup>lt;sup>326</sup> List is no longer available online; a copy is on file with author.

<sup>&</sup>lt;sup>327</sup> RESOLVE website, www.resolve.org/about/; Internet; Accessed 20 January 2014.

reliable third-party source of agency assessments is a step in the wrong direction in the context of an unregulated industry.

SART's efforts to bring some ethical standards to the industry are admirable, and likely at least somewhat effective, but as a professional organization, especially in such a new field, SART has no real teeth; there are no legal penalties for failure to join SART. Some of the major ethical issues about which SART has issued guidelines (under the umbrella of ASRM) are compensation of donors and protection of donors—in particular protection of their health.

The ASRM guidelines on financial compensation of egg donors state that compensation is ethically justified, but should be structured to acknowledge the "time, inconvenience, and discomfort" associated with the process of donation, as opposed to the number of eggs, the outcome of the cycle, or the characteristics of the donor.<sup>328</sup> The guidelines recommend that any fee above \$5000 requires justification, and fees above \$10,000 go "beyond what is appropriate."<sup>329</sup> The guidelines also state that donors should be taken through the informed consent process, and that physicians have the same duty to donors as to any other patient.<sup>330</sup> The 2012 Recommendations for Gamete and Embryo Donation include provisions on psychological screening, medical and reproductive history and status, infectious disease testing, compensation, and informed consent.<sup>331</sup> The document replaced by the 2012 Recommendations, the 2008 Guidelines, included a brief mention that "solicitation of donors should be in accordance with guidelines provided in the ASRM Ethics Committee Report on the subject;<sup>332</sup> this provision was excluded from the 2012 Recommendations.

The ASRM has also released guidelines on a number of other specific egg donationrelated topics. ASRM recommends that egg donors cycle no more than six times, as a prophylaxis against possible health risks, though no such risk has yet been demonstrated to occur.<sup>333</sup> In 2009, the ASRM also highlighted the need for full informed consent for donors, and encouraged clinics and agencies to respect donor choices about

<sup>&</sup>lt;sup>328</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

<sup>&</sup>lt;sup>329</sup> Ibid.

<sup>&</sup>lt;sup>330</sup> Ibid.

<sup>&</sup>lt;sup>331</sup> ASRM Practice Committee and SART Practice Committee, "Recommendations for Gamete and Embryo Donation," 54-58.

<sup>&</sup>lt;sup>332</sup> ASRM Practice Committee and SART Practice Committee, "2008 Guidelines for Gamete and Embryo Donation," S37; the Ethics Committee Report on donor solicitation may be found in ASRM Ethics Committee, "Financial Compensation of Oocyte Donors."

<sup>&</sup>lt;sup>333</sup> ASRM Practice Committee, "Repetitive Oocyte Donation," S195.

to whom they donate, as well as donors' wish to be informed of the outcomes of their cycles.<sup>334</sup> That document was updated in 2014.<sup>335</sup> The ASRM also released an opinion encouraging disclosure to children, but ultimately, supportive of the intended parents' decision on disclosure.<sup>336</sup> In 2013, ASRM released a guideline stating approval of egg donation to women over fifty years old, after consideration of the health risks to a particular individual.<sup>337</sup> Finally, the most recent opinion of the ASRM's Ethics Committee addresses misconduct by egg donors and intended parents, and what physicians should do about it.<sup>338</sup> The committee recommends that in order to resolve the situation without breaching confidentiality, the physician should attempt to convince the offending party to self-disclose; if they refuse, then weigh the risk of harm to the other party and future children against that of a breach of confidentiality. The physician may breach confidentiality in order to prevent greater harm, or he/she may withdraw from the treatment.<sup>339</sup>

#### Society for Ethics in Egg Donation and Surrogacy Standards

Where the ASRM guidelines are effective for the members of their professional organization and beyond, the standards of the Society for Ethics in Egg Donation and Surrogacy (SEEDS) are still new and trying to gain traction in the context of a new quasi-professional organization. SEEDS is a nonprofit organization for egg donor and surrogacy agencies, with the goal of creating a set of "best practices" standards to guide the business practices of agencies nationwide.<sup>340</sup> SEEDS is only a few years old, and its members are attempting simultaneously to grow the organization and to reach a consensus on standards for agencies. The currently proposed standards include the following topics:<sup>341</sup>

<sup>&</sup>lt;sup>334</sup> ASRM Ethics Committee, "Interests, Obligations, and Rights in Gamete Donation" (2009), 27.

<sup>&</sup>lt;sup>335</sup> ASRM Ethics Committee, "Interests, Obligations, and Rights in Gamete Donation" (2014), 675.

<sup>&</sup>lt;sup>336</sup> ASRM Ethics Committee, "Informing Offspring of Their Conception by Gamete or Embryo Donation,"48.

<sup>&</sup>lt;sup>337</sup> ASRM Ethics Committee, "Oocyte or Embryo Donation to Women of Advanced Age," 339.

<sup>&</sup>lt;sup>338</sup> ASRM Ethics Committee, "Misconduct in Third-Party Assisted Reproduction," 38-42.

<sup>339</sup> Ibid.

<sup>&</sup>lt;sup>340</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>341</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS) Standards, available from www.seedsethics.org; Internet; Accessed 8 September 2014. See Appendix III for the full text of the proposed SEEDS standards.

1. Agency competition: how to handle donors who have registered with multiple agencies, not creating "bidding wars" between agencies for donors, and not "stealing" donors from other agencies;

2. The agency's responsibility to gauge the "emotional maturity and commitment of egg donors;"

3. Checklists for a standard agency agreements with donors and with intended parents;

4. Definitions of terms for known vs. anonymous egg donation arrangements;

5. What information agencies should be obligated to share with donors or intended parents that might affect the parties' decisions to move forward with a cycle;

6. Standards for recruitment advertising for egg donors;

7. Guidelines for psychological and genetic evaluation of donors; and

8. Standards about what medical information agencies should provide to donors about the risks of donation.

The SEEDS standards, along with the draft ABA Model Act, are discussed in greater detail in Chapter Four, "The Project of Professionalization: Code of Conduct," and many of the standards themselves are cited throughout this dissertation.<sup>342</sup>

# 2002 Uniform Parentage Act

The Uniform Parentage Act is a uniform law, created in 1973 by the National Conference of Commissioners on Uniform State Laws, updated in 2000, at which point it incorporated the 1988 Uniform Status of Children of Assisted Conception Act, and amended most recently in 2002.<sup>343</sup> Article 7 of the Act addresses the parentage of children conceived via ART.<sup>344</sup> Specifically, the Uniform Parentage Act provides that a

<sup>&</sup>lt;sup>342</sup> See Appendix IV for the full text of the ABA Model Act Governing ART Agencies (*DRAFT*).

<sup>&</sup>lt;sup>343</sup> 2002 Uniform Parentage Act, available from uniformlaws.org/Act.aspx?title=Parentage%20Act; Internet; Accessed 7 September 2014. The Uniform Parentage Act is model legislation available for states to adopt in whole or in part; it is not binding law.

<sup>&</sup>lt;sup>344</sup> Ibid., § 702.

gamete donor is not the parent of a child resulting from the donation.<sup>345</sup> The legal parents of a child conceived with donor gametes are the people who consented to the reproductive procedure in writing beforehand, or, for a man in the absence of prior written consent, via his action of holding the child out to be his own during the first two years of the child's life.<sup>346</sup> The husband of a woman who gives birth to a donor-conceived child is presumed to be the legal father, and may only contest his paternity if he meets several criteria, including lack of consent before and after the birth, and the commencement of proceedings to adjudicate his paternity within two years of the child's birth.<sup>347</sup> But such a proceeding may be commenced at any time if the child was not conceived with the husband's sperm, the husband never held the child out as his own.<sup>348</sup>

The Uniform Parentage Act contains in Article 8 similar provisions establishing legal parentage for the intended parents using gestational surrogacy arrangements.<sup>349</sup>

The Uniform Parentage Act has seen much more legislative acceptance than the ABA Model Act Governing Assisted Reproductive Technology.<sup>350</sup> All states have adopted some form of the Uniform Parentage Act; only a handful have adopted the 2002 version that contains the provisions about children of ART (Alabama, Delaware, New Mexico, North Dakota, Oklahoma, Texas, Utah, Washington, and Wyoming).<sup>351</sup> Some states have independent statutory provisions or case law that donors are not legal parents (including Colorado, Connecticut, Florida, New York, and Virginia).<sup>352</sup> Several states,

<sup>346</sup> Ibid., § 704.

<sup>347</sup> "A man who provides sperm for, or consents to, assisted reproduction by a woman as provided in Section 704 with the intent to be the parent of her child, is the parent of the resulting child." Ibid., § 703.

<sup>348</sup> Ibid., § 705.

<sup>349</sup> Ibid., §§ 801 et seq.

<sup>&</sup>lt;sup>345</sup> "A donor is not a parent of a child conceived by means of assisted reproduction." Ibid.

<sup>&</sup>lt;sup>350</sup> American Bar Association Model Act Governing Assisted Reproductive Technology (February 2008), available from apps.americanbar.org/family/committees/artmodelact.pdf; Internet; Accessed 5 November 2014.

<sup>&</sup>lt;sup>351</sup> See, e.g., Alabama Code §§ 26-17-1 et seq.; 13 Delaware Code §§ 8-101 et seq.; New Mexico Statutes Annotated §§ 40-11A-701 et seq.; North Dakota Century Code §§ 14-20-59 et seq.; Oklahoma Statutes § 10-555; Texas Family Code Annotated §§ 160-701 et seq.; Texas Family Code §§ 160.001 et seq.; Utah Code Annotated §§ 160-701 et seq.; Washington Revised Code §§ 23.700 et seq.; Wyoming Statutes Annotated §§ 14-2-901 et seq.

<sup>&</sup>lt;sup>352</sup> Florida Statutes §§ 742.11 (1) & 742.14; McDonald v. McDonald, 608 N.Y.S.2d 477 (1994); Virginia Code § 20-158(A)(3).

including the District of Columbia, Louisiana, Ohio, and Virginia, provide that the birth mother is presumptively the legal mother.<sup>353</sup> Tennessee has case law that the intended parents are the legal parents.<sup>354</sup> While the Uniform Parentage Act has largely achieved its original purpose in making children born out of wedlock legally equal to "legitimate" children, it has yet to fully realize its potential for clarifying the legal parentage of children born via ART.

### ABA Model Act Governing Assisted Reproductive Technology

The American Bar Association (ABA) has also attempted to bring some order to the world of assisted reproductive technology by issuing the Model Act Governing Assisted Reproductive Technology in February of 2008.<sup>355</sup> The Model Act was created in conjunction with ASRM and SART, and includes provisions on informed consent, donor and recipient rights, parental rights, and donor compensation.<sup>356</sup> To date, however, the ABA Model Act has not seen legislative acceptance. The ABA is currently in the process of updating the Model Act to reflect new technology and practices.<sup>357</sup>

The ABA Model Act contains several provisions specific to egg donation. Egg donors may remain anonymous, as long as they provide non-identifying health information. If, however, they give permission for the release of identifying information, that permission may not be revoked after the egg donation occurs.<sup>358</sup> The Model Act also provides that donors are not the legal parents of children conceived from their donated gametes, but instead the person who intended to become a parent is the legal parent of

<sup>&</sup>lt;sup>353</sup> District of Columbia Code 16-909(a-1); Louisiana Civil Code § 184; Ohio Revised Code Annotated § 311.2; Virginia Code § 20-158(A)(1).

<sup>&</sup>lt;sup>354</sup> In re C.K.G., 173 S.W. 3d 714 (Tenn. 2005) (intended parents are legal parents).

<sup>&</sup>lt;sup>355</sup> ABA Model Act Governing ART.

<sup>&</sup>lt;sup>356</sup> Ibid.

<sup>&</sup>lt;sup>357</sup> Rich Vaughn, "ASRM Conference Offers Meeting Opportunity for Model Act Work," *International Fertility Law Group* (blog), posted 11 October 2013, available from www.iflg.net/Rich-Vaughn-Blog-ASRM-Conference-Model-Act; Internet; Accessed 7 September 2014.

<sup>&</sup>lt;sup>358</sup> ABA Model Act Governing ART § 204.

the resulting child.<sup>359</sup> The Model Act specifically states that it is not meant to supersede provisions of the Uniform Parentage Act.<sup>360</sup>

Article 8 of the Model Act addresses payment to donors and gestational carriers.<sup>361</sup> Donors may receive reimbursement for direct expenses incurred as a result of the donation, including premiums for insurance intended to cover potential harm from the donation process.<sup>362</sup> In addition, the Model Act provides that compensation for donors and surrogates must be "reasonable and negotiated in good faith between the parties," and cannot be conditioned upon the donor's genetic traits or the actual "genotypic or phenotypic characteristics" of the donor or of the child—an attempt to avoid the problem of eugenics.<sup>363</sup>

Finally, the ABA Model Act provides guidelines for the creation of registries of donors and participants in collaborative reproduction, intended to maintain "contact, medical, and psychosocial information about donors, gestational carriers, and children born as a result of ART, or to benefit the public health."<sup>364</sup> Such registries must enable the disclosure of non-identifying medical and psychosocial information to the children of assisted reproduction in a manner such that donors may preserve their anonymity, allow for the disclosure of identifying information with the mutual consent of all affected parties, and maintain updated medical and genetic information from donors (where the donor has previously agreed to provide such).<sup>365</sup> Registries must retain all their records for each child until the child has reached the age of forty.<sup>366</sup>

<sup>&</sup>lt;sup>359</sup> Ibid., §§ 602-603.

<sup>&</sup>lt;sup>360</sup> "It is not the intent of this act to conflict with or supersede provisions of the Uniform Parentage Act..." Legislative Note to Article 6, ABA Model Act Governing ART.

<sup>&</sup>lt;sup>361</sup> ABA Model Act Governing ART §§ 801-802.

<sup>&</sup>lt;sup>362</sup> Ibid., § 801.

<sup>363</sup> Ibid., §§ 801-802.

<sup>&</sup>lt;sup>364</sup> Ibid., § 1002.

<sup>&</sup>lt;sup>365</sup> Ibid.

<sup>&</sup>lt;sup>366</sup> Ibid.

# Draft ABA Model Act Governing Assisted Reproductive Technology Agencies

The American Bar Association is in the process of creating another model act on ART, this one targeted specifically at egg donor and surrogacy agencies.<sup>367</sup> Discussed in detail in Chapter Four, "The Project of Professionalization: Entry Qualifications" and "Code of Conduct," along with the SEEDS standards, the Draft ABA Model Act Governing Assisted Reproductive Technology Agencies was conceived approximately four years ago. It is much more basic than the SEEDS standards, and intended to work with them, rather than parallel to or in conflict with them. The ASRM has been involved in the creation of the Draft Model Act Governing ART Agencies, the October 2013 version of which has been approved by the ART Committee of the Family Law Section of the ABA.<sup>368</sup> The Model Act will next be submitted to the Family Law Section for approval, and from there it will move up to the ABA House of Delegates. The ART Committee of the ABA is hoping for final approval of the Model Act in the next one to two years.<sup>369</sup> The goal of the Model Act is to regulate conduct, and not to legislate moral or ethical issues among agencies.<sup>370</sup> One of its primary provisions is licensing for agencies;<sup>371</sup> it also covers agency service agreements, checklists for starting a donor egg IVF cycle, and a list of affirmative duties and obligations of agencies.<sup>372</sup>

# Analogous Regulation

# Organ Donation

Eggs are not organs, and organs have long been treated differently than human tissue under law. The National Organ Transplant Act of 1984 established at a federal level that human organs could not be sold.<sup>373</sup> Participation in the sale of organs can be punished

<sup>&</sup>lt;sup>367</sup> See Appendix IV for the text of the ABA Model Act Governing ART Agencies (*DRAFT*) as of October 2013.

<sup>&</sup>lt;sup>368</sup> Per a family formation attorney interviewee.

<sup>&</sup>lt;sup>369</sup> Per a family formation attorney interviewee.

<sup>&</sup>lt;sup>370</sup> Per a family formation attorney interviewee.

<sup>&</sup>lt;sup>371</sup> ABA Model Act Governing ART Agencies (*DRAFT*) § 301.

<sup>&</sup>lt;sup>372</sup> Ibid., §§ 302-304.

<sup>&</sup>lt;sup>373</sup> The National Organ Transplant Act of 1984, 42 USC § 274e.

with a penalty of up to \$50,000 or five years of imprisonment.<sup>374</sup> The prohibition against organ sales is the only regulatory provision of the Act, and was included because of the authoring committee's belief that human body parts should not be viewed as commodities.<sup>375</sup> Indeed, the sale of organs is prohibited in almost every country. In many countries, however, including Israel, India, Turkey, China, Russia, and Iraq, organ sales are "conducted with only a scant nod toward secrecy."<sup>376</sup>

Many scholars have documented the international organ trade. Lawrence Cohen, a UC Berkeley anthropologist, argues that poor people who sell their kidneys often do so to pay existing debts, but lapse into debt again soon after their surgeries.<sup>377</sup> Nancy Scheper-Hughes, another UC Berkeley anthropologist and co-founder of Organs Watch (the goal of which organization is to establish and promote a human rights agenda for dealing with violations of the bodily integrity of vulnerable populations), describes transplant surgery as practiced in many global contexts "a blend of altruism and commerce, of science and magic, of gifting, barter, and theft, of choice and coercion."<sup>378</sup> Although United States citizens sometimes travel to foreign countries to purchase organs (and sometimes arrange to have purchased organs transplanted in U.S. hospitals), the sale of organs is much more effectively prohibited in this country than abroad.<sup>379</sup>

#### Human Tissue Donation/Sale

Sales of human tissues such as blood, in contrast to organs, are permitted in the U.S., but they are regulated by the Food and Drug Administration (FDA), which classifies gametes as tissue.<sup>380</sup> Under 21 C.F.R. § 1271, tissue banks must register their activities

<sup>380</sup> 21 C.F.R. §§ 1270 et seq.

<sup>374</sup> Ibid.

<sup>&</sup>lt;sup>375</sup> National Attorneys' Committee for Transplant Awareness, Inc., Organ and Tissue Donation and Transplantation: A Legal Perspective.

<sup>&</sup>lt;sup>376</sup> Michael Finkel, "Complications," New York Times, 27 May 2001.

<sup>&</sup>lt;sup>377</sup> Lawrence Cohen, "Where it Hurts: Indian Material for an Ethics of Organ Transplantation," *Daedalus* 128, no. 4 (Fall 1999): 135.

<sup>&</sup>lt;sup>378</sup> Nancy Scheper-Hughes, "The Global Traffic in Human Organs," *Current Anthropology* 41, no. 2 (2000): 191.

<sup>&</sup>lt;sup>379</sup> Denis Campbell and Nicola Davison, "Illegal Kidney Trade Booms as New Organ is 'Sold Every Hour,'" *The Guardian*, 27 May 2012, available from www.theguardian.com/world/2012/may/27/kidney-trade-illegal-operations-who; Internet; Accessed 7 September 2014.

and comply with FDA standards of safety.<sup>381</sup> When the FDA regulations were instituted in 2001, it became clear that "a multi-million dollar industry [in human tissues] had emerged, which had powerful financial backing from hospitals, pharmaceutical companies, investors, and venture capital firms."<sup>382</sup> It is clear from federal law that people have at least a quasi-property interest in their tissues. That interest is not always realized, however, because many organ procurement agencies sell the peripheral tissues of organ donors to for-profit companies—without the consent of the donor.<sup>383</sup>

Perhaps the seminal legal case on ownership of biologic material is the California Supreme Court's *Moore v. Regents of the University of California,* in which the Court held that the plaintiff, Moore, did not have a property interest in tissue excised during his cancer treatment and then used by his physicians to create, patent, and sell a cell line, because the tissue no longer belonged to Moore once it was excised.<sup>384</sup> Furthermore, Moore had given his informed consent to have the tissue excised.<sup>385</sup> Consequently, Moore was not entitled to any of the proceeds of the cell line patent developed from his tissue.<sup>386</sup> Underlying this ruling was the court's concern for public policy. If Moore had a property interest in his excised tissue, that interest would carry over to the proceeds of the patent. The court feared that such an arrangement would inhibit medical research by diminishing researchers' profit, which would be to the detriment of society.<sup>387</sup>

In a convincing dissent, Justice Mosk argues that property law allows a person to have incomplete dominion over a thing.<sup>388</sup> The law allows a person to give organs away, but not to sell them, and Moore certainly had the power to exclude people from taking his tissue. Mosk characterizes Moore's property interest in his excised tissue as consisting of part of the "bundle" that makes up property rights.<sup>389</sup>

<sup>&</sup>lt;sup>381</sup> 21 C.F.R. § 1271.

<sup>&</sup>lt;sup>382</sup> Michele Goodwin, "Altruism's Limits: Law, Capacity, and Organ Commodification," *Rutgers Law Review* 56, no. 2 (Winter 2004): 386.

<sup>&</sup>lt;sup>383</sup> Ibid., 388.

<sup>&</sup>lt;sup>384</sup> Moore, 793 P.2d 479.

<sup>&</sup>lt;sup>385</sup> Moore, 793 P.2d 479.

<sup>&</sup>lt;sup>386</sup> Moore, 793 P.2d at 493.

<sup>&</sup>lt;sup>387</sup> Moore, 793 P.2d at 494-495.

<sup>&</sup>lt;sup>388</sup> Moore, 793 P.2d 479.

<sup>&</sup>lt;sup>389</sup> Moore, 793 P.2d 479.

Marjorie Shultz agrees with Justice Mosk, and argues that an integration of the commercial interests of both patient and physician, as well as concerns about the human dignity and personhood of the patient, was not possible with the majority's approach, which focused solely on the commodification aspect of the problem.<sup>390</sup>

In two subsequent cases, one in Florida and one in Washington, courts denied the plaintiffs' claims to genetic material they had donated for research purposes.<sup>391</sup> Both courts relied on *Moore*'s reasoning to hold that informed consent can "transfer exclusive ownership of human cells and tissues to another entity," and both courts cited the chilling effect that donor control over their own biologic tissues could have on future research.<sup>392</sup> *Moore* was not binding precedent for either court.

The law is inconsistent in the way it treats ownership of biologic and genetic material. Organs may be donated but not sold. Other tissues may be sold, but once removed from the body any ownership interest is terminated. Using the concept of a bundle of property rights, we seem to possess different sticks in the bundle depending on the type of body part and the context in which we are separated from it. Some of the difference may be explained the potential for exploitation; organs are non-replenishable, and retrieving them is a physically invasive process. As such, they command high prices on the black market, and the potential for exploitation of vulnerable populations might be considered to be high. In contrast, blood is replenishable and relatively easy to collect, and compensation is de minimus. Reproductive tissue adds an extra layer of complexity: the potential for life.

#### Reproductive Tissue

Most existing law on reproductive tissue concerns embryos, although some addresses sperm. The most definitive law on embryos comes from the courts, which nonetheless have fastidiously avoided reasoning substantively about the legal status of the embryo. Although many courts have had the opportunity to clarify the status of the embryo in the context of frozen embryo disposition cases, very few courts have taken advantage of

<sup>&</sup>lt;sup>390</sup> Shultz, "Questioning Commodification," 1850 and 1857.

<sup>&</sup>lt;sup>391</sup> Greenberg v. Miami Children's Hospital Research Institute, 264 F. Supp. 2d 1064 (S.D. Fla. 2003) (researcher patents discovered gene and charges a licensing fee for derived genetic test); Washington University v. Catalona, 2007 WL 1758268 (8<sup>th</sup> Cir. 2007) (neither research subject nor original researcher may withdraw tissue samples from a study hosted by Washington University because of the university's claim to the samples).

<sup>&</sup>lt;sup>392</sup> Ikemoto, "Eggs as Capital," 779; Greenberg, 264 F. Supp. 2d 1064; Catalona, 2007 WL 1758268.

it. Not infrequently, a couple who has used reproductive technology to attempt a pregnancy has leftover frozen embryos at the time of their divorce, and they disagree about whether the embryos should be saved for future use or destroyed. Most courts decide the issue based on the enforceability of the reproductive technology contract or the constitutional rights of the parents to procreate or not to procreate. In contrast, the Supreme Court of Tennessee chose to frontally address the legal status of the embryo itself.

In Davis v. Davis, the Supreme Court of Tennessee ruled in favor of a man who wished to have embryos (that he and his wife had created during their marriage) destroyed over the objections of his former wife.<sup>393</sup> The court established a framework in which a prior agreement between the parties should be enforced, and in the absence of such an agreement, the court should weigh the interests of the parties, typically ruling in favor of the party who wishes to avoid procreation. More importantly for the purposes of this dissertation, the court found that embryos are not "persons" in the constitutional sense because they are even less developed than fetuses, which are not constitutional persons.<sup>394</sup> But neither are they property in the pure sense. Rather, the court found that embryos occupy a position in between the two: "the preembryo deserves respect greater than that accorded to human tissue but not the respect accorded to actual persons."<sup>395</sup> This "special respect" is based on the embryo's potential to develop into a person, but limited by the fact that the embryo may never realize that potential. As such, the embryo occupies an interim category that grants the gamete-providers an ownershiptype interest, though not a true property interest, in them. This ownership interest gives the gamete-providers decision-making authority over the embryos, and so their wishes should be enforced where possible.<sup>396</sup>

Law professor and bioethicist Jessica Berg agrees with the reasoning of the Supreme Court of Tennessee: "there are normative grounds for recognizing property interests in embryos and fetuses . . . [but] developing personhood interests limit the property

<sup>&</sup>lt;sup>393</sup> Davis v. Davis, 842 S.W.2d 588 (Tenn. 1992). While the former husband wanted the embryos to be destroyed, his former wife at first wanted to implant them in herself, but then after she remarried, she changed her mind and wanted to donate them to another infertile couple.

<sup>&</sup>lt;sup>394</sup> Davis, 842 S.W.2d at 595.

<sup>&</sup>lt;sup>395</sup> Davis, 842 S.W.2d at 596, quoting Report of the Ethics Committee of the American Fertility Society, Journal of the American Fertility Society 53 (????): 34S-35S.

<sup>&</sup>lt;sup>396</sup> Davis, 842 S.W.2d at 597. The court held that when the wishes of the gamete providers conflict, a prior agreement should be enforced, and if no prior agreement exists, then generally the owner wishing to avoid procreation should prevail.

interests."<sup>397</sup> Other states have issued laws or judicial opinions that imply the embryo has a particular status, although there is no consensus on exactly what that status is. Louisiana treats embryos as children rather than property: disposition of embryos during divorce proceedings is governed by a "best interests of the embryo" standard, and amazingly, the embryo is a "juridical person" who has the right to sue or be sued.<sup>398</sup> In contrast, a district court in Virginia treated embryos solely as property. *York v. Jones* involved a dispute between an infertility clinic and a married couple about whether the clinic would transfer a frozen embryo to another clinic.<sup>399</sup> The court treated the embryo as property that had been left for bailment with the clinic, an analysis that implies the embryo holds the same legal status as a chair or a book.

The American Medical Association (AMA), the professional organization for all physicians in the United States, has developed guidelines for the disposition of frozen embryos that allow the creators to use them, thaw them, donate them for research purposes, or donate them to another woman, but not to sell them.<sup>400</sup> The American Bar Association (ABA) suggests similar guidelines.<sup>401</sup>

Because the legal status of embryos varies so widely from state to state, it is difficult to predict which legal standard might come to prevail. The states will be limited to some extent by federal constitutional law declaring that fetuses are not constitutional persons, with its implication that fetal precursors such as embryos also cannot be constitutional persons.<sup>402</sup> Yet constitutional law does not prohibit states from declaring embryos to be persons for other legal purposes, as has Louisiana.<sup>403</sup> The legal situation for eggs is even more uncertain, as egg donation has gone essentially unregulated thus far. But Tennessee's seminal case *Davis v. Davis* may give some insight as to how the legal status of human eggs might develop.<sup>404</sup>

<sup>&</sup>lt;sup>397</sup> Jessica Berg, "Owning Persons: The Application of Property Theory to Embryos and Fetuses," *Wake Forest Law Review* 40 (2005): 217-218. See also idem, "Risky Business: Evaluating Oocyte Donation," *The American Journal of Bioethics* 1, no. 4 (Fall 2001): 18-19.

<sup>&</sup>lt;sup>398</sup> Louisiana Revised Statutes § 131 and Louisiana Revised Statutes § 124, respectively.

<sup>&</sup>lt;sup>399</sup> York v. Jones, 717 F. Supp. 421 (E.D. Va. 1989).

<sup>&</sup>lt;sup>400</sup> American Medical Association Council on Ethical and Judicial Affairs, Code of Medical Ethics, Op. 2.141 (1999).

<sup>&</sup>lt;sup>401</sup> ABA Model Act Governing ART, Art. 5.

<sup>&</sup>lt;sup>402</sup> See Roe v. Wade, 410 U.S. 113 (1979).

<sup>&</sup>lt;sup>403</sup> In Louisiana, the embryo is a "juridical person" who may sue or be sued. Louisiana Revised Statutes § 124.

<sup>&</sup>lt;sup>404</sup> Davis, 842 S.W.2d 588.

The *Davis* court attempted to articulate an intermediate legal status of the embryo that balances its nature as human tissue with its potential to become a separate human life.<sup>405</sup> The idea of the embryo as a kind of quasi-property makes a certain amount of sense: the fetus has some legal entitlements, although it is not a constitutional person, and those entitlements are based on its potential to become a constitutional person. The embryo also has the potential to become a constitutional person, although that potential is significantly more improbable given that the embryo may not survive outside the uterus, may not implant properly, and may not ever be transferred into a uterus at all. At the same time, that slight potential for life might instill value in the embryo that is simply not present in a group of blood cells (at least not yet—the technology is rapidly getting there).

Taking the theme of potential life a step further, it could be argued that because the egg is the precursor to the embryo, it is also potential life. But the egg must overcome all of the obstacles faced by the embryo and the added burden of surviving on its own outside the ovary and becoming fertilized. Using the reasoning of the *Davis* court, the egg would be a quasi-property, like the embryo, yet the egg would tend more toward the property end of the spectrum than embryos because the egg has a lesser potential for life. The *Davis* court might conclude that even though this potential for life is very limited, it still exists, and that earns the egg a "special respect" like that of the embryo. Alternatively, the court might conclude that the egg is far enough removed from its potential as a human life—because that potential does not exist in the egg itself; it cannot become life without the addition of another cell—that it does not merit special treatment under law. In that case, the egg would be treated more like tissue: largely alienable.

In contrast to embryos and eggs, sperm donation is legislated in most states. While most states do not have statutes addressing compensation of the donor, which tends to be de minimis and paid on a donation-by-donation basis, the vast majority of states do have legislation declaring the consenting husband whose wife is inseminated with donor sperm the resulting child's natural (legal) father, and many of those states do not consider the sperm donor to be the legal father of any child born due to artificial insemination.<sup>406</sup> Arizona, Hawaii, Indiana, Kentucky, Rhode Island, South Carolina, South Dakota, Vermont, and West Virginia do not address sperm donation under their statutes or case law. In sum, although many states have legislation that addresses sperm

<sup>&</sup>lt;sup>405</sup> Davis, 842 S.W.2d at 595.

<sup>&</sup>lt;sup>406</sup> Most such laws are an adoption or adaptation of some version of the Uniform Parentage Act; the protections for sperm donors exist only if a physician is used in the conception of the child.

donation in one form or another, the laws are far from uniform, and vary widely across the United States.

# Adoption

While a detailed analysis of adoption law in the United States and abroad is far beyond the scope of this dissertation, it is worth noting that adoption is heavily regulated around the world.<sup>407</sup> A major difference between egg donation and adoption, is, of course, the existence of an actual child in the case of adoption, versus a single cell that has the potential to become a child in the case of egg donation. In the United States, children to be adopted are wards of the state, which vets the prospective adoptive parents for their ability to parent well.<sup>408</sup> Children are protected by the government, at least in theory, and the system is set up to abide by the best interests of the child standard.<sup>409</sup> There is no question of property, since children are not property by any reasonable definition, and the interests of the parents are largely sidelined. In egg donation, in contrast, the intended parents stand at the center of the transaction; without them, there would be no egg donation or resulting child.

Adoption law does protect the parents' interests after an adoption is finalized (which is really meant to create a stable home life for the child), as well as stringently protecting the birth mother's right to change her mind about giving up her child for adoption.<sup>410</sup> Egg donation lacks similar protections; most states have enacted legislation protecting donors from unwanted claims of child support or other obligations of legal parenthood, yet very few states give any other kind of protection to donors or intended parents. Adoption and egg donation are both practices that have implications for how we think of our ourselves, our families, and our humanity. Adoption laws exist to protect the child and the other parties in the creation of nonconventional families. Laws with a similar protective effect should be enacted for collaborative ART.

<sup>&</sup>lt;sup>407</sup> For a contextualized overview of adoption law in the United States, see Cahn and Hollinger, eds., *Families by Law.* 

<sup>&</sup>lt;sup>408</sup> Ibid., 37 et seq.

<sup>&</sup>lt;sup>409</sup> Ibid.

<sup>410</sup> Ibid.

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Egg donation is a new technology with a short history of practice and a patchwork of case law addressed to it, along with legislation that has failed to keep up with the current state of the ART. While some form of regulation is surely necessary for such a complex legal and emotional field, poorly thought out legislation has the potential to do more harm than good. Organizations such as the ABA Family Law Section ART Committee are working to ensure that legislators have a guide to regulating this difficult topic, which has its fingers in many pies: family, procreation, science, technology, insurance, politics, and our very humanity, to name a few. But given the lack of regulation thus far, this dissertation asks: what do agency decision-makers do?

# CHAPTER THREE

# Emergence of Norms in a New Field: Divergence to Convergence

"You try to keep standards always on tap." (Director, Southern California Agency)

Norms in a new field can develop any number of ways, including by spreading across a field, in response to uncertainty or pressure from outside forces (mimetic and coercive isomorphism), or as a result of professionalization (normative isomorphism). In a new field that is also essentially unregulated, such as egg donation, norms may have surprising origins, and rather than spreading, one agency to another, they may emerge as individual values, with individual origins, to converge in a center that becomes a set of norms and shared moral meaning.

Among my interviewees, I observed two simultaneous pathways to the creation of new norms, quite apart from the common desire for self-regulation and control of the appearance of the industry to outsiders, discussed in the next chapter. In this chapter, I discuss the ways in which agency decision-makers look inward, concerned with how their own business is functioning and how they can inform the decisions they make for their own agency. Because they are running their businesses in the midst of uncertainty —uncertainty because of the newness of the field, including its technology, uncertainty because of the ethical implications of the field, and uncertainty because of the complete lack of regulation of egg donor agencies—they must decide how to respond to that uncertainty.<sup>411</sup> Their responses involved, first, and, surprisingly, least frequently, convergence, in which they modeled their behavior on other agencies either directly or via consultation with their industry colleagues.

However, far more common was agency decision-makers' second response to uncertainty: divergence, in which they made individual decisions for their agencies, based on their own personal morality and/or distinguishing themselves from what they perceived as other agencies' poor practices, which were then implemented via the agency. These decisions were embedded in social context; the smaller context of the egg donation industry, including infertility clinics, mental health professionals, family formation attorneys, genetic counselors, and other agencies, and the larger context of societal value judgments about family, technology, commodification, and exploitation.

<sup>&</sup>lt;sup>411</sup> See Chapter One, "Feminist Legal Theory," and Chapter Two, "The Current State of the Law," for descriptions of these uncertainties.

Counterintuitively, because of the social context within which these "divergent" responses were made, these individual decisions, in addition to making visible individual actions in an organizational context and spreading those personal values outward, creating meaning for the agency decision-makers and their organizations, also resulted in a convergence of values; each individual decision was informed by the social context, and thus converged at a central point. It is from that central point that field norms began to emerge, and that a shared morality developed.

Agency decision-makers' individual decisions, made with an inward focus and concern for one's own agency, but also embedded in social context, resulted in a number of overlapping "internal standards," which comprise the beginnings of field-wide norms for egg donor agencies. The most commonly overlapping internal standards include policies for egg donor screening and to which intended parents to refuse service. But even more so than agencies' overlapping internal standards, there is a consensus about their ultimate purpose: while each agency owner came to the business from her own unique experience, they are all involved in it out of a sense of joy in building families and responsibility to those with whom they work. In essence, their shared purpose has become their shared moral meaning: caretaking of intended parents, egg donors, and future children.

While I cannot know whether my interviewees were accurately representing the reality of their decision-making and business practices, what they told me is how they want to be perceived, regardless of its essential truth. It is their representation of the truth, and thus a representation of their values, or at least the values that they wish to be seen to have. Agency decision-makers' self conscious differentiation, and their socially embedded perceptions of moral values and good business practices, paradoxically results in the emergence of new field norms and the creation of shared moral meaning.

### Uncertainty in a New Field

### Lack of Regulation, but Twenty-Five Years of History

Egg donation is a business that almost completely lacks regulation. As such, egg donor agency decision-makers have been making their decisions in the absence of legal guidance since the inception of their organizations, the first of which came into being approximately twenty-five years ago. That's a long time for such an ethically sensitive business to be without regulation, but the very fact of its history gives agency decision-makers some context to inform their decisions. However, during the existence of egg donor agencies, the technology for egg donation has changed rapidly, and has

repeatedly introduced new uncertainties into the business lives of my interviewees. The most recent of these technological developments is the advances in cryopreservation that made it possible to freeze eggs.<sup>412</sup> The availability of technology to freeze eggs prompted the advent of frozen egg banks, which serve as an impeccable example of uncertainty in a new field.

### An Illustration of Uncertainty: The Future is Frozen

If one area of egg donation is rife with uncertainty, it is the relatively new technology of freezing eggs before in vitro fertilization.<sup>413</sup> Donor egg banks are creating their own protocols, some following loosely in the mold of sperm banks, but other diverging from that model in order to avoid placing a price on individual eggs.<sup>414</sup> For example, Reproductive Biology Associates, a major frozen egg bank in Atlanta, Georgia, charges a flat rate for a frozen egg cycle, which includes a lot of six eggs and a guarantee that four eggs will survive the thaw, and that two good embryos will result, along with the medication and costs for transfer of those embryos to the intended mother's or surrogate's uterus.<sup>415</sup> Regardless of the structure of egg banks, however, there are a lot of unknowns about frozen eggs. Agency decision-makers disagree on whether frozen egg donation will eventually supplant fresh cycles; they disagree on whether or not agencies will still have roles in the egg donation industry if frozen does supplant fresh,

<sup>&</sup>lt;sup>412</sup> As opposed to the ability to freeze embryos, which are hardier and have been successfully cryopreserved since the early-mid 1980s. Associated Press, "First Baby Born of Frozen Embryo."

<sup>&</sup>lt;sup>413</sup> As noted in Chapter Two, "A Brief History," frozen eggs have only in the last few years resulted in clinical pregnancy rates similar to IVF cycles with fresh eggs, with the advent of vitrification, or rapid freezing technology. Most programs have found that IVF cycles using vitrified donor eggs have similar success rates to those using fresh donor eggs. See, e.g., Valojerdi et al., "Vitrification versus Slow Freezing;" Nagy et al., "First One Hundred Recipient Cycles Using Vitrified/Warmed Oocytes;" ASRM Practice Committee and SART Practice Committee, "Mature Oocyte Cryopreservation;" Trokoudes, Pavlides, and Zhang, "Fresh and Vitrified Donor Oocytes."

<sup>&</sup>lt;sup>414</sup> Most sperm banks sell frozen sperm by the vial, but most frozen egg banks sell an attempt at pregnancy—a single IVF cycle, sometimes with a guarantee of one or two good embryos. See California Cryobank, "Ordering and Shipment," available from www.cryobank.com/How-It-Works/Ordering-and-Shipment/; Internet; Accessed 16 August 2014. Some frozen egg banks, however, sell eggs in lots of, for example, six frozen eggs, with additional eggs available for purchase on a price-per-egg basis. See The World Egg Bank, www.theworldeggbank.com/recipients/recipient-faqs/; Internet; Accessed 7 September 2014: "You have the option of purchasing additional oocytes for a cost of \$2,750.00 each."

<sup>&</sup>lt;sup>415</sup> Reproductive Biology Associates, rba-online.com. RBA is a pioneer of egg freezing technology and has "outsourced" its egg freezing program to a network of clinics, which is now called My Egg Bank, myeggbank.com/. My Egg Bank offers eggs in lots of six, with additional eggs available on a price-per-egg basis.

and they feel that the high costs for providers (despite the consequent lower costs for intended parents) and uncertainty of the technology will prevent frozen egg donation from booming—though in fact, the high upfront costs of and extensive technology necessary for running a frozen egg bank may serve simply to concentrate such services in a few large clinics and bar entry to smaller clinics and agencies.<sup>416</sup>

Agency decision-makers were solidly divided on whether or not frozen donor egg cycles would eventually supersede fresh donor egg IVF cycles, and whether or not frozen egg banks would have a significant impact on the egg donor agency business. Some agency decision-makers didn't see frozen donor eggs taking off because they felt that donors would be unwilling to donate to clinics/banks, rather than to specific intended parents:<sup>417</sup>

I think that it takes a certain type of donor to agree to do a frozen [egg cycle] because most people don't want to just get paid \$5,000 to have their eggs distributed to three different families knowing that the clinic is going to be making money hand over fist on their eggs. (Director, Northern California Agency)

Interestingly, frozen egg banks follow the sperm bank model much more closely than the traditional fresh donor egg model, and men have never seemed to have any compunction about donating to the bank without knowing to whom their sperm will be given.<sup>418</sup> This is a gendered issue that Rene Almeling discusses in her book *Sex Cells*; presumably the reason that some agency decision-makers are convinced that egg

<sup>&</sup>lt;sup>416</sup> Although success rates from IVF cycles using frozen donor eggs have risen nearly to the level of success rates with fresh donor eggs, there is still a great deal of uncertainty about the ultimate outcomes of the technology, simply because it is so very new; vitrification of eggs was only introduced about five years ago. See Valojerdi et al., "Vitrification versus Slow Freezing;" Nagy et al., "First One Hundred Recipient Cycles Using Vitrified/Warmed Oocytes;" ASRM Practice Committee and SART Practice Committee, "Mature Oocyte Cryopreservation;" Trokoudes, Pavlides, and Zhang, "Fresh and Vitrified Donor Oocytes."

<sup>&</sup>lt;sup>417</sup> In a typical donor egg IVF cycle, the intended parents select a donor, who only at that point undergoes the majority of her screening and the medical cycle to donate her eggs. Consequently, the donor knows she is donating to a specific intended parent.

<sup>&</sup>lt;sup>418</sup> Rene Almeling reports that some sperm donors apparently don't even consider that their sperm will go to *anyone:* "Framing of donation as a job leads some men to be so removed from what they are donating that when a new employee at [sperm bank] excitedly told a donor that a recipient had become pregnant with his samples, she said it was like 'somebody hit him with this huge ball in the middle of his head. He just went blank, and he was shocked.' During his next visit, the sperm donor explained, 'I hadn't really thought about the fact that there were gonna be pregnancies.' The donor manager described this state of mind as 'not uncommon.'" Almeling, *Sex Cells*, 78.

donors will only want to do direct agreement donations is because of our gendered perception of women and motherhood.<sup>419</sup>

Other agency decision-makers felt that intended parents would be the limiting factor for frozen egg donation cycles. They thought that intended parents would prefer fresh cycles, whether because of a vague perception that fresh is the "right" way, or specifically because intended parents are more likely to have leftover embryos (for additional attempts at conception, or for siblings down the road) with a fresh cycle than with a frozen cycle:

I think parents are going to want fresh cycles. (Director, Southern California Agency)

I think the parents would want to pay the extra \$10,000 to do it the right way. (Director, Southern California Agency)

With a fresh cycle, intended parents are typically entitled to all of the eggs that the donor produces on that cycle, so they may end up with only a few embryos, or they may have fifteen embryos. In frozen donor egg cycles, clinics thaw only a few eggs at a time, with the goal of creating a single viable embryo that will grow into a baby, with no leftovers for further attempts in the event of a negative pregnancy test or miscarriage, or for siblings:<sup>420</sup>

I think if people want a family [more than one child], they'll go for a fresh cycle because when you get frozen eggs you're usually getting five eggs, which may be two embryos or one. (Director, Southern California Agency)

While not having any leftover embryos may be the goal of some families—who only want one or one more child, and do not want to have to decide what to do with embryos they do not plan to use—most families undergoing IVF want to hedge their

<sup>&</sup>lt;sup>419</sup> Part of what makes egg donation culturally acceptable, and the experience of commodification more positive, is the donor's perception of her own altruism: "When a woman calls her donation 'just an egg,' she is removing herself from any suspicion of being a bad mother, the kind who would sell her baby, and underscoring her contribution to the recipient's motherhood project, a contribution she defines as a 'huge gift.'" Almeling, *Sex Cells*, 167.

<sup>&</sup>lt;sup>420</sup> The remainder of the eggs from a particular cycle stay with the clinic/bank until another intended parent selects them. See the websites of four major frozen egg banks: My Egg Bank, www.myeggbank.com; The World Egg Bank, www.theworldeggbank.com; Donor Egg Bank USA, www.donoreggbankusa.com; and Reproductive Biology Associates, www.rba-online.com.

bets and have a "backup plan" in place. Trying again with leftover (frozen) embryos is much less expensive than doing an entirely new cycle.<sup>421</sup>

Frozen donor egg IVF cycles are much quicker for the intended parents than traditional fresh cycles; there is no need to wait for a donor to complete her screening (and possibly fail, and require the selection of a new donor), or to wait to sync the intended mother's menstrual cycle with the donor's menstrual cycle using hormonal medication.<sup>422</sup> For these reasons, and because frozen donor egg IVF cycles are also much less expensive than fresh cycles, at least as many agency decision-makers felt that frozen donor egg cycles will certainly supersede fresh cycles; though the technology of vitrifying eggs is still new, these decision-makers felt that it is bound to take off:

I've always thought it's the future of egg donation. I think everybody does. But it's not quite there yet and it will be and it's absolutely wonderful. (Director, Southern California Agency)

It's open for interpretation at this point but I think we're going to start seeing more and more cycles going towards egg freezing. I think fresh egg donation—it will probably even truly decline quite sharply. We're seeing a little bit of a decline but it's really right now so the Wild West; some people really believe in it. Some are thinking it's experimental. So it's kind of all over the map right now but I think eventually it's definitely going to impact fresh donations. (Director, Southern California Agency)

Whether or not frozen donor egg cycles eventually supplant fresh cycles remains to be seen: success rates have nearly risen to the level of fresh cycles, and they are improving.<sup>423</sup> And if the technology gets there, cost may be the determining factor.

<sup>&</sup>lt;sup>421</sup> In the San Francisco Bay Area in 2014, a fresh donor egg cycle, including all medical procedures, medications, agency fees, and donor compensation, can run \$35,000-\$40,000 or more. In contrast, a frozen embryo transfer is closer to \$4000 or \$5000, including medications and procedure fees.

<sup>&</sup>lt;sup>422</sup> In a fresh donor egg cycle, the recipient's uterus must be prepared to receive an embryo; she must be in mid-cycle when the donor's eggs are mature enough to be retrieved. In essence, reproductive endocrinologists use hormonal medications to ensure that the two women experience their menstrual cycles in parallel.

<sup>&</sup>lt;sup>423</sup> See Nagy et al., "First One Hundred Recipient Cycles Using Vitrified/Warmed Oocytes;" ASRM Practice Committee and SART Practice Committee, "Mature Oocyte Cryopreservation."

Frozen donor egg cycles are much less expensive for intended parents than traditional fresh cycles.<sup>424</sup> In a fresh cycle, agencies or in-house programs do basic screening of donors, but it is not until a donor is selected by an intended parent that her in depth screening is completed, at the intended parent's cost. Then the intended parent pays an agreed-upon fee to the donor and to the agency for the donor to actually undergo the cycle. In a frozen donor egg arrangement, the full screening *and* egg retrieval is performed before the intended parent enters the picture. Therefore, it is a much higher upfront cost to agencies or clinics, who must bear the cost of the entire cycle with no guarantee that those eggs will be purchased. Each frozen egg cycle costs intended parents receive many fewer eggs to work with (typically, though a fresh cycle may result in a low number of eggs—one of the risks of fresh egg donation), and are unlikely to have leftover embryos.<sup>425</sup>

As several agency decision-makers noted, even if intended parents might prefer a direct agreement with their donor, frozen donor egg cycles are so much less expensive that they might choose to go frozen just to save money, or they may only be able to afford a frozen cycle (and even so, it is still very expensive).<sup>426</sup>

Intended parents are attracted to the egg banking because of the lower cost of getting frozen eggs. (Director, Northern California Agency)

And then of course there's the fact that it's much less money for someone to get pregnant. (Director, Southern California Agency)

For the recipients there's so much more opportunity. They don't have the risk, we take the risk that the cycle might not be good. It's a great affordable way to do egg donation for many people. (Director, Southern California Agency)

There are intended parents who are just happy to have an option, and this is less expensive. (Director, Northern California Agency)

<sup>&</sup>lt;sup>424</sup> Where a traditional fresh donor egg cycle would cost \$35,000-\$40,000 or more, a frozen donor egg cycle costs only half that or less.

<sup>&</sup>lt;sup>425</sup> "Some patients will have additional embryos to cryopreserve; however, there is no guarantee." Donor Egg Bank USA, donoreggbankusa.com/faqs; Internet; Accessed 7 September 2014.
<sup>426</sup> \$16,000 or more.

Although frozen donor egg IVF cycles are significantly less expensive for intended parents, and agency decision-makers appreciate the resulting increased access to donor egg IVF for intended parents, decision-makers remain concerned about the financial cost of frozen egg cycles for the service providers:

It is super expensive to do ... I hand pick donors who are extremely prolific, who make more than the usual number of eggs but more importantly more than the usual number of embryos and pregnancies on a cycle.... So someone who either couldn't afford this donor or because sometimes they're far away as well, or someone who wouldn't get her because she can only do one cycle gets to have the donor of their dreams. (Director, Southern California Agency)

Or, put more succinctly:

It's more cost-effective for the intended parents. However, it's more of a gamble up front for the facility or the clinic. (Director, Southern Agency)

And one agency decision-maker said that she wouldn't get involved with frozen egg banking because of the upfront costs:

Just factoring in medication, the donor's compensation, you're at least spending \$8000 on that donor.... So it's an investment up front for sure, which is why we wouldn't be in the frozen bank industry. So it seems like a really big gamble. (Director, Southern Agency)

While an agency may wish to avoid the upfront costs of building its own frozen egg bank—which, in addition to the cost of full screening and retrieval for each donor, includes a great number of overhead costs and the costs of high tech medical cryopreservation equipment—agencies need not run their own frozen egg banks to remain active in the industry.

Instead of running a frozen egg bank, an agency may work with frozen egg banks in a similar role that they play now with clinics: as egg donor recruiters. Some frozen egg banks (usually owned and/or run by physicians—experts on the clinical aspects of frozen egg IVF, but not on locating appropriate donors) utilize the services of egg donor agencies to recruit appropriate donors. Frozen egg banks can also take advantage of egg donor agencies' existing donor databases, picking and choosing donors who have already completed a donation cycle or two through the agency and have proven

themselves to be high yield producers (lots of eggs retrieved) with successful outcomes (pregnancy achieved in the intended mother). As one agency decision-maker pointed out, that role is slightly different than their current role:

If we go to mostly frozen cycles then we're in the position where we've kind of become an agency for donor recruitment more so than matching services. (Director, Southern California Agency)

Yet at least part of the current agency role remains in the context of frozen egg banks, and some agency decision-makers see themselves continuing to recruit donors and perform initial screening in that context:

You still have to screen the donor and educate her as to the process. She is still going to have to take the injections and go through a stimulation and retrieval. (Director, Northern California Agency)

In fact, according to this agency decision-maker, clinics (i.e., the institutions which perform the medical procedures of egg donation, some of which host small in-house egg donor programs) cannot perform the same role as agencies (i.e., organizations which recruit egg donors and facilitate matches with intended parents, but do not perform any medical procedures), which are highly specialized for the functions of recruiting and educating donors:

Clinics have tried and tried and tried to replicate the agencies, and they just have not been successful because their focus is not recruiting donors and educating them and being advocates for them. So no matter what, I don't think the agency's role—I mean even with egg banks, I don't the agency's roles will change because they'll still need those great caliber egg donors, so to speak. (Director, Southern California Agency)

Another agency decision-maker, however, failed to see why frozen egg banks would retain the services of egg donor agencies for recruiting and educating donors, when they could do the job themselves for much less cost—even if not as well:

The big clinics that I know ... they pretty much tell people [intended parents] they need to go frozen. You know, they have someone on staff and that's what that person does. It's cheaper for them to pay a nurse \$35,000, \$40,000 per year ... I think doctors would look up and say, why are we outsourcing this when I could just have somebody on staff taking care of this for me? And most doctors overwork those nurse coordinators anyway, so they'll probably be doing it.... If frozen becomes the way then I don't see much room for an – at least there won't be room for as many agencies are there are right now, that's for sure. (Director, Southern Agency)

Frozen egg donation cycles represent the height of uncertainty in the egg donation industry; the technology is still improving and there is uncertainty about whether egg donors will be willing to donate to banks, owning a frozen egg bank involves huge upfront costs, and it is unclear what the role of agencies may be when all is said and done. Agency decision-makers do not agree on what the outcome of any of these issues will be. What they do agree on is that we have no long term knowledge about whether or not using frozen eggs to conceive is safe.

Some agency decision-makers find this lack of knowledge—which, while mimicked in other aspects of egg donation, such as how doing multiple IVF cycles in her twenties affects a donor's future health, also suffers from its utter newness and therefore complete lack of even anecdotal evidence—to be the biggest problem with frozen egg donation.

I guess the truth is we don't really know how that's going to affect these children down the line, to be a frozen egg and then a frozen embryo and then a—frozen sperm, everything's been frozen. We know how it is. There's something new that happens and then twenty years down the line we find that all develop cancer by the time they're nineteen, and there's no data on that. (Director, Southern Agency)

I guess we're not going to know for another ten or fifteen years what the real upside or downside [of using frozen eggs] is going to be. (Director, Northeastern Agency)

However, as with other unknowns in the industry, egg donor agency decision-makers press forward, making the best decisions they can based on the knowledge that they have. With no legal, or even medical, guidelines to follow, they must fall back on means of decision-making that ultimately result in the convergence of field practices and the creation of field norms.

## **Responses to Uncertainty**

Without legal regulation to direct their actions, egg donor agencies must manage conflicting institutional logics: what is required of them by their professional colleagues, such as physicians, mental health professionals, and genetic counselors? What is required of them by the market, by intended parents and potential egg donors? And to what resources do agency decision-makers appeal in order to manage those conflicts? A theory of inhabited institutions speaks to managing conflicting institutional logics: how people behave at the epicenter of conflicting logics, such as professional, medical, market, legal, familial, and parenting logics.<sup>427</sup> Inhabited institutions brings into relief the agency of individuals working within institutions; how the behavior or actions of individuals suffuse organizations with moral meaning.<sup>428</sup> Agency decision-makers act within the social context of their organization, and within the larger social context of competing institutional logics. And their actions create meaning, but that meaning is derived not only from the individual decision-maker, but also from the organization which implements their decisions. An inhabited institutions approach to the creation of norms and moral meaning reflects ethics on the ground: how agency decision-makers behave "in real life."

In effect, an inhabited institutions approach makes visible the ways in which agency decision-makers have sought to distinguish themselves from other agencies or practices in the field. In this way, they have deliberately attempted to diverge from one another. This is apparent in some agency origins stories, such as when the interviewee has left work at another agency in order to start her own agency because she had philosophical differences with the previous agency's owner. Sometimes these decisions have involved "reverse modeling," in which the decision-maker modeled her decisions on those of other agency. but instead of imitating the other agency, she does the opposite within her own agency.<sup>429</sup> Sometimes the decision-maker referred only to her own "gut feeling" in order to make decisions for her agency. Occasionally, agency decision-makers engaged a convergent decision-making manner, by consulting with industry members to inform their decisions, and by modeling their own agencies on others.

<sup>&</sup>lt;sup>427</sup> On conflicting institutional logics, see Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

<sup>&</sup>lt;sup>428</sup> See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; and Smets, Morris, and Greenwood, "From Practice to Field."

<sup>&</sup>lt;sup>429</sup> "Reverse modeling" is my own term for the described phenomenon in this dissertation.

Counterintuitively, although an inhabited institutions approach makes visible individual agency decision-makers' actions and attempts to differentiate their agencies from other agencies, the norms that emerge as a result, and the moral meanings created by those individual decisions—and by their implementation in individual agencies—are often shared among many agencies. As a collective, these differentiating decisions return agencies to the same moral center: a position of caring for their charges: intended parents, egg donors, and future children. By acting as individuals, on an individually felt moral imperative to assist people who interact with their agency, agency decisionmakers embed those moral meanings within their organization, and within the context of society more generally. With multiple agency decision-makers participating in the process, these individual decisions that refer to the same individual moral imperative become norms for the industry. Similarly, because the standards that each agency decision-maker implements for her own agency are embedded in an industry and larger social context, those individual decisions, expressed through agency organizational behavior, overlap with one another in such a way that new norms for the field of egg donation agencies begin to emerge.

Thus, in the case of divergence, whether intentional divergence through reverse modeling, or unintentional divergence through diverse agency origins, the actions of the individual create both new field-wide norms, and meanings that are distinct from field norms, but end up functioning as norms: a shared moral meaning.

### Divergence: Individuality Among Agencies: Origins, Business, and Ethics

In many ways, my interviewees sought inspiration and guidance in creating their own agencies from similar places, and built their businesses with similar attitudes: a joy in building families and compassion for intended parents. Yet their agencies came to be in a variety of ways. Some women had previous experience in the business world. Some had previous experience working at another agency. Others transferred laterally from social work or mental health professions, often expressing the desire to do the positive work of helping people to build their families as opposed to the work of fixing broken families. Some started their agencies as a way to fill a perceived gap in the market, whether it was to help physicians recruit donors in the early days of egg donation, or to improve upon what existing agencies were already doing. And some, of course, came to work in egg donation as a result of their personal experience as an egg donor, surrogate, or intended parent. All of these elements impacted the ways in which my interviewees make decisions in running their businesses, and, perhaps unexpectedly, led to the development of shared moral meanings.

Half of my interviewees founded their agencies or became involved in the field because they saw a market need for the services that they felt particularly qualified to provide. A couple of my interviewees were among the early adopters of the concept of egg donor agencies. Others realized that they could help eliminate deficits in the industry after experiencing those deficits for themselves. After a frustrating search for an egg donor for herself, one agency decision-maker said,

I had a very close friend, who ... was a third party coordinator at a large fertility practice, and she said, ... 'Every donor agency that exists already has some problem or problems, and you'd be really good at it.' So—and she was sort of my inside track to tell me, OK, what are the problems with current agencies, and what do fertility physicians and their clients look for, etc. (Director, Northern California Agency)

Another noted that agencies at the time that she was an infertility patient did not provide the patient advocacy that she realized she (and other patients) needed:

At the time, as a patient walking through the industry, it stymied me that there was no patient advocate to help the process. Honestly, what I learned at the time was the answers you get are only as good as the questions you ask. But the problem was, as a patient, I didn't even know what questions to ask. This is why I really found a passage to the industry. (Director, Midwestern Agency)

Finally, one agency decision-maker, after experiencing difficulty trying to disentangle the state of the law for a surrogacy arrangement into which she wished to enter with a friend, thought that she and her friend surely weren't the only people with this problem and that they shouldn't have had to reinvent the wheel:

> After I had my son, [a friend] asked me would I carry her baby for her.... And so we started trying to navigate our way through the process, and ... we were sort of looking into legislation, and the laws, and precedent for obtaining pre-birth orders, and ... I'm like no one ... is doing this. This is crazy that there's not an agency we can go to to ask for help. And it was just like this epiphany and I was like, 'This is what I should be doing.' And it kind of just snowballed into a business. (Director, Northeastern Agency)

Other agency decision-makers saw specific niche needs that they could fulfill after working in the industry in other capacities:

As I was working doing the surrogacy assessments, I kind of fell in love with the field, and saw that there was a real need and there was this niche where—there's a lot of work that needed to be done still [in evaluating donors and surrogates], so I kind of changed [my] whole career one-eighty and ended up working in fertility. (Director, Southern California Agency)

And this agency decision-maker developed her business almost by accident, when, while working at an in-house egg donor program, she started finding donors of a particular ethnic background for friends on the side:

And so I had this private practice which kept growing and eventually ... I was working like a normal, very, very, very full time job with a huge amount of responsibility, and then coming home and working evenings and weekends.... So it's been a struggle financially [to leave the in-house program and go out on her own], but it's been amazing. It's been amazing. (Director, Southern Agency)

These agency decision-makers established their own agencies, or otherwise became involved with the field, because they saw a need for a service that didn't yet exist: they began their businesses on the basis of differentiation from what came before.

Many of my interviewees drew inspiration for their agencies from their own personal experience in the industry, either as a patient, or as a donor or surrogate. Almost sixty percent of my interviewees joined the industry after having some personal experience with it; of those, a little over half had been egg donors and/or surrogates, and the remainder had been intended parents. Several agency decision-makers developed a passion for building families as a result of their experiences as egg donors. This agency decision-maker met her intended parents at a time when such meetings were very uncommon, and she was glad that she did:

That was very moving to me, because I was able to see from a firsthand basis, right out of the gate, what this meant to somebody. (Director, Southern California Agency)

Although she didn't know at that point that she would one day start her own egg donor agency, another agency decision-maker said of her experience donating eggs:

I left the hospital that day [after her egg retrieval] feeling pretty damn proud of myself, because I thought I had just made a massive impact on someone's life. And I was hoping that I could help someone, even if I never knew who these people were, I wanted to help them. I mean, it was a really amazing experience. (Director, Northeastern Agency)

Though a few agency decision-makers criticized their compatriots who join the industry after an experience as an intended parent, egg donor, or surrogate as lacking the qualifications to run an agency, other agency decision-makers admire the passion of those who join the industry with an intense desire to either help more people, or to help others the same way (or even better than) they were helped.

I think that's a great place to come from. I mean, it doesn't get ... any better, because you have the firsthand experience of what you've gone through, but then also the passion that drives you to push for change to occur. And I think that's amazing, that combination. (Director, Southern California Agency)

And speaking of one agency started by a former egg donor, an agency decision maker said:

And because of having been a donor, it just gave them [the director of the other agency] that much more of a commitment for wanting to do this, and help other people. (Director, Northern California Agency)

While, as one agency decision-maker recognizes, some agencies started by people because they have some experience as a patient or a donor are poorly run and poor representatives of the field, sometimes origins in personal experience can lend a power to the business of that person:

There are others that I think are really good, they may be small, mom and pop sort of organizations, but they have a real heart for doing this. They may be someone ... who has been through this, and says, well, I want to be taken care of better than what I was, so I'm going to do this myself. And they will bend over backward, their fees are really low, just because they really want to help others through this process. (Director, Northern California Agency)

My interviewees' agencies came into being in a variety of ways; many because of the personal experience of the decision-maker or in response to a perceived market need. They are also individual in the ways they make decisions. When asked whether their

agency had created formal ethics policies, a third of my interviewees answered that they had no formal policies, but that they relied on their own instincts when making decisions with ethical implications.

I basically do a gut check. (Director, Northern California Agency)

I just kind of did it [structured her agency] based on what made the most sense to me. (Director, Northern California Agency)

Well, it's informal. It's in my head. (Director, Southern California Agency)

It's based on my own moral values, ethics. (Director, Midwestern Agency)

One agency decision-maker felt that making such decisions was difficult; she has had to figure it out from experience:

Oh God, it's so hard, because you have standards, and you have ways you do things, and you don't want to always be stubborn, but you kind of—you know, you kind of want to learn as you go on some things. (Director, Southern California Agency)

Another felt that her gut was insufficient to provide answers to the ethical dilemmas that arise in her business; she was thinking of procuring some formal training:

I would say multiple times a week we are faced with moral ethical issues, and there's always something that comes up for us that makes us have to really think carefully, and to the point where I've actually—I was thinking of going and getting a master's [degree] in medical ethics just to help me process some of the stuff that has to go on because it's so huge, way huge. There are so many huge issues that come up. (Director, Southern Agency)

By referencing their gut instincts, these agency decision-makers diverge from their colleagues, looking inward for inspiration on their decision-making. In addition to diverging on ways they came to the field and ways they make ethical decisions, half of my interviewees engage in entrepreneurial divergence—a deliberate attempt to differentiate their business from other agencies—by "specializing." They try to serve a particular corner of the market by recruiting egg donors that fit some type of difficult-to-find profile. That can mean anything from a donor with excellent standardized test

scores and an advanced degree, to donors with particular ethnicities who rarely donate or racial mixes that are rare in the general population, to repeat donors who have a history of successful cycles (i.e. cycles that resulted in pregnancy). Regardless of their speciality (or whether or not they in fact have different donors than other agencies), agency decision-makers use the specialty to advertise their differences from other agencies.

# Divergence: Reverse Modeling

Agency decision-makers look to the practices of other agencies, and when they don't like what they see, they "reverse model" their business practices on those others, deciding to do the opposite of that which they don't like.<sup>430</sup> Both individual agencies and groups of agencies were sources for these disapproved-of business practices. Two of my interviewees started their own agencies in response to practices they wanted to "fix" at other agencies:

I started working [as a temp at an agency] for a project, and then ultimately ended up becoming [an executive] of that company, and then deciding that, philosophically, the industry and me and everything was very different from this company.... And that's when I decided to break off and just sort of become my own entity and sort of take a different path. (Director, Southern California Agency)

I went through the process [as an egg donor] myself so that I could speak to it. Speak to it I did because it was very lackluster. I thought, 'well, no wonder you're having a hard time finding women, if this is the way you do it.' So, I just built something different. (Director, Midwestern Agency)

Rather than referencing individual agencies, many more agency decision-makers cited East Coast norms when discussing the reverse modeling of their own agencies. The two groups most commonly mentioned in this context were East Coast independent agencies (for the purposes of this dissertation, agencies in the Northeastern census region), and, often conflated with East Coast agencies, in-house programs in that region. While my interviewees didn't typically talk about local (California or other non-Northeastern) in-house programs, they did speak about in-house programs as if such

<sup>&</sup>lt;sup>430</sup> Again, "reverse modeling" is my own term for the described phenomenon in this dissertation.

programs were (Western) agencies' equivalent in the Northeast.<sup>431</sup> While independent egg donor agencies do exist on the East Coast, this conflation is likely because the proportion of in-house programs to independent agencies is significantly higher in that part of the country (36% independent in the Northeast v. 73% in California).<sup>432</sup>

Agency decision-makers see themselves as adding value and humanity to what is otherwise a clinical or business interaction, a quality that they felt was particularly strong on the East Coast. My interviewees indicated that egg donor programs on the East Coast, both independent agencies and in-house programs, are more insular and subordinate to clinical norms than are independent agencies in California and other parts of the country outside the East Coast. In-house programs are also generally smaller than independent agencies, e.g., they have smaller databases of egg donors, and are therefore less likely to be able to find (or even to care about finding) the "right" donor for a particular intended parent.<sup>433</sup> In general, in-house programs are, perhaps unsurprisingly, since they are typically headed by clinic physicians, more subordinate to clinic norms than independent agencies.

Agency decision-makers complained that in-house programs refuse to share their donors with other programs or agencies:

They're somewhat insular. (Director, Northern California Agency)

A lot of in-house programs don't want to share profiles. (Case Manager, Northern California Agency)

They also noted that in-house programs tend to offer a much smaller selection of donors; even if those donors are chosen with care, the implication is that in-house programs cannot meet the needs of a diverse group of intended parents, although those who find appropriate donors are well served:

[In-house programs] ... usually [have] a small, select number of women. My experience was that the fertility clinics that do in-house do a pretty careful selection. (Director, Southern California Agency)

<sup>&</sup>lt;sup>431</sup> I refer here to the opinions of all of my non-Northeastern agency interviewees. Since the majority of those were in California, and their opinions differ vey little, I lump them together as "Western," though some may actually be located in the Midwest or the South.

<sup>&</sup>lt;sup>432</sup> See Appendix I for a visual representation of relative concentrations of independent agencies and inhouse donor egg programs in the United States.

<sup>&</sup>lt;sup>433</sup> Clinic recruiting programs tend to be smaller in scope, as the focus of the organization is on providing medical care. Egg donor agencies, on the other hand, exist solely to recruit donors and match them with intended parents, so they tend to have a larger selection of donors available.

Adding to in-house programs' inability to serve their clients in the way in which Western agency decision-makers felt obligated, in-house programs on the East Coast limit the amount of control that intended parents have in selecting their donors:

Sometimes there's a waiting list, so it's whoever comes up. 'Oh, you're Asian, so we're going to match you with an Asian. Never mind that you're Chinese and this person [the donor] is Indonesian.' (Director, Southern California Agency)

They [in-house programs on the East Coast] don't tend to be as particular about certain things that most intended parents are wanting, which is someone [a donor] that they like and can relate to.... Or they'll [the in-house program] pick the donors for the intended parents, and say, 'Here, this person's kind of your height and eye color and hair color, be happy.' (Director, Northern California Agency)

These criticisms carry over generally to East Coast agencies, an area of the country which has a much greater concentration of in-house programs as opposed to independent agencies. Agency decision-makers also criticized East Coast programs, both agencies and in-house, for being overly concerned with privacy and anonymity.

> On the East Coast there tend to be more internal donor egg programs; they tend to be very leery of agencies.... I feel like on the East Coast, the doctors and clinics, they really want to be in tight control of this, and they see it as being 'no one needs to know,' total anonymity is the best and only way. (Director, Northern California Agency)

In California, it is unusual but becoming more common for an egg donor and the intended parent(s) to meet face-to-face after being matched, but such a practice is considered (according to both Northeastern and non-Northeastern agency interviewees) unacceptable by East Coast programs, which place great value on keeping the entire process of egg donation anonymous for both intended parents and donors.

As far as I know, all of the recruitment and screening and everything of the donors is done by the fertility clinics themselves [on the East Coast]. They don't have independent agencies. [sic] And they never have people meet their donors. They find it completely shocking that people on the West Coast do that.... I think the East Coast is a lot more uptight than California. (Director, Northern California Agency)

On the West Coast, the mentality is: just as long as two parties are both open to that type of agreement [the donor and intended parents meeting], the agencies will facilitate it. Whereas on the East Coast, absolutely, the agencies are very much, 'Well, that's not what we do. It's anonymous.' (Director, Southern California Agency)

Similarly:

[The] West Coast seems to be more liberal than [the] East Coast, in that they're more willing to be open and known [between donor and intended parent]. (Director, Midwestern Agency)

This criticism holds true with the opinion of one Northeastern Agency director, who had this to say about meetings between donors and intended parents:

Absolutely not, to me that's not anonymous. You're still getting to meet the person, and you're still finding out who they are. Absolutely not. Under no circumstances. We don't even let them do phone calls. (Director, Northeastern Agency)

On the West Coast, it is standard practice for donor profiles to include both childhood and adult photos of a donor, but on the East Coast, if photos are included at all, they are only childhood photos in order to avoid compromising the donor's privacy.

> On the East Coast ... the clinic-run agencies don't do that [give out donor photos]. They [intended parents] don't get photos. They get childhood photos only. They get minimal information. (Director, Southern California Agency)

> When I first started in this industry, [the] East Coast didn't even show photos of the donor, and still some places don't. Whereas [the] West Coast came out saying, 'No, everyone gets photos of the donor right off the bat.' (Director, Southern California Agency)

> As of recently, very recently [agencies in New York] were not showing adult pictures of egg donors. OK. And ... I don't know anybody who would go for that.... A lot of [infertility] practices do have their own egg donor programs there, so I don't know how

they're handling it right now. But as of a couple of years ago, that's what the practice was. (Director, Southern California Agency)

Finally:

Sometimes they [in-house programs on the East Coast] don't show any pictures, or if they do, they're only childhood pictures. (Director, Northern California Agency)

East Coast agencies, consistent with their emphasis on donor privacy, also discourage the disclosure to the child of his or her genetic origins, because such disclosure is likely to compromise the anonymity of the arrangement:

And a lot of the other states, especially back East, they don't encourage the intended parents to tell the child how it was conceived, and they don't tell the donor what the results were. They can't even get it. I can't get it. I can get maybe how the donor was stimulated [when working with a donor who has previously donated on the East Coast]. (Director, Northern California Agency)

In fact, some of this knowledge comes from the migration of intended parents from the East Coast to the West Coast in order to work with a program that will give them more information about the donors.

We have a lot of people coming here from New York or using donors from our agency because they want to a) meet with them, b) Skype with them, c) see adult pictures, and New York is very provincial. I would never think of the East Coast as provincial, but it is rather provincial. California is just way liberal when it comes to this. So Florida is fine, there's pockets on the East Coast that are easier to deal with than other places. (Director, Southern California Agency)

People will go from the East Coast to the West Coast to have more of a say. And to be able to have that—when I talk to some people who are from the East Coast, they'll say, 'Well, do I get to see pictures? Do I get to see adult pictures? Because that's really important to me.' And I say, 'Yes, absolutely.' (Director, Northern California Agency) When criticizing the practices of East Coast agencies and/or in-house programs, agency decision-makers are looking to the norms of those particular groups of egg donor programs for examples. When they disapprove of what they see, they make different decisions for their agencies. Counterintuitively, since many non-Northeastern agencies look to East Coast practices of emphasizing anonymity (by prohibiting donor/intended parent meetings and only allowing childhood photos of the donor) and preventing intended parents from making the best donor match (by having a limited donor pool and doing the matching rather than allowing intended parents to choose for themselves), they end up implementing similar business models of transparency and customer service, in deliberate contrast to what they see on the East Coast. In effect, their attempts to differentiate themselves from practices that they oppose among other groups of agencies leads to a kind of convergence in their own behavior, and the development of shared moral meaning.

# Convergence: Exception to the Divergent Rule, in Consultation and Modeling

When faced with uncertainty, another response agency decision-makers have is to consult with their colleagues, whether within their own agency or outside of it. They worried that they were unable to make decisions about the "grey area" ethical issues on their own, and felt more comfortable if they could make those decisions after discussion with other agency owners, or those in complimentary professions, such as mental health professionals.<sup>434</sup> About one-third of my interviewees used consults with industry members to help them make their agency decisions.

One agency decision-maker relies on her officemates to help make group-informed decisions about "what's right" for their clients and donors:

I'm very lucky because I have a large office that I'm always at and people have been with me for up to eight or nine years. And I always go to them for their feel about it. It's almost, maybe it's not daily, but every week we have decisions to make about how to do things right. There's so many cycles and there's so much going on and you just want to keep trying to do what's right for everyone. (Director, Southern California Agency)

<sup>&</sup>lt;sup>434</sup> These consultations are a version of DiMaggio and Powell's modeling, or mimetic isomorphism. DiMaggio and Powell, "The Iron Cage Revisited," 69-70. It is also an example of the reproductive processes of an institution outlined by Jepperson in "Institutions, Institutional Effects, and Institutionalism."

This agency director relies on her staff to inform her decisions that have ethical implications, but some agency decision-makers look outside their own agency for help.

Another agency decision-maker made an affirmative choice to engage those working in other agencies in her thinking about the tricky issues that come up in the course of business, because, although she felt alone, she knew that she couldn't be, and that talking to one another would help:

I thought, well, you know, these are people that are doing the same thing as me. I felt very alone a lot of times when something would come up with intended parents or donors that was just ... I didn't know what the right thing to do was either on an ethical side or just ... emotionally or as a good business decision. Like when am I taking advantage of someone or when is someone taking advantage of me? I didn't have anyone to run that by because nobody talked to one another. And I felt very alone in the industry. And so ... I said let's start working together. (Director, Southern California Agency)

Or, put more succinctly:

We need people that we can bounce stuff off to know that we're making the right decisions. (Director, Southern California Agency)

Several agency decision-makers expressed the opinion that a decision made in consultation with others in the egg donation industry was objectively a better decision:

Where you're getting more than one voice weighed in so you can make a decision that's a little bit more informed and thought out and so other people can bring up things. (Director, Southern California Agency)

Egg donor selection was a specific example that a few agency decision-makers cited when discussing relying on others to inform their decisions. This agency director and her partner seek help from other agencies and professional colleagues when making difficult decisions about which donors to accept:

> We have many colleagues out there who help us, which is great because it can be a very isolating experience when you're just working in your own practice. We use all [those] resource[s] to try

to figure out what's acceptable [when screening donors], what's not. (Director, Southern Agency)

Another agency director allows three people, including herself, to make decisions about which donor applicants will be accepted into their donor pool. When they disagree about a particular candidate, they dig deeper, and sometimes consult other professionals to help make the final decision:

> Part of that is just years of experience and trust among ... us. And every once in awhile we might differ on opinion, in which case we will ... do a little bit further research, do a few more questions trying to get a little further down the road, or maybe we might even decide to pay the psych out of pocket at that point [i.e., the agency will foot the bill for a psychological evaluation for the donor, something for which the intended parents normally pay], just to see a professional opinion before we add somebody [to the donor database]. (Director, Southern California Agency)

Agency decision-makers feel more comfortable making decisions that fall into ethical or other "grey areas" when they can do so with input from their colleagues, within their own agency, at other agencies, or in infertility field professions. Seeking certainty in consensus is one response that agency decision-makers have to the uncertainty of their unregulated field.<sup>435</sup>

Similarly, but less frequently, agency decision-makers model their decisions based on those of others, without discussion.<sup>436</sup> Interestingly, very few agency decision-makers mentioned analogous organizations, such as sperm banks or adoption agencies. They mostly looked to one another, although very few brought up their modeling behavior during their interviews. One agency decision-maker noted that she models her egg donor compensation on that of other agencies, a business decision:

I was like looking around at what other agencies were paying, and just sort of scratching my head thinking what can I do to get more donors. (Director, Northern California Agency)

<sup>&</sup>lt;sup>435</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-70. Consensus is a form of reproduction. Jepperson, "Institutions, Institutional Effects, and Institutionalism."

<sup>&</sup>lt;sup>436</sup> A more traditional application of the "modeling" of mimetic isomorphism. DiMaggio and Powell, "The Iron Cage Revisited," 69-70.

However, most agency decision-makers talked more about referring to their own, internal sense of how to do things "right" (discussed in the previous section) than about consulting with industry members or looking to the behavior of other agencies to inform their decisions.

Modeling behavior was most visible in agency website design. The agency websites look very similar to one another: prominently discussing access to an egg donor database, separate information pages for intended parents and donors, sometimes extensive educational materials.<sup>437</sup> All websites claim that they care about the viewer, whether he or she be potential intended parent, or egg donor candidate. They feature pictures of beautiful young women, babies, and happy families. They resemble one another to such an extent that it is impossible to imagine that they are not modeled on one another.

Consultation with industry members and modeling the behavior of other agencies were two responses that agency decision-makers had to the uncertainty of running an ethically tricky business without legal regulation.<sup>438</sup> This convergent response differed from the majority divergent responses of individual decision-making and reverse modeling.

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Agency decision-makers' responses to uncertainty, while primarily divergent and individualistic in nature, nonetheless have led to a convergence of standards—and the emergence of new norms for the field—and the development of a shared moral meaning. Because the individual decisions of agency directors are made in the context of the egg donation industry and of larger society, they tend to converge in such a way as to render them norms.

### Convergence of Values: Emergence of New Norms and Shared Moral Meaning

Paradoxically, although agency decision-makers' primary response to the uncertainty of the relatively new (and completely unregulated) field of egg donation is divergent—making individual decisions with reference to one's individual morality, and reverse

<sup>&</sup>lt;sup>437</sup> For an example of the similarities among agency websites, see the websites of the following agencies (these agencies were not among my interviewees): Elite Fertility Solutions (based in Southern California), www.elitefertility.com/, and Circle Egg Donation (based in the Northeast), www.circleeggdonation.com.

<sup>&</sup>lt;sup>438</sup> As might be expected per DiMaggio and Powell, "The Iron Cage Revisited."

modeling based on other agencies—those supposedly differentiating decisions lead back to a center in which norms begin to emerge and a shared moral meaning is developed.<sup>439</sup> All agency decisions are made in the context of the egg donation industry, including (and especially) infertility treatment clinics, mental health professionals, genetic counselors, and family formation attorneys. Agency decisions are also made in the larger context of society, with its values about the worth of human life and dignity, and logics about family and how family should be structured. Because all of my interviewees' decisions are embedded in those social contexts, they tend to fall towards a common center. Additionally, as those decisions are implemented via agency organizational behavior, they can also spread outward and pull other agencies in through mimetic isomorphism, or modeling on other agencies.<sup>440</sup> Thus the standards and shared moral meaning created by agency decision-makers simultaneously stem from a common origin and create commonality by spreading themselves across the field.

My interviewees talked about many different standards they developed for and implemented within their own agencies, which I will call here "internal standards." The two types of standard discussed more than others were standards for egg donor screening and standards for when to refuse to work with intended parents. The agency decision-makers also created a shared moral meaning—the responsibility for caring for their clients, donors, and future children—by making decisions according to their own personal morality, which, it turns out, is not so personal after all. Together, these individual decisions, embedded in social context, converge into the beginnings of new norms for the new field of egg donation, and into a shared moral meaning.

### **Emergence of New Field Norms**

Every last one of my interviewees discussed the standards they had created for themselves and their agencies. These standards were policies created by the individual agency decision-maker for the benefit of and implementation by her agency; their purpose was to help the business thrive, typically in an ethical way. In creating these "internal standards," agency decision-makers had an inward focus, looking toward

<sup>&</sup>lt;sup>439</sup> The "inhabited institutions" theoretical approach is visible here in the way in which agency decisions are founded on decision-makers' individual beliefs, and then translated into organizational behavior. See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; and Smets, Morris, and Greenwood, "From Practice to Field."

<sup>&</sup>lt;sup>440</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-70.

their own business, as opposed to an outward focus, concerning the appearance of the industry as a whole to the outside world (which is discussed in Chapter Four). As one agency decision-maker put it:

It is what it is and we've created our own standard of practice. (Director, Southern Agency)

These standards run the gamut from accurate bookkeeping to offering high quality donors. My interviewees named two types of standards more than others: egg donor screening and restrictions on intended parents. Yet despite each agency decision-maker creating their own, individual standards for their businesses, these standards have a lot of overlap, perhaps because the people creating them start from a position of embeddedness in the industry (especially in clinic norms) and in larger societal values.<sup>441</sup> And those overlaps, stemming originally from society's values, formed the basis for the emergence of norms for the field as a whole.

### Internal Agency Standards

My interviewees discussed many different internal standards that they had developed for their agencies. One fifth of my interviewees mentioned ensuring that they were representing donors accurately, as to their traits and their availability, on the agency's donor database. One quarter of my interviewees stated that they feel responsible for advocating for egg donors throughout a cycle. Another quarter made a point of coordinating with other professionals to inform their agency decisions and ensure a smooth experience for everyone. And a fifth of my interviewees talked about their standards for their clients' and donors' legal representation, whether the agency provided contracts or insisted that each party retain its own legal counsel. A very few interviewees mentioned fair billing practices (such as making clear exactly what is included in the agency fee and what is not), solid record keeping (including preserving records for seven years or longer), and apologizing and compensating for agency mistakes (in other words, taking responsibility for agency error, and offering refunds and/or free agency services in order to make up for an error).

<sup>&</sup>lt;sup>441</sup> The individual decisions of my interviewees are embedded in a larger social context, but the origins of the values on which their decisions are based are also embedded in a larger context, both within the infertility industry and society more generally. The ways in which my interviewees resolve the conflicts between these institutional logics can be thought of in the context of an institutional logics perspective. For studies of how individuals manage such conflicts, see Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

Two agency decision-makers talked about fair donor matching practices—though they had opposite ideas about what that meant:

The only way we know how to be fair is first-come, first-serve.... We don't play favoritism just because I like intended parent B. That's just strictly forbidden here. (Director, Southern California Agency)

Another agency decision-maker felt that it was most fair for the agency to choose which intended parent a donor would be matched with, with the best interests of the donor as a goal.

I also feel very concerned when somebody, two or three people, really want a donor at exactly the same time. And the way we choose by that, and we do have the power of position to choose, is we try to choose is what's the best place for the donor to be, where the doctor's office is, kindest and most successful and whatever you know. But it's really hard because you're kind of playing God when you do that. (Director, Southern California Agency)

Although these two agency directors have opposite takes with their donor matching practices, they both have well thought out policies.

Almost half of my interviewees talked about their commitment to only offering "high quality" egg donors, which could mean everything from donors whose prior donations had resulted in live births to donors with particular physical or intellectual traits. Certainly many intended parents look for "proven" donors, and agencies aim to please:

I think probably forty percent of them [donors in her database] are prior donors and that's a great percentage. (Director, Northern California Agency)

This agency decision-maker said that her agency's strong reputation was founded on its donor database:

That reputation is based upon having really great screening and really good donors. (Director, Midwestern Agency)

And these agency decision-makers felt that their tough donor selection processes resulted in high quality donors (and they happened to cite the same numbers):

I would say we take one out of twenty [donor applicants]. (Director, Southern California Agency)

We probably get about twenty applications per day, and I would say out of those twenty, we probably take one or two every couple of days. (Director, Northeastern Agency)

These agency decision-makers prided themselves on offering only the best quality donors to intended parents, and staked the reputation and success of their agencies on that quality. And in fact, agency decision-makers named a large number of egg donor screening standards that they employ to maintain that high quality of donors.

# Egg Donor Screening Standards

Some of the internal standards developed by agency decision-makers are simple matters of the physical condition of the donor applicant: her age, her body mass index, whether or not she smokes or uses alcohol or drugs. These criteria are necessary for the agencies to succeed as a business, since they are required by clinics. Many agency decision-makers have donors fill out an application with this information first thing, and donors who fall outside the agency's established parameters will not be invited to continue the application process:

> The initial application that comes in, she [the case manager] will not send them [the donor] the full application if they are not height/weight proportionate, if they're under or over a certain age range, if they're a smoker, use of antidepressants, etc. (Director, Northern California Agency)

We check their health history and things like that to make sure there's nothing glaring. (Director, Northern California Agency)

Similarly, this agency decision-maker "weeds out" donor applicants who fall outside basic physical parameters:

A lot of times, people are already weeded out. So if you're a smoker or if your BMI is a certain level, if your age is [over or under] a certain [number], then you're already out. (Director, Southern California Agency) The earlier they know that a donor will not pass muster, the less wasted time for everyone:

We have some basic requirements that they're going to have to pass. For example non-smoker, ...twenty-one to thirty, no serious health risks or anything like that. (Director, Southern California Agency)

While all agencies have these basic pre-screening criteria, they differ slightly from agency to agency:

They first go through a pre-screen application which asks basic things, are they meeting BMI requirements. I mean the big thing that kick people out is probably BMI, family health history, more than three of one potentially hereditary thing on one side of the family, or like any cancer under fifty with an immediate family member. Age, of course—we use twenty-one to twenty-eight. We do the twenty-eight. That's lower than some people do, but we do the twenty-eight because we feel like that allows them a little bit of time to actually get selected as a donor. (Director, Southern Agency)

Just over forty percent of my interviewees mentioned donor age as a basic pre-screening element, and just under forty percent talked about height/weight proportionality and body mass index:

Well, of course if they're not height-weight proportionate [a donor applicant will be rejected]. (Director, Northern California Agency)

Being overweight, or having too high a body mass index, automatically disqualifies egg donor applicants at most agencies:

Maybe it's not healthy for them because they're grossly overweight and they shouldn't be taking these hormones. (Director, Southern California Agency)

In addition to inappropriate age and weight, smoking and drug use are two elements that often disqualify donor applicants; one quarter of my interviewees mentioned asking about smoking and drug use in their initial donor application:

They have to ... have a certain BMI level, where they have to be a healthy weight. So that height/weight proportion, they have to be a

healthy weight. They have to be nonsmokers ... they're tested for recreational drug use, and they cannot be smoking marijuana, or taking any recreational drugs. (Director, Northeastern Agency)

The basic standards for initially weeding inappropriate donor applicants out of the donor pool are largely physical and behavioral traits that affect their health; infertility clinics would not accept unhealthy donors, since they would be less likely to produce healthy eggs that would result in a child. Other clinic-based donor criteria include the psychological evaluation, mentioned by almost forty percent of my interviewees, and the clinic medical review of the donor's suitability, mentioned by twenty percent of my interviewees.

How agencies go about screening donors after they have passed the initial "weeding out" phase of the application process is less restricted by clinic norms. The most commonly mentioned donor screening standard was the use of a self-reporting questionnaire as part of the application process. Half of my interviewees mentioned using such a questionnaire, to conduct pre-screening and for physicians and other professionals to rely on later on during the egg donation process. Questionnaires are often followed by interviews; the questionnaire plus face-to-face (or Skype) interview is a standard mentioned by almost half of my interviewees.

Some of the questionnaires are primarily medical in nature:

They first fill out a medical questionnaire online, and then, if everything on that looks OK, then I send them a personality questionnaire, and then I meet with them. (Director, Northern California Agency)

We spend between three and six months to screen our donors—to pre-screen our donors, just gathering the medical information that they have in their family. So if we accept them at the end of that, but in that final very long Skype interview that I do with them, and I'll spend an hour and a half, two hours just hanging out with them. (Director, Southern Agency)

Other questionnaires specifically include information about the donor beyond her medical history:

After they do the pre-screen then they go through a long application process. Ours is about eighty-three questions and it's more detailed about them and their family health history, hobbies, interests. Then they go through an interview with our staff. And it's usually over the phone, sometimes Skype depending on where they are. (Director, Southern Agency)

These agency decision-makers use a combination of self-reporting questionnaires and interviews to suss out donors who are unqualified to participate in egg donation.

One agency decision-maker found that her agency's medical questionnaire was useful for weeding out donor applicants on more than one level: she figured that if they couldn't be bothered to fill the whole thing out, they wouldn't do well with the commitment involved in a donor egg IVF cycle:

Then when they complete the application, which is a long application so a lot of women get weeded out right there because they don't want to take the time.... If you can't commit to like a ten page application, it's probably not going to work. (Director, Southern California Agency)

The interview can function both to weed out inappropriate donor candidates, and to educate the donors:

The interview is really important.... I do a face-to-face. Yeah, you want to see are they on time, how are they dressed, what's their hygiene. (Director, Northern California Agency)

They [case workers] meet with our donors, each of our donors and further vetting just to make sure that the process is for them. (Director, Southern California Agency)

All told, more than half of my interviewees mentioned the medical questionnaire and in-person/Skype interview as standards for the donor application process that they have established for their own agencies.

Other donor criteria standards are dictated solely by intended parent demand. One quarter of my interviewees discussed their requirements for educated donors; donors who are currently attending a four-year college, or some similar level of achievement. In fact, for some, lack of education eliminates even more donor candidates than obesity or smoking:

My recipients are usually highly educated, and they want somebody in college, or on their way to a four-year school. So that's the biggest eliminator. (Director, Northern California Agency)

Particularly I'm looking for what I would consider to be academic achievers. (Director, Southern California Agency)

While undoubtedly intended parents also want their donors to be healthy, people who utilize egg donation are often older, highly educated people who want a donor from a similar background.<sup>442</sup> This fact informs the standards of the agencies.

Similarly, one quarter of my interviewees perform criminal background checks on their egg donor candidates, largely to reassure intended parents—perhaps falsely so. As one agency decision-maker explained:

Some agencies will say that they do a background check, but a background check, all that does is tell you whether a person has a criminal record.... It's pretty useless, I mean, the bar is a lot higher than that. (Director, Northern California Agency)

But while some agency decision-makers believed that the criminal background check could be useful, there could be no doubt that every little step taken to bolster the confidence of intended parents was good for business.

Agency decision-makers mentioned egg donor screening standards more than any other type of standard, but the criteria for which agency decision-makers will refuse to work with intended parents also merited a lot of attention.

### Agency Restrictions on Intended Parents

For the most part, agency decision-makers claimed not to engage in restricting intended parents' access to agency services. They defer to clinic norms on issues that have both a

<sup>&</sup>lt;sup>442</sup> This accounts only for people who are *able* to seek treatment with donor egg IVF, which is so prohibitively expensive it is limited to those in the higher socioeconomic classes. But infertility, while common to women who have delayed childbearing in order to establish their careers, is not limited to the wealthy and professionals. "Many people who presumably would *like* to enter the baby business are forced by their finances to the sidelines, because the price—of IVF, donor eggs, a gestational surrogate, or a foreign adoption—is simply too high for them to pay." Spar, *The Baby Business*, 30.

medical and a social component, such as intended parent age.<sup>443</sup> A few agency decisionmakers pointed out the obvious: that they wouldn't work with criminals—or at least with people with a criminal record. And a few agency decision-makers said that they placed no restrictions at all on their intended parents; as one agency decision-maker put it:

> Who am I to judge who should be a parent and who shouldn't? (Director, Midwestern Agency)

Despite an apparent disinclination to refuse to work with intended parents, however, over sixty percent of my interviewees reserved the right to reject intended parents that they felt were too difficult to work with, would make questionable parents, or whom agency decision-makers felt were emotionally unprepared to proceed with egg donation.

Sometimes intended parents were simply too angry or hostile to maintain a working relationship with them, according to one third of my interviewees. Some intended parents take out their anger and grief on the agency staff:

If people are really really difficult, I won't work with them, just because I can't work with them ... you know, just very demanding, very angry, it's my fault that they don't have a child. (Director, Northern California Agency)

You have to be able to establish a professional relationship, so, if it's antagonistic before anything starts it's not going to get better. (Director, Southern California Agency)

Obviously in my business, if anybody talks with any sort of cruel or name calling, or any sort of questionable behavior to anybody on the staff, we back out even if I have to refund money, and yes, we have done that, we have done that. (Director, Southern California Agency)

And some intended parents show hostility toward their donor as well:

<sup>&</sup>lt;sup>443</sup> See more in depth discussion in Chapter Four, "Deferral to Medical Professional Guidelines and Clinic Standards."

If they become difficult to work with or difficult towards their donor, then we refund their money and cancel the cycle on them. (Director, Northern California Agency)

When they're litiginous, entitled, angry at the donor, you know.... People who are I don't know entitled or really nasty about the donor or I've had couples fight with each other on the phone. You know, I ask them to describe each other and I've had people say nasty—not often but sometimes nasty things about each other. (Director, Southern California Agency)

When agency decision-makers saw that intended parents were unable to behave in a civil manner to their spouse, their donor, or to agency staff, agency decision-makers would give them the boot. Egg donation is a sensitive process that requires a good working relationship all around, and at least some of my interviewees wouldn't proceed if that relationship didn't exist, for the benefit of everyone concerned.

A hostile working relationship was one problem, but another third of my interviewees said also that if they suspected that the intended parents would not make good parents —specifically, if they felt that the future children would be in danger living with them—the agency decision-makers would refuse to work with those intended parents.

When I start seeing evidence that they're [the intended parents are] not stable really, I reserve the right to say it's just not a good match because again, I'm into sleeping at night and I'm into—no, I have to work in the way I think is morally right. (Director, Southern Agency)

Some of my interviewees would seek help in the form of a second opinion from clinic staff or mental health professionals if they suspected that intended parents might not make a good home for their future child.

If something sort of strikes me as a little odd I will just call up the nurse and say, 'Can you give me a background on this person?' ... We reserve the right to require it [psychological screening]. So if I get sort of an uncomfortable feeling about someone then I can certainly send them to somebody. I've only really implemented that a couple of times and I'm very grateful that I did. (Director, Southern California Agency)

However, agency decision-makers emphasized that for the most part, they refrain from judging whether or not intended parents will make good parents, and that seeking a psychological evaluation of the intended parents, or refusing to work with them outright, is something they only do in extreme cases.

Sometimes you will see a noticeable—or hear something very wrong in their tone, the way they speak, the way they act; and in those situations if we feel that they'd be a danger.... Who is to say this person can't have a child? We're not here to judge that. But if something is very, very obvious, then absolutely. (Director, Southern California Agency)

A quarter of my interviewees mentioned that if they felt that the intended parent was emotionally unprepared to proceed with a cycle, they would gently suggest that they wait, give themselves time to grieve, and/or seek counseling.

When I hear, 'I just had a miscarriage last month and now ... my doctor said I should choose a donor,' that's where I kind of pull a little short, and say 'well, tell me a little more.' So what I tell them is that sometimes, if you're not really ready, everyone is [all donors are] going to look bad to you. And you will not be able to find anyone that you like.... Because it is a very slow evolution. If you're out there looking for a replacement for yourself, you're not going to find that person. (Director, Northern California Agency)

Whether because of a sensitivity to the emotional readiness of the client, or because of difficulty working with them or suspicion that they would be a danger to the future child, the decision to refuse to work with a particular intended parent is one that is made within the clinic, by the individual agency decision-maker. Yet, as with other standards, including egg donor screening standards, there is so much overlap among agency decision-makers on these points that they begin to converge.

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The standards discussed in this section are internal to each agency; each agency decision-maker developed her own policies about what she will allow and not allow; where she will draw the line. Yet because those decisions are made in the context of the egg donation industry—and thus subject to already-developed clinic norms—and embedded in larger society, they are dependent on outside norms and societal morality

in such a manner that the standards begin to converge.<sup>444</sup> Each individual decision made while embedded in the industry and the society is, in a sense, not individual at all. And as those decisions are implemented via organizational behavior, those values not only spread from the outside world in to the world of egg donor agencies, but also outward from the individual agency decision-maker to other agencies in a process of mimetic isomorphism.<sup>445</sup> In such a way, these internal standards begin to emerge as field-wide norms. It is through a similar process that agencies developed a shared moral meaning.

## Shared Moral Meaning

Agency decision-makers, despite arriving in their business through different means, attempting to fill market niches in unique ways, and "reverse modeling" their agencies on business practices of which they disapproved, often ended up creating moral meanings that are shared among many agencies. Although the agency decision makers may be driven by a desire to succeed in the market, they are also directed by shared moral meaning, the reason that most of them wind up in the egg donation industry. The fundamental shared moral meaning created by agency decision-makers in the absence of legal regulation is an ideal of customer service: caring for their clients, donors, and the children whom they are helping to create, and taking joy in building families. Divergence prompted by attempts to one-up other agencies thus results, paradoxically, in shared moral meanings.

Agency decision-makers all participate in the creation of this shared moral meaning, yet it is simultaneously highly individual: a decision-maker takes personal pleasure in improving lives of her charges. But with great circularity, those individual preferences are embedded in the social context of her organization: her agency converts that individual creation of meaning into an organizational apparatus, itself embedded in the

<sup>&</sup>lt;sup>444</sup> This is one surprising result of an "inhabited institutions" approach to examining organizational behavior. Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field." It is perhaps one way in which agency decision-makers manage conflicting institutional logics. See Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

<sup>&</sup>lt;sup>445</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-70. Additionally, Friedland and Alford's concept of multiple institutional logics is at play here: social values, moral values, organizational logics, and infertility field logics, among others. Friedland and Alford, "Bringing Society Back In."

larger infertility industry and within society in general.<sup>446</sup> And in consequence, such meanings are both created within individual agencies, by their individual decision-makers and disseminated among agencies, resulting in the creation of shared meanings for the organizations themselves.<sup>447</sup>

# Concern for Agency Charges: Intended Parents, Egg Donors, and Future Children

This shared moral meaning of general concern for their charges is apparent in the ways that agency decision-makers discussed intended parents, donors and future children. Agency decision-makers saw their concerns for their charges almost as a moral imperative.<sup>448</sup> They worried about intended parents; how much information they should receive about egg donors, the emotional support of which they were in need, and the high financial cost of egg donation. With egg donors, agency decision-makers were concerned about ensuring they had sufficient information about intended parents, about protecting them emotionally, and about the medical risks they were undertaking. Finally, they worried about the children they were helping to create; whether they would have appropriate access to information about their donors and the ability to avoid situations of consanguinity. Together, these concerns are part of a shared moral meaning in egg donors, and future children alike.

## Concern For Intended Parents

Agency decision-makers attempted to differentiate themselves from one another by emphasizing their compassion for their clients, the intended parents, who have been

<sup>&</sup>lt;sup>446</sup> On the effect of individuals on organizational behavior (inhabited institutions), see Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; and Smets, Morris, and Greenwood, "From Practice to Field." For descriptions of how individuals manage conflicting institutional logics, see Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

<sup>&</sup>lt;sup>447</sup> DiMaggio and Powell, "The Iron Cage Revisited;" Meyer and Rowan, "Institutionalized Organizations."

<sup>&</sup>lt;sup>448</sup> A moral imperative is a principle that compels a person to act.

through so much before ending up looking for an egg donor.<sup>449</sup> Many of them emphasized that their compassion for intended parents was greater than that of other agencies, yet all but one of my interviewees expressed such compassion. They demonstrated their compassion through a variety of specific concerns, ranging from how much information about egg donors intended parents should be given to intended parents' need for emotional support. Many agency decision-makers expressed a general sympathy with the sadness, grief, and fear that intended parents suffer. A number of agency decision-makers were concerned about the heightened vulnerability of intended parents by the time they seek the agency's help, and part of their concern stemmed from the sheer expense of using egg donation, and intended parents' need to make decisions that are of critical importance financially, emotionally, and socially during a time when the they are especially emotional.<sup>450</sup> Some agency decision-makers offered some sort of concrete assistance, such as a donor rematch policy; others simply offered sympathy. The result was that in their attempts to distinguish themselves from one another, agency decision-makers ended up making similar business decisions according to a shared moral value about their role as caretakers of intended parents.

Some agency decision-makers were concerned about how much information intended parents should be given about their donors. It's a fine line, trying to protect the donor's privacy while also providing transparency and maximum information to intended parents. The agency decision-makers who discussed this fine line all felt that intended parents were entitled to more information rather than less. One agency decision-maker felt that intended parents should have access to information about whether or not their children had genetic half-siblings out in the world:

I feel like they [intended parents] should be able to find out easily, 'Oh, my donor donated six more times. There are five other siblings

<sup>&</sup>lt;sup>449</sup> Often, intended parents seeking treatment with donor egg IVF have been through multiple rounds of IVF and other treatments themselves, using their own eggs, and sometimes they do not even have a diagnosis or an understanding about why they are unable to get pregnant. A Southern agency director mentioned that gay families, because they know they will need help to conceive a baby, arrive at her agency with a much smaller emotional burden: "They're a little bit different, I would say, than my straight families. There's a definite difference. Because they don't come to you beaten up already. They're not emotionally spent by the time they come to you. They kind of get that they'll have to go in this direction. So they're actually an easier population emotionally to work with."

<sup>&</sup>lt;sup>450</sup> Infertility takes a serious toll on its sufferers: "Infertility wreaks inestimable havoc on those who suffer from it.... it tends to produce an emotional reaction akin to major illness." Spar, *The Baby Business*, 16; A. Domar, P. Zuttermeister, and R. Friedman, "The Psychological Impact of Infertility: A Comparison with Patients with Other Medical Conditions," *Journal of Psychosomatic Obstetrics and Gynecology* 14 (1993): 45-52.

—you know, there are five other half siblings for my child from these separate donations.' (Director, Southern Agency)

Other agency decision-makers felt that intended parents should have access to as much information as possible about the donor, in order to inform as well as possible their choice of donor:

Agencies, some are still very split on this. Some believe that as long as they pass their psychological evaluation, the evaluation should not be shown to the intended parents. They should just simply be told it was a pass or fail situation. I have a very different philosophy on that. If someone's going to have your genetics, I'd want to see a full report. Certainly done by psychologists in the industry who can write a very thorough background of the donor. (Director, Southern California Agency)

And, in the same vein, some agency decision-makers felt that if the intended parents found that they were uncomfortable with anything they learned about the donor, whether in her self-reported profile, medical testing, genetic testing, or psychological evaluation, the intended parents should have the prerogative to cancel the cycle, no matter how far it had progressed:

I always felt more information was key, and if intended parents get a psychological or genetic evaluation back before medical screening, and see something on there they're not comfortable with, then I think it's their prerogative to back off. Because there's been psychological evaluations where the psychologist says, 'I do recommend this donor go froward,' but then the intended parent said, 'You know what? There's just a couple things in her background I'm not comfortable with.' ... I don't think that's our [the agency's] call. It's disappointing, yes, hopefully they choose another donor with us. (Director, Southern California Agency)

Such policies would, of course, have potentially negative consequences for the agency's financial bottom line.<sup>451</sup>

<sup>&</sup>lt;sup>451</sup> Several agency decision-makers mentioned that their businesses were not especially lucrative; presumably, if they suffered a number of setbacks such as canceled cycles and the need to give refunds, it could potentially put them out of business.

Another agency decision-maker noted that sometimes new information about a donor comes to light after a cycle has commenced (or been completed). With some such information, the proper course of action is clear:

When the donor calls and says, 'I just found out my grandfather was schizophrenic,' because that's huge. Those kinds of things. And those are the things you share and you really have to. (Director, Southern California Agency)

But in other cases, the path is less clear. If the new information is something the agency decision-maker considers to be minor, but might be important to the intended parents, the agency decision-maker must make a judgment call on whether to share that information with the intended parents:

Where you get some information mid-cycle or something happens and ... you're really stuck in between a rock and a hard place about what the ethical thing to do in a situation is. You know, where a donor might start acting ... in such a way where you start to question something about their personalities in general. And the question is: I'm not a therapist, what do I do about this? Do I just share the information? Do I not give that kind of stress to the intended parents? And I've been on both sides of the coin on this, where I shared the information and had the intended parents get livid at me for sharing that type of information.... And then other times where you don't share the information and so the nurse does, and they say, 'Why didn't you tell me?' (Director, Southern California Agency)

In these cases, according to this agency decision-maker, there is no right or wrong, but the agency decision-maker must refer to her own moral sense to make the determination about whether to share the new information with the intended parents. And if she chooses not to share it, it might be to protect the donor's privacy, but it might also be to protect the emotional state of the intended parents—to protect them from unnecessary worry, or at least worry about that which they cannot control.

The creators of SEEDS (discussed in detail in Chapter Four, especially in "Professional Body") felt that the issue of disclosure of egg donor information to intended parents required a standard to guide future decision-making:<sup>452</sup>

<sup>&</sup>lt;sup>452</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

Emotional Disclosure of Information to intended parents regarding the egg donors during the matching process of the cycle should include non-identifying information that allows the IP's to make an informed decision about the egg donor they are using. The IP's should be informed of the following:

Job, moves, school and/or other obligations that are causing stress and/or fear (i.e. loss of a job, failing a class, moving to another location, etc.).

Donors' perceived enthusiasm and/or response and understanding of questions, obligations and appointments (including promptness of returned phone calls/emails/texts, etc).

Donor's social support system.

New relationship within the time-frame of being chosen.

Donor's empathetic response to the intended parents.

They have not shown signs of verbal abuse to the agency and/or their staff.

There is no known criminal record, drug or physical abuse.

There are no signs of instability or obvious mental illness present.<sup>453</sup>

This standard addresses not only the information commonly understood to be important—medical and genetic—but also the donor's emotional state and ability to follow through with the cycle. As such, agency decision-makers might follow this standard in an effort both to fully inform intended parents' choice about their donors, and to protect them from an unnecessarily canceled or failed cycle.

Almost half of my interviewees discussed their role in providing emotional support to intended parents. They spoke about it generally; that needing to engage an egg donor in order to have a much-desired baby is a difficult position to be in, and that actually doing so is a difficult thing to do, all around.

<sup>&</sup>lt;sup>453</sup> "Agency's Responsibility Regarding Emotional Disclosure: Intended Parents," SEEDS Standards.

My position is is that it's already a thing of trust to be hiring a donor and especially when most of the time you deal with things online as opposed to meeting in person. So anything that I can do to kind of assuage people's fears about its issues is something that's important to me to do. (Director, Northern California Agency)

Agency decision-makers found themselves in counseling roles that they were not necessarily trained for, when intended parents depended on them for emotional support, as well as logistical support during their cycles:

I call myself the mother-in-chief because on the other side of the equation some of the intended parents really lean on me a lot for support and I'm not a psychologist, I'm just like a mom and a business person. (Director, Southern California Agency)

And in general, agency decision-makers tried to make the process of egg donation as smooth and easy as possible for their intended parents:

For me it's very much about trying to inspire patients to take this journey in a way that's going to make it easier for them. (Director, Southern Agency)

We really think our job begins when a cycle starts, when they choose a donor. There's a lot of work to be done to facilitate all this for people and explain it and be by their side and make sure it goes smoothly. And I don't know that that's always done [in other agencies and in-house programs]. (Director, Southern California Agency)

As a general rule, making the process of egg donation smooth for the clients is good business—satisfied customers breed more customers—but agency decision-makers did not speak about it in business terms, but rather as a moral imperative. Their businesses exist to assist intended parents, and assisting intended parents, however they might, is the duty of the agency.

Some agency decision-makers observed that intended parents are typically not in a good emotional state when they arrive on the agency's doorstep. And those intense emotions can interfere with good decision-making on the intended parents' part:

I have many very educated families coming to me. We have extremely successful people. And they're bright. But ... when the emotional stuff gets in the way they're less bright. (Director, Southern Agency)

On occasion, agency decision-makers found themselves counseling intended parents who may not be emotionally ready to choose a donor:

I can sort of tell if there's a lot of anger there, or a lot of hesitation, then they may not necessarily be ready. So I spend a lot of time kind of finding out what their story is, kind of telling them pitfalls to avoid. (Director, Northern California Agency)

And in some instances, agency decision-makers felt they had to tell intended parents to take more time, seek professional counseling, and wait until they were emotionally ready to proceed with egg donation:

In other cases if I'm talking to somebody and they're just all over the place and they're fear based and they've been looking for a donor for over two years and they can't find anyone that's right, I will have the [discussion]—'I just don't think it's the right time for you because it shouldn't take two years to find a donor. If you want to be a parent then you choose fairly quickly and you move forward ... because it really comes down to I'm just tired of this journey and I want to be a mom or a dad.' (Director, Southern California Agency)

Agency decision-makers also tried to give intended parents specific advice or help to ease their egg donation path. This decision-maker felt that intended parents have an easier time choosing a donor if they do not look at photographs right off the bat; she spoke of one client who was having a hard time choosing a donor because she couldn't get past the donors' appearances:

> So had she not been looking at photos, she would've really been able to clue in to the other qualities that are so important, the family history, the donor's personal qualities. But the second those photos emerge you really lose your ability to not judge based on that, which is why at least at a minimum I encourage my families, not so much not to look at the photos but not to look at photos before they've read the donor's profile. (Director, Southern Agency)

And while a little empathy can go a long way, concrete financial assistance helps, too:

Sometimes just being empathetic and saying, 'OK, you know what, that sucked and that wasn't your fault.' And I guess that's why we have that rematch policy, is we feel that once you decide to work with us, it's kind of a team. We're in it together. (Director, Southern California Agency)

Overall, agency decision-makers assumed the role of protector for intended parents; because these clients often came to them after a long and difficult period of trying to conceive through other means, agency decision-makers tried to help them decide whether to proceed, and then supported them financially, emotionally, and logistically to the best of their ability:

Because actually, the people who I think need the most protection, generally speaking, are the intended parents.... We are sort of the intended parents' advocates. Because so often what I find is that everybody's got their own agenda.... We like to think of ourselves as being that neutral party. We don't get any referral fees from agencies or clinics ... we can't do that legally anyway. But so I think too often that nobody's really looking out for the intended parents, and that's what we really try to do. They're the ones that are really vulnerable, because they're the ones that are brand new to all this, and they're the ones that are emotionally—they want to believe, and they don't know who to trust. So that's the part that I—feel for them. And sometimes they become a little jaded, after they've been burned. (Director, Northern California Agency)

Agency decision-makers spoke about the ways in which they support intended parents emotionally as if it were a moral imperative, that agencies exist not only to facilitate matches between egg donors and intended parents, and to see egg donation cycles through from beginning to end, but also to advise and support intended parents, who are often emotionally devastated, while they make a series of difficult and life-changing decisions.

Interestingly, the most commonly expressed concern about intended parents—by over sixty percent of my interviewees—was the extreme cost of infertility treatment with donor eggs.<sup>454</sup> Agency decision-makers knew that not everyone could afford such treatment:

<sup>&</sup>lt;sup>454</sup> In the San Francisco Bay Area in 2014, a fresh donor egg cycle, including all medical procedures, medications, agency fees, and donor compensation, can run \$35,000-\$40,000 or more.

What about people that ... are just scraping by? They don't have that option [of using egg donation]. That's where I think insurance may be helpful. (Case Manager, Northern California Agency)

They were also distressed that sometimes their clients left without achieving success and bringing home a baby.

But it's very frustrating to me, because ... when someone spends \$30,000 and they still don't have a baby, that's a tragedy. (Director, Northern California Agency)

One agency decision-maker was distraught at the cost of egg donor IVF, and despite herself running a business, presumably with a financial bottom line, thought that the business should be in part about minimizing costs for intended parents building their families:

It should be about that people can create families at an affordable cost. It shouldn't be about ... it shouldn't be about the bottom line of profit. (Director, Northeastern Agency)

While needing to make a profit in order to continue doing business, agency decisionmakers talked about the cost of egg donor IVF in terms of the intended parents' perspective; how high that cost is, unreachable for some, and a compounding factor for the calamity of infertility.

In an effort to mitigate the costs and extend intended parents' ability to pursue treatment with egg donation, some agency decision-makers offered refunds of their agency fees or a new donor match for no additional agency fees in the event of a canceled or failed cycle:<sup>455</sup>

And of course there's nothing sadder than when it doesn't work and they spent all this money. But you just try to stick with them

<sup>&</sup>lt;sup>455</sup> Per my interviewees, agencies offer a number of different types of refund and shared risk programs: They offer to find another donor free of charge, or give a refund (50% to 100%, depending on the agency), if a cycle is canceled (but not if a cycle is completed but does not result in a pregnancy), and some offer to rematch with another donor free of charge if the cycle itself fails (i.e., the donor completes the cycle, but it does not result in a pregnancy). In all of these cases, the donor fee must be paid in full or in part, depending on how far the cycle has progressed, but the agency fee is waived or refunded. Other agencies offer a shared risk program, in which the intended parents pay a slightly higher agency fee up front, but then if the cycle fails, they can undergo another cycle with no further agency fees, and benefit from agency-negotiated discounts from other professionals (mental health, clinics) in subsequent cycles. Other agencies offer no refund or shared risk program.

and find alternatives that make sense or give them discounts. But you can't just do five donors for nothing but you try to help. (Director, Southern California Agency)

If they go through a cycle and they have no more frozen embryos and there's no successful pregnancy—which we define as a take home baby—we will have them come back for another cycle with no agency fee. (Director, Southern California Agency)

Such policies may mean that agencies lose money on specific clients, but agency decision-makers felt that their occasional loss was more than outweighed by the benefit to intended parents in need of multiple cycles.

The only other thing that really does set us apart I think, at least that I've heard of is, our agency fee is—even once they paid an agency fee—our agency fee is good until a successful retrieval.... from a business perspective it doesn't happen that much, and we might as well just eat it when it does because for the intended parents that we end up having to help out, it makes a world of difference for them. (Director, Southern Agency)

Almost three-quarters of my interviewees' agencies have some sort of agency fee refund or donor rematch policy to aid intended parents in the event of a canceled or failed cycle. These policies are concrete evidence that agency decision-makers place great emphasis on helping intended parents in whatever way they can, including, to some extent at least, when it affects their own business finances.<sup>456</sup>

Agency decision-makers were also concerned about the financial impact that a donor could have on intended parents. While there is general agreement in the industry that egg donors should not be financially responsible for any part of the cycle, one agency decision-maker thought that it was a deficit in the system, to the intended parents' disadvantage:<sup>457</sup>

I think probably the one thing that intended parents would really like to see is an ability to go after a donor if she breaches her

<sup>&</sup>lt;sup>456</sup> 60% of my interviewees' agencies offered some sort of agency fee refund or shared risk program.

<sup>&</sup>lt;sup>457</sup> Per my interviewees, there is general agreement that holding egg donors responsible for incurred costs at the time that they back out of a cycle could be considered exploitative, though not all of my interviewees agreed: some required donors to pay for incurred costs if they backed out for any personal reason, as a means of protecting intended parents by helping to ensure that donors followed through with the cycle to which they had committed.

contract, like if she backs out. That's the biggest complaint I get. (Director, Northern California Agency)

When egg donors threaten to back out of a cycle in favor of another, more lucrative cycle with other intended parents, one agency decision-maker reminds the donors that the original intended parents are depending on her to see through her commitment to the cycle at the originally agreed-upon fee:

All of us on the agency end and the intended parent side know when they've chosen a donor, they've gone through a lot to get to that point. They really are hoping and counting on that person to be there. And then to find out that she just left because someone else was offering her higher. So then, what that does is put them in a position of saying either, 'I match that or go higher, or I just let her go.' ... I will absolutely say, 'I'm not going to go back to the parents. You already agreed to this. They're counting on you. You promised this and you can do your next cycle for twice as much.' (Director, Southern California Agency)

But sometimes it's not the donor's fault that the cycle is canceled:

I feel really bad for intended parents ... they choose someone, and then that donor goes to have their evaluations, and then they don't pass. And so I wish there was a way to do that in advance. (Director, Northern California Agency)

And, as another agency decision-maker observed, while there are some steps that could be taken to minimize the likelihood of cycle cancelation either due to medical reasons or to donor capriciousness, such steps may well lead to increased cost for intended parents, which is unlikely to help much:<sup>458</sup>

So could those things [better donor screening and education] be changed in the industry? Could it make the industry better? Of course, it could. But at what cost and who is going to absorb that cost? The intended parents are already absorbing a huge cost. (Director, Midwestern Agency)

<sup>&</sup>lt;sup>458</sup> Infertility treatment, including IVF with donor eggs, is rarely covered by health insurance, so intended parents usually pay for all costs—physician, procedures, lab, medication, agency, donor—out of pocket.

Even more so than disclosure of egg donor information and intended parents' need for emotional support, agency decision-makers worried about the high financial cost of egg donor IVF for intended parents, and the potential to spend an exorbitant amount of money and still wind up childless.<sup>459</sup> To mitigate the financial impact on intended parents, many of my interviewees' agencies have fee refund or donor rematch policies in place, in case intended parents' first (or even second) cycle is unsuccessful. As with intended parents' need for emotional support, agency decision-makers expressed sympathy with intended parents' plight, and spoke of helping them financially as if it were a moral imperative.

Half of my interviewees expressed a general sympathy with intended parents, and with their heartbreak, grief, and fear from the path that brought them to the agency through the egg donation process and beyond. Agency decision-makers commiserated with intended parents, and the state in which they arrive at the agency:

Families come to me and they're very burnt out. Often they're very burnt out. They've been through horrible, horrible, horrible journeys, very difficult, very challenging. It certainly challenges them emotionally. (Director, Southern Agency)

Couples who stay up late at night worrying are the ones who don't have a baby and are heartbroken. (Director, Northern California Agency)

And agency decision-makers tried to help intended parents to understand the loss of control that is part and parcel of infertility and infertility treatment:

That's the one thing I hate about my job, because, when it doesn't work, a lot of times, you know, people think that there's a reason and they don't understand that it's just a roll of the dice and it's all about numbers. (Director, Northern California Agency)

You lose control of so much in IVF. You can make the best decisions possible, and there are still bumps in the road. That's what I share with my clients early on. There are realistic expectations that you just have to assume, and you have to realize you do not have one hundred percent control. (Director, Midwestern Agency)

<sup>&</sup>lt;sup>459</sup> Many intended parents do not achieve success, even with the higher success rates of donor egg IVF. In 2012, fresh donor egg IVF has a single cycle live birth rate of 56.5%. SART, Clinic Summary Reports 2003-2012.

In addition to the loss of control that is part of egg donation, agency decision-makers recognized that even arriving at the decision to use donor eggs represents a history of grief that intended parents are likely to be carrying with them still:

I think they are in a vulnerable place and they probably are—this is a very emotional decision, and especially using an egg donor, because now you're not only losing the control of carrying your own child, if you're husband and wife or man and woman, but now you're also losing that genetic link, so a lot of times there is that mourning period for a lot of parents, especially for the moms. (Director, Southern California Agency)

In general, whether or not they had experienced infertility themselves, or served as egg donors themselves, my interviewees shared an empathy for the difficult experiences of their clients, and the sense of sadness, grief, and fear that was likely to be part of the emotional burden that intended parents carry with them into the egg donation process.

One agency decision-maker specifically opened her agency with the intent to mitigate the stress and sadness that intended parents experience when searching for an egg donor:

So I just thought, you know, all of this is stressful enough. The eggs —the finding a donor piece actually should be the least stressful part. And so I set about trying to treat people the way I wished that I had been treated, and it's worked pretty well. (Director, Northern California Agency)

And another agency decision-maker criticized other agencies for not providing intended parents with the empathy that they deserve:

I had one client tell me that [at] the other couple of agencies they visited they felt like they were going to a puppy mill and they were just churning out babies. I said yeah, a lot of them are kind of like that. (Director, Northeastern Agency)

These agency decision-makers desired to make the process of choosing an egg donor and participating in an egg donation cycle as pleasant as possible for intended parents. Agency decision-makers also acknowledged that intended parents might experience a number of concrete fears about conceiving with an egg donor. One such fear is the threat to their own parenthood:<sup>460</sup>

They have a fear that some donor's going to show up twenty years later wanting the kid. Couples have that fear. (Director, Northern California Agency)

And for foreign intended parents, there is the additional fear of working in a culture different from your own:

And also you're coming overseas so there's a fear and probably mistrust because it's a different culture.... It's hard to put the amount of money and emotional situation that they're going through in the hands of somebody in a different country who they don't know. (Director, Southern California Agency)

In addition to the fears that most intended parents must have about failed cycles and large financial investments with questionable return, agency decision-makers recognized specific circumstances and fears that intended parents bring with them to the process.

All but one of my interviewees expressed concern about their clients, the intended parents. Those concerns were about what information about egg donors should be disclosed to intended parents, intended parents' need for emotional support, and the financial cost of egg donation. Agency decision-makers also expressed general

<sup>&</sup>lt;sup>460</sup> While some sperm donors have sought legal paternity (see, most recently, the high profile and complex case of Jason Patric and Danielle Schrieber: Brooks Barnes, "Does 'Sperm Donor' Mean 'Dad'?' The New York Times, 2 May 2014, available from www.nytimes.com/2014/05/04/fashion/Jason-Patric-Does-Sperm-Donor-Mean-Dad-parental-rights.html?\_r=0; Internet; Accessed 14 November 2014. One of my family formation attorney interviewees said that he had never seen such a case with an egg donor: "Not once. And I will give you the benefit of [over twenty] years of experience. I have not been in the business for [over twenty] years, but the two attorneys that I've worked with, the two partners that I started working with, have been in the business since the early 90s, and it's never happened. And we've done thousands of cases. Thousands." Aside from the fear that the egg donor will claim legal maternity, intended parents also worry that they will not feel like the child's parents. Intended mothers fear that they will be unable to love and bond with the baby, as they would have had the baby been their genetic child. See, e.g., Briony Walker, "Donor Eggs: But Will the Baby Feel Like Mine?" The Guardian, 13 May 2011, available from www.theguardian.com/lifeandstyle/2011/may/14/donor-eggs-pros-consconception; Internet; Accessed 7 September 2014; Amy Klein, "Would a Pregnancy Through a Donor Egg Feel Like 'Mine'?" Motherlode (A New York Times Parenting blog), 13 January 2014, available from parenting.blogs.nytimes.com/2014/01/13/would-a-pregnancy-through-a-donor-egg-feel-like-mine/; Internet; Accessed 7 September 2014.

sympathy for the plight of intended parents, and for the heartache, grief, and fear they've experienced during their attempts to conceive. While these concerns were individual, located at the agency decision-maker's personal feelings and feelings of moral duty, they were shared by almost all other agency decision-makers, and put into action through agency policies.<sup>461</sup> As such, they were both individual and institutional, and, as a consequence, shared. The shared moral meaning of concern for intended parents has its origins in the individual, embedded in the organization.

## Concern For Egg Donors

Eighty percent of my interviewees expressed concern of some type for the egg donors who participate in cycles through their agency. Those concerns ranged from worries about the donor's emotional experience with egg donation (for which they attempted to provide emotional support) to the medical risks that donors undertake by donating. Agency decision-makers wanted to ensure that donors thought through the decision to donate, in order to avoid future regrets; they wanted to ensure that donors knew the outcomes of the cycles in which they participated; they wanted to be sure the donors were truly comfortable meeting intended parents, when the intended parents so requested. Agency decision-makers also expressed concern about the risk of ovarian hyperstimulation and unknown medical risks in egg donation. The varied concerns articulated by agency decision-makers comprise part of the shared moral meaning of their work: acting as caretakers of those who agree to participate in the business of their agency.

Almost half of my interviewees said that they tried to provide emotional support to their donors. One agency decision-maker lauded her donors, admitting that she doesn't think that she herself could have brought herself, emotionally, to be an egg donor:

I honestly will share with you that I don't think I could've donated my eggs. Emotionally, I don't think I could've done that. I have a huge amount of respect for these women. I have a huge, huge, huge amount of respect and love for my donors, because they are very special young women, but it's not for everyone. (Director, Southern Agency)

<sup>&</sup>lt;sup>461</sup> A version of "inhabited institutions" at work. See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field."

Another agency decision-maker worried about the emotional impact of rejection on her donor applicants, the vast majority of whom she turns away:

We turn down so many donors and I hate to do it. We write a nice letter, but we can't call them and say, 'Here's why you were turned down, I'm so sorry.' And it's really hard, you know, you think, somebody's putting themselves out there. We've made it so that they just fill out a very short application to start with, so it's not so much effort. But it still feels really sad every time we turn someone down. It doesn't feel good. (Director, Southern California Agency)

A primary way in which agency decision-makers provided emotional support to their donors was to make sure that donors were enabled as much as possible, even though they are young, to envision the long term consequences of donating their eggs.

From the emotional side, I wonder if they'll regret this later on as they get older and stuff. A lot of them who come to us are fairly young and students and need the money for stuff. So I wonder, are they going to regret doing this in the future? I certainly hope not. (Director, Southern California Agency)

That's probably the major thing, you know, from a donor standpoint, that they understand the process, they understand the risks.... Also emotionally that they—technically, this is their genetic material and technically, if you have children one day, that this will be their half siblings. (Director, Southern Agency)

One mental health professional explained that the best way to ensure that donors had thought through the long term consequences of donating their eggs is to have them counseled by a professional:

The next best case scenario really is just having egg donors understand ... really really understand that this is not a blood donation. You know, one sustains life and the [other] creates life and there's going to be a real live person that comes from this who may have lots of questions and curiosity down the road. Generally, when women really understand the sort of permanent long-term nature of what they're giving, they are much more open to say, 'You know, I think that would be OK in fifteen, twenty years, if you want or need to contact me.' But then they also have to think about who else they're going to share the info with and are they going to tell a future spouse that they donated so nobody is shocked. (Mental Health Professional)

In the context of donation to frozen egg banks, a few agency decision-makers felt that it was even more important for egg donors to be counseled about the potential consequences of their donations, since they would not be engaging in a direct agreement with a specific intended parent, and their eggs could go to multiple sets of intended parents:<sup>462</sup>

One concern that we have is that when someone does a fresh cycle, a donor is releasing their eggs to a specific and intended parent, and even our intended parents and donors agree upon what will happen to those future embryos. So do they use them just for themselves, do they donate them to another family, are they destroyed, are they donated to research, and everybody agrees on those terms.... I think it's a little scary that a donor just releases their eggs to a clinic, and a clinic then sells them to an intended parent, because that's what they're doing. (Director, Southern Agency)

I wonder, are donors really well enough informed and do they really understand the implications of donating eggs [to a frozen egg bank] versus donating eggs to a particular intended parent. And frozen eggs are so much like the sperm donation model, which is you could be a father of sixty kids out there. You'd never know. And I wonder, do these twenty-something-year-old girls really understand that potentially, they could be genetically related to so many kids versus helping just one family? And I don't know that that information clearly comes across to the egg donor, because typically these egg banks are held by fertility centers and, honestly, I don't believe that the fertility centers counsel the donors well enough through that process. (Director, Midwestern Agency)

These agency decision-makers felt that donating to a frozen egg bank exacerbated the potential emotional complications of egg donation. They worried that the consequences would be more widespread, with more families receiving eggs from each donor, and that the donors wouldn't be as well counseled to think through the long term

<sup>&</sup>lt;sup>462</sup> In contrast to traditional fresh cycles, the eggs frozen from a single donor's cycle are sold a few at a time, potentially to two or three or more sets of intended parents, rather than all at once to a single intended parent.

consequences of donating if they weren't participating in a traditional egg donation cycle.

Finally, agency decision-makers provide emotional support in the context of donors meeting intended parents or donor-conceived offspring. While donors are often happy to meet parents, agency decision-makers try to look out for their donors who are not comfortable with meeting, whether such a meeting is proposed at the time of the cycle or as a meeting with an older donor-conceived child:

So initially when I started to speak to the donor about it ... whether she wanted to meet [the intended parents], her first reaction to me —again, as a young women in her twenties—was, 'Oh, OK.' And I asked her more questions. And the more I asked her, the more I realized that she really hadn't thought it through carefully.... So this family met this donor and the donor called me afterwards, and I think she really regretted the meeting, and not because she didn't like them or think they were nice people, but it just kind of put it on a new level for her. (Director, Southern Agency)

Why this agency decision-maker didn't stop this meeting from going forward is unclear, but she took it as a lesson for what might happen with donors in the future. Another agency decision-maker understood when a donor didn't want to meet a donor-conceived child at an emotional time in the donor's own life:

But it was one of those things where I had someone who said, 'Gee, my daughter is now about eight and she's starting to ask questions. Do you think my donor would be willing to have contact?' I contacted the donor, and this was a young woman who was just a sweetheart, and she had one daughter herself. Her daughter was going off to college at that point. And I think it would have been a little—and she said, 'No, right now I really don't want to have contact.' And I think that, for her, it was a little—I know I've been through the empty nest and my kids are grown, and I think that it might have been just a little more emotionally difficult than she might have anticipated. You can't predict how you're going to feel in the future. (Director, Northern California Agency)

While, generally speaking, agency decision-makers support meetings between donors and intended parents, and contact between donors and donor-conceived children, they recognize that such contact may not be emotionally healthy for each individual donor, and seek to protect donors from inappropriate contact with intended parents and children.

Agency decision-makers also expressed concern that egg donors, who typically receive much less information about intended parents than vice versa, receive at least a basic amount of information about the intended parents and about the results of the cycle.<sup>463</sup> As one agency decision-maker said, her agency gives egg donors "basic" information about the intended parents with whom she is matched:

Where they're located, and what kind of work that they do, and the clinic they're working with. Just some very basic—well, it is better if they meet or if they talk on the phone. (Director, Northern California Agency)

And in fact, SEEDS has also created a standard to ensure that egg donors receive a certain amount of information about their matched intended parents, in order to inform the donor's choice:

Emotional Disclosure of information to egg donors regarding the intended parents during the matching process of the cycle should include non-identifying information that allows the egg donor to make an informed decision about the family she is donating to. For example, an egg donor should know if they are working with a single parent, a gay family, a heterosexual couple and/or the marital status [of the intended parent]. She should be informed of the following:

They are capable of supporting a family.

Intent for future contact.

That the agency, clinic, and/or licensed psychologist feel they are emotionally prepared to move forward with this process.

<sup>&</sup>lt;sup>463</sup> Intended parents review extensive profiles of many different egg donors in an agency database in order to make their choice, and after they are "matched," they continue to receive information about the donor, including whether she passed her psychological evaluation, and sometimes how many follicles the reproductive endocrinologist could see in the donor's screening ultrasound. Egg donors sometimes find out the general area in which the intended parents live, and the fields in which they work. The exchange of information is highly unbalanced.

They have not shown signs of verbal abuse to the agency and / or their staff.

There is no known criminal record of drug abuse or physical abuse.

There are no signs of instability or obvious mental illness present.<sup>464</sup>

This basic information would, at least in theory, enable a donor to refuse to donate to a family with whom she felt uncomfortable, whether because of religious or personal difference, or out of concern that the resulting child would not be well cared for.

Agency decision-makers also felt that egg donors deserve to know the outcomes of the cycles in which they participated—that these young women should know whether they had any genetic children out in the world. One agency decision-maker said that not all agencies ensure the donors know the results of their cycles, and sometimes donors come to her agency after donating at such an agency:

But when donors come to me and they say, 'Oh, I have no idea how successful it was or if they [intended parents] donated the embryos,' that makes me a little uncomfortable, I guess. (Director, Southern Agency)

Similarly, this agency decision-maker felt that egg donors should, as a matter of course, be informed about the outcomes of their donation cycles:

I do feel like that it is the right of that donor to know the number of eggs that were retrieved, if they fertilized, and really, if there is biological child that ends up being born via their donation. (Director, Southern Agency)

Another agency decision-maker discussed the way in which her agency tries to ensure that their donors have access to cycle results:

We also require that the intended parents must be open to letting the donor know if there is a positive live birth through the clinic [i.e., the intended parents must be willing to share with the donor the information that the donor egg IVF cycle was successful and a child was born as a result]. So should the donor call, the clinic can

<sup>&</sup>lt;sup>464</sup> "Agency's Responsibility Regarding Emotional Disclosure: Donors," SEEDS Standards. See further discussion of this standard in Chapter Five, "Respect for Egg Donor Choices."

say, 'I am donor 1234 and I want to know if any of the intended parents that I worked with did achieve success.' We give them the sex and the year that they were born. That requirement we put into the contract. We request that to happen. Whether that is happening as far as enforcing it, we don't know yet, because that time hasn't lapsed so we don't know. But we do know that that's what we require of the clinics. (Director, Southern California Agency)

As this agency decision-maker noted, it is unclear which of these provisions might be acknowledged by a clinic, much less be enforceable by a court, but the agency decisionmaker is, at the least, doing what she can to enable donor access to cycle results.

Many agency decision-makers also expressed concern about the medical risks that donors undertake by agreeing to participate in a medically unnecessary (for them) procedure. Some of those concerns are general:

Well, yeah, if they get injured or something. (Director, Northern California Agency)

Although they are few and far between, there are still, of course, risks from donating. (Director, Southern Agency)

And this agency decision-maker, even though she realized that statistically speaking, the acute risks to donors from the medications and egg retrieval are minimal, worries constantly about her donors:

I feel responsible for these young women, and I don't take it lightly. I don't take the medical risks lightly. I never sleep well when we're going through a cycle, because I always want to see the person recover. Obviously, if I thought something terrible would happen, I wouldn't even be doing this work, period. But still, I don't take it lightly and we're very serious about it and we're really devoted to the young women who do this for our families. (Director, Southern Agency)

Another agency decision-maker pointed out that part of the problem is that every person is an individual, which means they have individual reactions to medications and other medical interventions. And one of her donors might be one of the few people who reacts poorly to a part of the egg donation process: So while ... most doctors would say egg donation is as safe as getting wisdom teeth removed, ... you could have a reaction to anesthesia doing either one of those things. And that reaction can be bad or ... you might be like one of those needle in a haystack people who has a bizarre and strange unexpected reaction to a medication that nobody else has. (Director, Southern California Agency)

One agency decision-maker has implemented a policy that is part of her agency's effort to ensure that her donors are healthy after donating their eggs; her donors don't receive the last portion of their fee until they have had a follow up appointment with a physician to check on their recovery from the ovarian stimulation and egg retrieval:

> One week post-retrieval, they [donors] have to go back to the fertility clinic for a check-up, just to make sure they don't have any adverse side effects, that they're feeling OK, that things are just getting back to normal. So we pay the last \$1000 [of the donor's compensation] within two business days post follow up of that appointment. Essentially, we don't want to pay them the [full compensation at retrieval] because what happens if they don't show up to their appointment, and then something goes wrong? We want to make sure they actually go back to that follow up appointment and make sure they're feeling OK and everything's fine. So that—the last \$1000 is intended to make sure they actually go to that appointment. (Director, Northeastern Agency)

The primary medical concern for donors during an egg donation IVF cycle is ovarian hyperstimulation syndrome (OHSS), when the ovaries become excessively swollen, and fluid leaks into the belly and chest.<sup>465</sup> This condition can be life threatening, but is much less common today than it used to be, with new medical protocols, conservative management of donors, and more intense monitoring.<sup>466</sup> Yet, as agency decsion-makers noted, there's no foolproof way to prevent OHSS:

<sup>466</sup> See A.K. Datta, "Improved Clinical Outcomes and Lower OHSS Risk with GnRH Agonist Trigger and hCG Incorporated Luteal Support, Compared to hCG Trigger in GnRH-Antagonist Protocol for Anticipated High Responders," *Fertility and Sterility* 100, no. 3 (Sept. 2013): S517; K. Gordon et al., "Adverse Events and OHSS by Age Category in IVF Center in North America: Data from the Pursue and Engage Trials," *Fertility and Sterility* 101, no. 2 (Feb, 2014): e35.

<sup>&</sup>lt;sup>465</sup> "Ovarian hyperstimulation syndrome," *Medline Plus*, www.nlm.nih.gov/medlineplus/ency/article/ 007294.htm; Internet; Accessed 6 July 2014.

I don't think there have been any donor deaths in at least a decade, that I know of. But even donors who have no warning signs that they are likely to develop OHSS, I think can develop it. I think it can be minimized, and usually avoided, and managed when it happens, but I don't think it's ever going to be completely avoidable, even with the best care. (Director, Northern California Agency)

And because OHSS is uncommon, not all physicians will recognize it for what it is. If a donor is really unlucky, and develops OHSS and ends up with an emergent treating physician who does not recognize what she has, the donor could be injured further:

You might hyperstimulate and go to an emergency room and the doctor doesn't know what's going on, and ... they do something that they shouldn't. (Director, Southern California Agency)

A few agency decision-makers expressed their concern that OHSS was making a comeback with the advent of frozen egg banks, many of which are owned by reproductive endocrinologists, who thus have a vested interest in a donor producing as many eggs as possible (which can then be sold to two or three separate intended parents).

At the last ASRM conference, I spoke to a lot of people, and there's been a spike in occurrences of ovarian hyperstimulation.... And I really think that has to do with the conflict of interest [that arises when reproductive endocrinologists own frozen egg banks]. (Director, Southern California Agency)

From the donor's standpoint, that's going to be a major health risk that—we've almost gotten away from hyperstimulation ... we are seeing it less and less. But when you go back to doctors needing as many eggs in order to get—I mean, because what—they're doing frozen cycles because it's better for their bottom line, and it makes everything easier in my opinion. So I have a feeling we may trend in an opposite direction from a donor's health perspective. (Director, Southern Agency)

OHSS is the medical bogey man of egg donation, in a way, and agency decision-makers worry that their donors will be the unlucky victims of it. To prevent their donors suffering from OHSS, they try to ensure that donors have appropriate follow up, and they refuse to work with clinics that are careless with donors' health (as discussed in greater depth in Chapter Four, "Bad Apples Spoil the Barrel"), but their concern is part of the shared moral meaning of the industry as caretakers of egg donors.

Agency decision-makers also worry about donors who do more than the ASRM recommended six cycles, although there is no real evidence about at what number it becomes dangerous for a donor (or more dangerous).<sup>467</sup> Following the ASRM guidelines gives agency decision-makers the sense that they are doing something to prevent injury to donors:

I just don't think it's something that donors should do more than five or six times. And I think five or six is even on the high side of things. (Director, Midwestern Agency)

And donors who "game the system" and lie about how many cycles they have done in order to exceed the ASRM guidelines are, in this agency decision-maker's opinion, simply uninformed about the risks they are undertaking:

Honestly, those are the girls that really don't understand the risks that they hold by—by donating too many times, the risks that they hold for themselves.... They need to understand the implications of what they're doing. (Director, Midwestern Agency)

When donors wish to exceed six cycles openly, this agency decision-maker will allow it (with the approval of a physician), but only after the donor has been educated about the risks by at least two physicians:

[Donors] have to at least talk to two [reproductive endocrinologists], and they also have to sign a form with our agency, and with the attorney, that it's against the ASRM suggested guidelines, and that they understand ... [the] ASRM suggested guidelines, and that they have talked to a medical professional. And based on all of this, they still feel completely comfortable moving forward. (Director, Southern California Agency)

One way in which agency decision-makers try to alleviate the potential for medical injury to their egg donors is by providing a separate insurance policy for donors, purchased either by the agency itself or by the intended parents. Such policies are

<sup>&</sup>lt;sup>467</sup> "Currently, there are no clearly documented long-term risks associated with oocyte donation, and as such, no definitive data upon which to base absolute recommendations. However … it would seem prudent to consider limiting the number of stimulated cycles for a given oocyte donor to approximately six." ASRM Practice Committee, "Repetitive Oocyte Donation," S194.

supposed to cover any medical complications a donor experiences after participating in an egg donation cycle, and all agency decision-makers who shared copies of their legal agreements included provisions for donor insurance policies.<sup>468</sup>

Interestingly, very few of my interviewees expressed concern about donors' future fertility; although there is no evidence to date that participating in egg donation compromises donors' fertility, it is one of the most commonly asked questions by potential donors and a question that is address on all of my interviewees' agency websites.<sup>469</sup> One agency decision-maker, however, expressed that concern, or more specifically, the fact that the reason there is no evidence that egg donation affects donors' future fertility is because it simply hasn't been studied. She felt unable (reasonably enough) to fully inform donors of the medical risks they were undertaking in donating their eggs:

I worry about their future fertility. All these egg donations doesn't seem to affect their future fertility, but I would like to have more information about that, and maybe track a little bit of donors over time and being able to say exactly if there's any kind of ramifications for them going forward, or are they going to have future problems themselves? (Director, Southern California Agency)

The question of future fertility of egg donors is a big one in the media, and one that cannot be properly addressed for donors or for society at large until and unless scientific studies are undertaken to determine whether egg donation has any long term medical effect on donors.

The majority of my interviewees expressed some sort of concern for the donors that participate in egg donation cycles through their agencies. They attempted to provide emotional support to egg donors, and to minimize the emotional impact on donors of having genetic siblings out in the world, and from meeting intended parents and/or donor-conceived children. They generally tried to ensure that donors were well educated and counseled enough to have thought through the long term consequences of their choice, so that they would have the best chance possible of not experiencing regret in the future. Agency decision-makers also felt that donors were entitled to information about the outcomes of their cycles; that they should know whether or not genetic children had resulted from their donations. And finally, agency decision-makers worried about the medical risks donors undertake by donating with their agencies.

<sup>&</sup>lt;sup>468</sup> See further discussion of insurance policies in Chapter Six, "Medical Treatment."

<sup>&</sup>lt;sup>469</sup> See note 467 for ASRM statement on the risks of egg donation.

They worried about OHSS, about rare reactions to medications and medical procedures, and about all the unknown medical risks in a field that is understudied. All of these concerns, taken together, form part of the moral meaning created by individual agency decision-makers, implemented within their agencies, and used to differentiate themselves—"unlike other agencies, our agency actually cares about you!"—while simultaneously acting to bring together ethical agencies in a shared moral meaning: the caretaking of egg donors.

## Concern For Future Children

Three quarters of my interviewees expressed some concern about the children whom they were helping to create with their business. By far the most common concern—three quarters of those concerned about the children—was that the children have some access to information about their donor in the future. Other concerns included potential issues of consanguinity and the prospect of having older parents, though the latter concern, surprisingly, was only expressed once:<sup>470</sup>

As an industry, we have an obligation to the future children to protect them the best we can. And ... there seems to be a general consensus across the U.S. now that fifty-five is the maximum age that a doctor will work with. (Director, Southern California Agency)

Only one agency decision-maker expressed a complete lack of concern for future children:

It's out of my hands! (Director, Northern California Agency)

Several agency decision-makers were concerned about the potential for issues of inadvertent consanguinity.<sup>471</sup> The ASRM advises "an arbitrary limit of no more than 25 pregnancies per sperm or oocyte donor, in a population for 800,000, in order to minimize risks of consanguinity."<sup>472</sup> But, as the ASRM further notes, "This suggestion may require modification if the population using donor gametes represents an isolated

<sup>&</sup>lt;sup>470</sup> For a discussion of the public reaction to news stories of much older women (e.g., 59 years old) becoming new mothers via egg donation, see Lisa C. Ikemoto, "The In/Fertile, the Too Fertile, and the Dysfertile," *Hastings Law Journal* 47 (1995-1996): 1007.

<sup>&</sup>lt;sup>471</sup> Consanguinity means "blood relation." In the context of egg donation, "inadvertent consanguinity" is when two people who are unknowingly genetic siblings because they were conceived via gametes from the same donor, meet and potentially have a sexual relationship.

<sup>&</sup>lt;sup>472</sup> ASRM Practice Committee, "Repetitive Oocyte Donation," S194.

subgroup or the specimens are distributed over a wide geographic area."<sup>473</sup> Accordingly, agency decision-makers worried that children conceived with the same donor's eggs in different families would one day meet and marry, especially in small towns:

I don't really like fertility centers sharing donors within a small community ... because they reuse these donors five and six times, and we don't avoid the consanguinity issue.... It affects the intended parents who have kids all around the same community, who may grow up, date and marry. Who knows? What are the risks? (Director, Midwestern Agency)

Sometimes agency decision-makers found themselves placed in a position to prevent intentional consanguinity:

We have sometimes gay couples who will—they're like really good friends, and they'll ask if they can both use the same donor. For me, it's like, OK, so let's look in the future now. We're going to end up with two families that are close to one another. They're close friends, and there's going to be two children born in two different families that are genetically related. Are you going to tell them? I mean, you're kind of forcing them to have a sibling outside of their family that they still have this strange weird relationship with. So I mean, yeah, I definitely try and look at it from that perspective before I permit something like that. (Director, Northern California Agency)

In other words, two separate couples come to the agency with the desire to share an egg donor, and thus have genetically related children in their two separate families. The agency decision-maker helped her clients to think through the long term ramifications of such a relationship; consanguinity is not a normal feature of the relationships between otherwise unrelated friends, and the agency decision-maker felt that if the intended parents were to proceed with the same egg donor, the resulting children should be informed that they are genetic half siblings—since they would be the children in separate families, such a relationship would be unexpected, and since their parents are friends, they will likely grow up close to one another, thus creating a risk for genetically incestuous dating relationships.

<sup>&</sup>lt;sup>473</sup> Ibid.

Or, alarmingly, one agency decision-maker found that frozen egg banks could make issues of consanguinity much more likely, as eggs from a single donor's single cycle could be distributed to two or more families, thus at least doubling the distribution of that genetic code:<sup>474</sup>

Sometimes I have families who I refer to other resources [frozen egg banks] if I can't help them, and I want them to understand how these egg banks work.... [And to one egg bank] I said, how many families can one donor help—to how many families would you allow eggs and babies? And I remember him saying twenty-five. (Director, Southern Agency)

Other agency decision-makers expressed concern about the potential for relationships or lack thereof—among genetic half-siblings from egg donation.

> I do wonder ... how will [the biological] children [of egg donors] feel about them potentially having half siblings? (Director, Southern Agency)

I will tell you there's the Donor Sibling Registry, [which] I dislike very much, simply based on its name.... They're not siblings.... They might have a genetic connection on that same level, but they're not siblings. So to them, you're interjecting a whole new set of expectations. (Director, Southern Agency)

While it's possible that some donor-conceived offspring would welcome interaction with their genetic half-siblings, agency decision-makers felt that no such interaction should be imposed on the children against their will.

The other major concern of agency decision-makers was that donor-conceived children have access in the future to information about their donor. Access to donor information, agency decision-makers explained, need not consist of direct and non-anonymous contact, but could be achieved through a third party service such as the Donor Sibling Registry, an independent website with voluntary registration of donors, intended

<sup>&</sup>lt;sup>474</sup> This is a minimal estimation of the risk of inadvertent consanguinity; if the eggs from one donor often go to three families, the risk of consanguinity would increase proportionately.

parents, and donor-conceived children, aiming to connect those parties who wish to seek out their genetic relations.<sup>475</sup>

As time goes on, you know, there's a Donor Sibling Registry, so that may prove to be a really good resource for people, too. (Director, Southern California Agency)

There's also the DSR, the Donor Sibling Registry. We discuss that with them [intended parents] as well. Because a lot of times, it's important for the parents, like [if there's] a medical issue, and they want to know, 'Hey, is this a genetic issue?' Then they have a place they can turn to. (Director, Southern California Agency)

Most of them just do the Donor Sibling Registry. That's usually what we advocate, is for them to do that, keep in contact. (Director, Southern Agency)

And I'm hearing more intended parents that say, you know, 'We still want an anonymous donation,' and some of those people don't even want to meet their donors, but 'We want to have the option for our child to seek additional information at the appropriate time,' and that's when we refer them to the Donor Sibling Registry. (Director, Southern Agency)

I do think that the Donor Sibling Registry is a good idea. Because I think that it's natural to wonder. But I don't think there's anything unhealthy about it. (Director, Northern California Agency)

I do endorse websites where, there's that—the Donor Sibling Registry, where you can register, and at least you are putting it out there in the ethos, 'My child wants to meet their egg donor, if she wants to meet them.' Here's a place to go where people can kind of congregate or even know if you've got a half sibling somewhere or something to that effect. (Case Manager, Northern California Agency)

<sup>&</sup>lt;sup>475</sup> The Donor Sibling Registry, www.donorsiblingregistry.com/. Their stated mission: "The Donor Sibling Registry (DSR) was founded in 2000 to assist individuals conceived as a result of sperm, egg or embryo donation that are seeking to make mutually desired contact with others with whom they share genetic ties.... DSR advocates for the right to honesty and transparency for donor kids, and for social acceptance, legal rights and valuing the diversity of all families. *The DSR's core value is honesty, with the conviction that people have the fundamental right to information about their biological origins and identities.*" (emphasis theirs)

While the Donor Sibling Registry is the most common fallback to allow some sort of future contact between donor-conceived children and their egg donors, some agency decision-makers point out that there might be other alternatives, and that such contact does not have to take place through that particular website:

I personally think that its healthier to have communication—not necessarily for the donor and the intended parent, but for the donor and the offspring. If that child grows up and wants to have communication, to have that ability and to have that open door to reach out to an agency or third party registry of some sort to have communication. I think that's really important. (Director, Southern California Agency)

I would like to see some kind of future correspondence. We have donors who are great that will contact us and say, 'I need to update. My grandma passed away from breast cancer,' or whatever.... If we could get ... future information, that would be helpful to these children who are being created. (Director, Southern California Agency)

Part of what concerns agency decision-makers about future children is that these people do not exist at the time the agency arranges a cycle, so their desires and future needs must be guessed at.<sup>476</sup> Based on the research of the mental health profession, donor-conceived children seem to do best—grow up to be healthy, well-adjusted adults—when they are informed early and often of their origins, and allowed to explore any curiosity about their genetic origins.<sup>477</sup> Part of the duty of agency decision-makers, therefore, at least for those who see this as a concern, is to enable these as-yet-

<sup>&</sup>lt;sup>476</sup> The fact that the children do not exist at the time of the donor egg IVF cycle makes it impossible to apply a "best interests" standard, as conceived by the law, since that standard relies on its application to the facts of the particular case, including information about the child at stake. "The best interests of the child standard represents a considerable ideological and rhetorical advancement over child custody standards that focus on the parents' interests. Forcing parents to articulate their claims to children in terms of the child's welfare expresses a societal preference for protecting children over protecting adults, a preference which, though not inevitable, is easily defended." Katharine T. Bartlett, "Re-expressing Parenthood," in *Families by Law: An Adoption Reader*, eds. Naomi R. Cahn and Joan Heifetz Hollinger (New York and London: New York University Press, 2004), 261.

<sup>&</sup>lt;sup>477</sup> See, e.g., Blake et al., "'Daddy Ran Out of Tadpoles;'" Daniels and Thorn, "Sharing Information with Donor Insemination Offspring;" Jadva et al., "Adolescents and Adults Conceived by Sperm Donation;" Mahlstedt, LaBounty, and Kennedy, "The Views of Adult Offspring of Sperm Donation;" Paul and Berger, "Topic Avoidance and Family Functioning;" Scheib, Riordan, and Rubin, "Adolescents with Open-Identity Sperm Donors."

nonexistent people to access that information, and the Donor Sibling Registry is an already established means of doing so.

In general, the concerns for future children expressed by my interviewees had to do with the elements of egg donation that differentiate these children from normally conceived children. Most of my interviewees expressed some sort of concern for the children, and the primary concern was that of enabling the children to access information about their donor. Another major concern was agency decision-makers' feeling of responsibility for preventing inadvertent consanguinity, which they felt they had some amount of control over—such as limiting a single donor's number of cycles and not allowing friends to engage the same donor in different families—and a more general concern about how the children would feel about having genetic half-siblings out in the world, about which decision-makers could do nothing but wonder. Otherwise, my interviewees simply had an underlying desire that the children whom they helped to create would, in addition to fulfilling their parents' wishes to become parents, enjoy full and healthy lives.

# Contact between Egg Donors and Intended Parents (and Future Children)

A very specific way in which agency decision-makers expressed their concern about intended parents, donors, and future children alike was in their views on contact between intended parents and donors, and, in the future, between donors and the donor-conceived offspring of intended parents. Ninety percent of my interviewees encouraged contact prior to a cycle, or at least thought it should be an option for intended parents and donors. And almost seventy percent of my interviewees also thought that ongoing contact after a cycle could be beneficial, although such contact is more complicated and agency decision-makers reasonably expressed some reservations about post-cycle contact between donors and intended parents is a specific form of concern for their charges; those decision-makers who encourage such contact seek to ensure that intended parents and donors are satisfied with the process of egg donation and that donor-conceived offspring have a healthy sense of identity.

<sup>&</sup>lt;sup>478</sup> Some concerns expressed by my interviewees included the novelty and potential complexity of an ongoing relationship with someone an intended parent had no knowledge of previously, but is now genetically related to their child; agency decision-makers were concerned that such contact could distort the intended mother's identity as the child's mother. Other agency decision-makers had practical concerns about lengthy ongoing relationships, such as the consequences for the intended parents should the donor fall on hard times and request help from the intended parents, or simply the possibility of a long term source of stress for all parties if the relationship turned out to be less than smooth.

The issue of contact is one that agencies seeking to establish norms for the field have addressed: SEEDS proposes a standard that encourages agencies to have intended parents and egg donors think through the question of contact, both for during the current cycle and into the future:

Will the donor be willing to meet the family who chooses her? What about the child(ren) that result from the donation?<sup>479</sup>

Contact may be semi-anonymous, in which identifying information is not exchanged, or open, in which it is.

Over half of my interviewees encouraged contact between the donor and intended parent(s) prior to participating in a cycle, for the benefit of the intended parents, the donor, or both. This type of contact is often deemed "semi-anonymous," where the parties meet one another face to face but do not exchange last names, addresses, or other "identifying information." Per the SEEDS standard:

SEMI-ANONYMOUS—LIMITED/OPEN: Describes an arrangement in which the Intended Parents and the Egg Donor see each other face to face. They can meet in person, have a video call, and/or communicate via telephone. They exchange first names but limited identifying information beyond that. Generally they do not communicate beyond this interaction and do not exchange contact information.<sup>480</sup>

Some agency decision-makers felt that contact with the donor was valuable to the intended parents, a chance to establish a deeper connection with the person whose genetics their child would share:

I encourage some degree of openness, even if it's as little as just doing a brief phone call.... It's so that you [the intended parent] can have the opportunity to ask her [the donor] questions, or just see her mannerisms, and make some sort of connection. (Director, Northern California Agency)

I would recommend meeting or having a phone conversation or a Skype meeting or a face to face. I think it's healthier not to create a

<sup>&</sup>lt;sup>479</sup> "Agency's Responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors," SEEDS Standards.

<sup>&</sup>lt;sup>480</sup> "KNOWN VS ANONYMOUS Egg Donation Terms," SEEDS Standards.

fantasy of who this person is, but rather meet them [the donor] and they become real. (Director, Southern California Agency)

Similarly, an agency decision-maker explained how important it was for one particular set of intended parents to make a connection with their donor:

They [intended parents] just wanted to be able to tell their child one day: we met her, she was super sweet, you know, we loved her and we are so thankful that she was willing to do this for us, and it was just important for them to put their eyes on her. (Director, Southern Agency)

Meeting intended parents can also be important for egg donors; they become invested in the cycle outcome during the course of the cycle:

Oh, they [donors] love it, they love it. They always want to know the results, sometimes couples will send me photos of the baby that they say that I can forward to the donor; the donors are thrilled to receive those. (Director, Northern California Agency)

And, of course, if the cycle is successful, the result is a child genetically related to the donor. Thus, even in anonymous donations, there remains a residual link to the intended parents and their child. As one agency decision-maker notes, mental health professionals advocate for greater openness in part for this reason:<sup>481</sup>

It's just become something that they [mental health professionals] feel [should be] encouraged because eventually, it becomes the donor's story, not just the intended parent. (Director Southern California Agency)

Half of my interviewees felt that semi-anonymous contact prior to a cycle should at least be available when it is desired by both donor and intended parent.

A case by case basis. It really depends. (Director, Southern California Agency)

That's completely their [intended parents'] decision.... So if they want a relationship, and it's important to them, I think that's great.

<sup>&</sup>lt;sup>481</sup> All of my mental health professional interviewees advocated greater openness in the relationships between intended parents and egg donors, and said that this was the general consensus in the field; that open relationships were generally healthier for the adults and also for the future children.

I don't think there's any problem. (Director, Southern California Agency)

As far as the intended parents and the donor I'm kind of neutral. I think that it's whatever works best for them. (Director, Southern California Agency)

About twenty percent of my couples meet their donor. And, you know, for a lot of people that's really important. (Director, Northern California Agency)

These agency decision-makers, like their counterparts who assertively encourage contact, also speak out of concern for intended parents and donors; they want what is best for them, primarily as defined by the intended parents and donors themselves, sometimes with a nod to the mental health professionals:

It's much more black and white when it's anonymous, but I think when you're dealing with humans that are all so different, it's very difficult to say, 'this is the only peg and this is the only peg we're going to use.' ... And from a mental health standpoint, it's healthier for everyone involved to have more communication. (Director, Southern California Agency)

Only one interviewee voiced disproval of semi-anonymous pre-cycle meetings, and she simply had a different take on what was best for intended parents, so she also spoke out of concern:

For a straight family, the concerns I have for the recipient mom is, my goal for these families is to have these children fall in love and go on with their lives. I don't personally think it's so healthy for a recipient mom to have an image of their donor burned into their brain, and there's a huge difference between hanging out and spending time with someone in a physical location and giving them a hug, and seeing a profile photo. (Director, Southern Agency)

Rather than seeing contact between donor and intended parents as a means to a deeper connection and comfort with one another, this agency decision-maker was concerned that meeting the donor would interfere with an intended parent's ability to bond with

their future child.<sup>482</sup> But the sentiment, like those of her peers, originates from the shared moral meaning of a deeper purpose to their work: a concern for her charges and the importance of building families.

A third of my interviewees felt that ongoing open contact after a cycle is successfully completed can be of benefit to donor-conceived offspring in particular. Such contact, as defined by a SEEDS standard, is:

OPEN: Describes an arrangement in which the Intended Parents and the Egg Donor can meet, have a video call, and/or a telephone consult. They exchange full names and contact information. The level of communication beyond this interaction will vary. Some relationships may continue to grow during the pregnancy. Some people will leave the door open to communication only if medically necessary or if the resulting child wishes to know more about the Egg Donor at age of 18.<sup>483</sup>

Some agency decision-makers thought that open relationships could assist donorconceived offspring in keeping up to date on any new and relevant medical information from the donor:

> I am extremely in favor of that.... Put it in [the] legal contract that [they] would exchange emails so that [the donor] could keep [the intended parents] in touch of important medical information that might come from [the donor's] family. (Director, Southern California Agency)

It depends on the couple and the donor. They'll exchange email addresses and phone numbers and whatever.... I think it's a good thing. Yeah, I've got people calling me: 'My child's seven years old and she's got allergies, what is the donor, have there been any changes in her health?' And I don't keep my records beyond seven years. 'I don't have your record any more.' (Director, Northern California Agency)

<sup>&</sup>lt;sup>482</sup> As mentioned above, some agency decision-makers were concerned that the donor's presence, and her status as the child's genetic mother, would interfere with the intended mother's ability to identify as the baby's mother and to bond with the baby.

<sup>&</sup>lt;sup>483</sup> "KNOWN VS ANONYMOUS Egg Donation Terms," SEEDS Standards.

Other agency decision-makers felt that contact with the donor was important to help donor-conceived offspring develop a strong sense of their own identity; that access to information about the donor was a critical element of that development:<sup>484</sup>

I think it's [contact is] a healthy thing to do.... It helps them [children] answer questions one day.... I do think that most children will likely benefit from being able to ask the question if they want to, and I think my opinion is we will see more offspring of donors of completely anonymous cycles frustrated that they have no options. (Director, Southern Agency)

I do think some kind of contact between the donor and the intended parents and possibly future child is probably for the best interest of the child.... I do worry about that [donor-conceived children not having access to donor information]. (Director, Southern California Agency)

The idea that open relationships between donor-conceived families and egg donors are healthier for all involved, and in particular for donor-conceived children, parallels the general consensus among mental health professionals that open adoptions are healthier for adoptees and their families: "…decades of experience lead us to believe that open adoption is the best approach. It minimizes emotional and psychological harm, and it allows all parties to meet their continuing responsibilities to each other."<sup>485</sup>

One agency decision-maker spoke about the positive open relationships a few of her clients had developed with their donors:

Some of them, about five percent, choose to be non-anonymous. I've had donors who've met the baby. I have one donor who has an ongoing relationship, she babysits for the child. (Director, Northern California Agency)

Almost half of my interviewees felt that such open contact could be a positive thing, but that it was not appropriate for everyone; whether there was to be open contact, and of what that contact would consist, was something that should be decided on a case by

<sup>&</sup>lt;sup>484</sup> This belief comes from research into the emotional experiences of children and adults conceived through sperm donation. See note 477 for citations.

<sup>&</sup>lt;sup>485</sup> Annett Baran and Reuben Pannor, "Perspectives on Open Adoption," in *Families by Law: An Adoption Reader*, eds. Naomi R. Cahn and Joan Heifetz Hollinger (New York and London: New York University Press, 2004), 166.

case basis. Sometimes it's just a matter of exchanging contact information, so that contact is possible, but not establishing any other type of relationship:

That's up to the couple and the donor.... I just have that in the contract. If there's a birth, then the couple would pay for the demographics on the donor, her social security, name, and address. (Director, Northern California Agency)

It's by mutual agreement. Not that many [people have open contact]. Some, but not that many. What usually has happened is they've like set up anonymous email addresses so they can contact each other, but it's rare. (Director, Southern California Agency)

Other agency decision-makers noted that an ongoing relationship is a possibility, and can be a positive experience for intended parents and donors alike:

So my opinion on meeting and open relationships is it's totally up to them, whatever they feel comfortable with. (Director, Southern California Agency)

I think that's probably on a case by case basis.... For some, it can be a great thing. I know of people who go on vacation with the person who was their donor, or just said they went to the donor's wedding. So for some, it can work out just great. Others kind of like the idea like every once in a while I can see photos of the child and that's fine. (Director, Northern California Agency)

One decision-maker felt similarly, that open contact should be arranged per the preferences of the donor and the intended parents, but that it had the potential to leave the parties legally vulnerable:<sup>486</sup>

I think that it's OK in some circumstances and, again, what are [the donor's and intended parents'] personal preferences? But I also feel that legally, there is typically more protection for everybody if donors remain anonymous. (Director, Midwestern Agency)

<sup>&</sup>lt;sup>486</sup> Legal vulnerability includes the donor's contact with the intended family leading to her desire to have greater contact with and/or parental rights to the child, or, more likely, missteps or poor behavior on the part of either party in what is inevitably an emotionally charged relationship, leading to legally actionable claims against one another.

This decision-maker is concerned that contact between donors and intended parents makes more likely the possibility that a donor will claim legal parental rights, in particular if she develops a bond with the child, or that interactions between the parties as part of a relationship that has the potential to be emotional complicated will lead to some type of legally actionable claim.

Even those agency decision-makers who have reservations about ongoing open contact between donors and intended parents harbor those reservations as a result of concern for their clients and donors. One quarter of my interviewees actively discouraged open contact between donors and intended parents for various reasons. Some felt that such contact was unfair to donors, who did a good deed by donating their eggs but shouldn't be subjected to any sort of long term obligation as a result; these four agency directors expressed this view in startlingly similar language:

> If they donate, that means they give an egg. It doesn't mean that for the next twenty years, somebody can knock on their door any time they want and want a relationship without their permission. (Director, Southern California Agency)

> They want to help at this moment in time, but they don't anticipate twenty years from now having a relationship. (Director, Southern California Agency)

They don't want to be tracked down necessarily for a cozy relationship in eighteen years. (Director, Midwestern Agency)

Your donor didn't come to donate eggs to sign on to a new family, and I'm not sure you're being fair if you expect that of her. (Director, Southern Agency)

Still other agency decision-makers worry that open contact would be detrimental to the intended parents. They are concerned that such contact would threaten the intended mother's identity as a mother:

We don't do that [open contact] at all.... I think it muddies the waters, honestly. (Director, Midwestern Agency)

Or that the intended parents would feel an unfair obligation to the donor if she fell on hard times in the future:

I actually would be worried about that [if she, the agency director, were the intended parent]. Not so much that the donor would ask for help, but that I myself would feel obligated to help her if she was unemployed for a couple years, or going through an expensive divorce, or whatever.... I mean, I have a hard enough time dealing with the family members I have. I don't really want more. It's just kind of a fuzzy relationship, I guess. (Director, Northern California Agency)

These agency decision-makers are trying to foresee the potential negative consequences of an open relationship between the donor and intended parents, in addition to any potential positives that might arise from such a relationship, and they judged that the negatives could easily outweigh the positives for both donor and intended parent.

While the majority of my interviewees encourage contact between donor and intended parent in some form, semi-anonymous or open, or at least feel that such contact should be an available option, those who disagree with them do so for the same reasons the majority support contact: out of concern for their clients and donors.<sup>487</sup> From their diverse backgrounds, and their divergent attempts to take advantage of the market, agency decision-makers have arrived at a shared moral meaning for their practices: taking care of their charges and building families. Each agency decision-maker wants what is best for intended parents, donors, and future children alike, although what that might be varies from person to person, and is not necessarily clear, as in the case of trying to predict the development of future relationships. Consequently, agency decision-makers simultaneously have divergent interpretations of what's "best," but a shared sense of underlying moral meaning and purpose.

Agency decision-makers, acting individually, thus create shared moral meanings. They come to the industry from individual perspectives, and attempt, by "reverse modeling,"

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<sup>&</sup>lt;sup>487</sup> Katherine M. Johnson argues that even though agencies are moving toward encouraging contact between intended parents and donors, the agencies themselves still maintain control of those relationships, creating "bounded relationships." Agencies use three major strategies "to construct family boundaries: 1) creating identity categories to symbolically delineate family membership [e.g., "intended mother" and "egg donor"]; 2) managing personal information exchange between donors, recipients, and donor-conceived children [as discussed at length in Chapter Five, "Forms of Commodification in Egg Donation," and Chapter Six, "Privacy"]; and 3) managing interactions between parties [as in facilitated pre-cycle meetings]." Katherine M. Johnson, "Making Families: Organizational Boundary Work in U.S. Egg and Sperm Donation," *Social Science and Medicine* 99 (2013): 64-71.

to differentiate themselves from other agencies.<sup>488</sup> But they refer to their own sense of moral duty, a moral imperative of sorts, to care for the intended parents, egg donors, and future children for whom they feel responsible. Inhabited institutions shows us how those individual decisions, based on personal morality, are expressed by and embedded in the agency decision-maker's organizational behavior.<sup>489</sup> And a collective of those organizational behaviors results in a shared moral meaning—caring for agency charges—that functions as an industry-wide norm.<sup>490</sup>

# Divergence to Convergence: The Emergence of Norms and Shared Moral Meaning in a New Field

Surprisingly, when agency decision-makers look inward and seek to make the decisions that will most benefit themselves and their agencies, they don't often look to other agencies or analogous organizations for models. Much more commonly, they rely on their own "gut instincts," and make even the most complicated ethical decisions based on what seems right to them. Occasionally they reverse model on other agencies' practices that they want to avoid in their own agency.<sup>491</sup> These responses to uncertainty in their field—the newness of their organizations and lack of legal regulation—these self conscious attempts to differentiate themselves from other agencies, are embedded in the social context of the egg donation industry and society as a whole, and make visible the actions of an individual through the behavior of her organization.<sup>492</sup> Because these decisions are both made within a deeper social context, and affect the social context through organizational behavior, they create meanings both for the decision-maker and

<sup>&</sup>lt;sup>488</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-70.

<sup>&</sup>lt;sup>489</sup> Inhabited institutions at work. See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field." It is also an example of the management of conflicting institutional logics. See Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

<sup>&</sup>lt;sup>490</sup> DiMaggio and Powell, "The Iron Cage Revisited;" Meyer and Rowan, "Institutionalized Organizations;" Jepperson, "Institutions, Institutional Effects, and Institutionalism;" Friedland and Alford, "Bringing Society Back In."

<sup>&</sup>lt;sup>491</sup> DiMaggio and Powell, "The Iron Cage Revisited," 75.

<sup>&</sup>lt;sup>492</sup> For an account of the inhabited institutions approach, see Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; and Smets, Morris, and Greenwood, "From Practice to Field." For an account of how individuals manage conflicting institutional logics, see Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

for the organization. Counterintuitively, these individual, internally-focused decisions return to converge in a moral center, resulting in overlapping internal standards—the emergence of norms in a new field—and a shared moral meaning.<sup>493</sup> A focus on the individual decision-maker makes visible the "ethics on the ground" among egg donor agencies. Yet another way to see ethics on the ground at work among egg donor agencies is through examination of their decision-making in response to external pressures, for which agency decision-makers look outward, concerned with the appearance of their industry to outsiders—the problem of legitimacy.

<sup>&</sup>lt;sup>493</sup> This is a form of institutional isomorphism not directly addressed by the previous literature. See DiMaggio and Powell, "The Iron Cage Revisited;" and Meyer and Rowan, "Institutionalized Organizations."

## CHAPTER FOUR

# The Problem of Legitimacy and the Project of Professionalism

*"Right now, we can pretty much do whatever the hell we want." (Director, Northeastern Agency)* 

Egg donor agencies function within an unregulated legal environment, and the subject of their business involves a number of serious ethical issues, including, most prominently, the commodification of women's eggs and/or their reproductive labor, and the potential for exploitation of egg donors. Because they are not subject to the law in the same way as a more regulated business, and because their business matter can be highly controversial, egg donor agencies are particularly susceptible to pressures exerted on them by other organizations on which they are dependent (such as clinics, mental health professionals, and family formation attorneys), and by the cultural expectations of society. Egg donor agencies feel these pressures from largely negative media coverage of egg donation, and of infertility treatment in general, and as a result of the unethical or downright criminal behavior of other agencies—which in turn gives rise to societal judgment.<sup>494</sup> Finally, agencies feel pressure to conform to developing group norms as a result of market pressures brought to bear by savvy intended parentclients, who communicate with each other about reputable agencies.<sup>495</sup> This process is one of coercive isomorphism; agency decision-makers take a group perspective and make similar business decisions in response to concern with how their field as a whole appears to outsiders.<sup>496</sup>

The process of coercive isomorphism, in other words, involves seeking legitimacy, both within the field among clinics and other field professionals, and outside of the field,

<sup>&</sup>lt;sup>494</sup> Even *The New York Times*, which is normally a liberal publication, mostly publishes pieces critical of the infertility industry. For a selection of negative press on egg donation, see: Benjamin, "Which Comes First: The Woman or Her Eggs?" *Huffington Post Science*; Darnovsky and Fogel, "Let's Not Expand the Market in Women's Eggs," *Huffington Post Los Angeles*; Dziura, "The Truth About Egg Donation," *The Gloss*; Griffin, "The Cost of Life," *Huffington Post Women*; Irvine, Associated Press, "Increase in Egg Donors Raises Concerns," *The Washington Post*; "Inside the Lucrative Life of an Egg Donor," *ABC News*; Johnson, "Egg Prices at Top Universities," *The Washington Post*; Rabin, "Demand for Donor Eggs Soars," *The New York Times*; Tuller, "Payment Offers to Egg Donors Prompt Scrutiny," *The New York Times*.

<sup>&</sup>lt;sup>495</sup> Communication among intended parents takes place readily (and anonymously) via social media and internet discussion forums such as Fertile Thoughts, www.fertilethoughts.com/, and IVF Connections, www.ivfconnections.com/.

<sup>&</sup>lt;sup>496</sup> DiMaggio and Powell, "The Iron Cage Revisited," 74. See also institutional reproduction processes described by Jepperson in "Institutions, Institutional Effects, and Institutionalism."

among potential clients, potential egg donors, and society at large. The search for legitimacy results in isomorphism as agency decision-makers begin to communicate with one another and respond to outside pressures in ways they collectively decide will minimize media damage and maximize their claims to legitimacy.<sup>497</sup> Some of the ways in which agency decision-makers claim legitimacy are through close association with infertility clinics, affiliation with infertility support groups, and attempts to undermine the stigma of egg donation by encouraging disclosure to children and contact between intended parents and donors.

Another way in which agencies show a collective concern about the perception of the field to outsiders is via the process of professionalization.<sup>498</sup> Professionalization is an attempt to control the field, in which the would-be professionals (egg donor agency decision-makers in this case) demarcate their field of expertise by creating entry criteria, a professional body, and a code of conduct for members.<sup>499</sup> Professionalization results in a kind of normative isomorphism, in which norms are spread through professional networks and through professional requirements.<sup>500</sup> Egg donor agencies have not yet launched a full professionalization effort, though part of such an effort is in the works in the form of a nonprofit organization called SEEDS, whose mission is to establish best practices standards for agencies (and consequently partially filling the requirements for professionalization as a professional body, and the creation of a code of conduct).<sup>501</sup>

Although clearly a biased sample (since they did agree to speak with me), my interviewees were enthusiastic about this research, in part because they wanted to communicate to the "outside" how ethical their intentions are, and what norms they would like to see established to ensure ethical practice among all agencies:

I love what you're doing. (Director, Southern California Agency)

I think it's wonderful and I support that [this research]. (Director, Southern California Agency)

<sup>&</sup>lt;sup>497</sup> This is an instance of coercive isomorphism. DiMaggio and Powell, "The Iron Cage Revisited," 74. Individual agency is visible here in intra-agency communication.

<sup>&</sup>lt;sup>498</sup> Ibid.," 70-75; Larson, *The Rise of Professionalism*, 49-52. See also Scott, "Lords of the Dance," for the role of professions in institutions.

<sup>&</sup>lt;sup>499</sup> DiMaggio and Powell, "The Iron Cage Revisited," 70-75. According to W. Richard Scott, professions have leading roles in the "creation and tending of institutions." Scott, "Lords of the Dance," 219.

<sup>&</sup>lt;sup>500</sup> DiMaggio and Powell, "The Iron Cage Revisited," 70-75. Professions are involved in devising normative prescriptions for institutional behavior. Scott, "Lords of the Dance."

<sup>&</sup>lt;sup>501</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

I was just going to say thank you. I appreciate the fact that there are people that aren't in the industry that are just passionate enough to want to make change, and I think that's this kind of same drive that the groups in SEEDS have, I mean, the women and men. (Director, Southern California Agency)

I love your project. (Director, Southern California Agency)

It's refreshing to ever meet anybody who's concerned enough about it and wants people to have a higher standard of practice. (Director, Southern Agency)

I'm really interested in your research. (Director, Northeastern Agency)

I'd love to see the results of your work. (Director, Midwestern Agency)

Agency decision-makers were enthusiastic about receiving attention from an academic source, which is, at least in theory, likely to be more objective than the clearly negative media coverage from which they have suffered over the years.<sup>502</sup> They wanted to get the "truth" of their business practices out in the world, and that truth consists of a claim to legitimacy and a fledgling endeavor at professionalization—both of which are responses to the pressures exerted on the field from the outside. In this chapter I explore those pressures and agency decision-makers' responses to them.

#### **Pressure from Without**

Organizations change in response to pressures that are exerted on them by other organizations on which they are dependent, by the cultural expectations of society, and by the marketplace; these pressures can result in coercive isomorphism, which stems from the problem of legitimacy.<sup>503</sup> Egg donor agencies may tend toward isomorphism as a result of pressures from (largely negative) media attention or as a result of their

<sup>&</sup>lt;sup>502</sup> See note 494 for some examples of negative media treatment of egg donation.

<sup>&</sup>lt;sup>503</sup> DiMaggio and Powell, "The Iron Cage Revisited," 74. Coercive isomorphism reveals individual agency within organizations to some extent; Amy Binder argues that an inhabited institutions approach demonstrates how human agency is integrated into organizational dynamics, expanding on DiMaggio and Powell's claim that organizations stake a claim of legitimacy on "ceremonial adherence to [institutional] scripts." Binder, "For Love and Money," 549.

dependence on intended parents' good opinion to keep business going. Their legitimacy may be threatened by the unethical behavior of other agencies, clinics, or related organizations; criminal actions by agencies, and, to a lesser extent, unscrupulous practices at other agencies or clinics tarnish the reputation of the field of egg donation, and can negatively affect both the judgment of society at large and of agencies' target market, intended parents. In such a way, media attention and unethical practices of other agencies, clinics, and organizations in the field, as well as intended parents' sentiments about egg donation, can cause a process of coercive isomorphism, in which agencies shape their practices in an effort to gain legitimacy for themselves and the field as a whole.<sup>504</sup>

## Media Pressure Cooker

Perhaps the primary source of pressure on egg donor agencies from society at large is via the media, in particular negative press about various aspects of egg donation. Agency decision-makers felt that the media rarely reflected the truth of their business, and that in fact, it often deliberately misled its readers/viewers, because, as one Northern California agency director put it:

The media loves drama and conflict. (Director, Northern California Agency)

A Midwestern agency director gave an example of the sensationalism that characterizes media portrayals of the infertility industry:

There are always those extreme cases which make media. Like I'm thinking of Octomom right now.<sup>505</sup> (Director, Midwestern Agency)

One agency decision-maker wished that such sensationalism was prohibited:

I hate negative press from people who don't know what they're doing. I think it [media coverage of egg donation] should be regulated. (Director, Northeastern Agency)

<sup>&</sup>lt;sup>504</sup> DiMaggio and Powell, "The Iron Cage Revisited," 74.

<sup>&</sup>lt;sup>505</sup> See note 624 for a discussion of the media coverage of Nadya Suleman, "Octomom," who bore eight live children after an IVF cycle in 2009.

Of course, any attempt to regulate media coverage of the infertility industry would necessarily implicate serious First Amendment issues.

Agency decision-makers also thought that the media was guilty of making statements that it could not feasibly defend:

Sometime in the nineties, there was a really lengthy article in the *New Yorker* about egg donors. And the person writing it was very cynical. And at one point she said, 'no one even pretends that the donors are doing it for anything but the money.' And I was just so annoyed by that statement; I mean, it's just so ridiculous on so many levels, I mean, like this woman knows what's in the mind of every egg donor? (Director, Northern California Agency)

This particular article appealed to the general societal condemnation of commodification, blaming donors for being greedy and portraying the industry in a negative light.

Other media that emphasizes the commodification aspect of egg donation is problematic in agency decision-makers' eyes. One media narrative is how wealthy intended parents are exploiting vulnerable young women; again, an account that makes the industry look bad indeed.

The *Today Show* did a special and it didn't use the word 'wealthy'—'well off' I think is what they said—well off couples using an egg donor to have a baby and I went, I don't know that I would call it 'well off.' I mean, some of the intended parents that I work with definitely have money and plenty of it, but I work with plenty of intended parents who don't, and this is just the best avenue for them to develop their family, but definitely not the most cost effective way to do it. And so that's just kind of frustrating, that it's almost associated with taking advantage of donors, when that's not what's been happening. (Director, Southern Agency)

Other media pieces discuss the possibility of eugenics, according to a Northern California agency director:

A lot of the media portrays couples doing fertility treatments as sort of these ultra-rich, snobby people who are trying to genetically engineer the perfect child. And it's not that at all. They just want to have a kid. (Director, Northern California Agency) Media coverage of egg donation that criticizes its commodification aspect put the practice in a bad light, and cause society at large to judge the industry as a whole.

Agency decision-makers are particularly frustrated when they learn that the media is deliberately emphasizing the sensational and closeting the normal:

I have a friend who had two children through surrogacy, and *Redbook* wanted to interview her for a piece they were doing, and when they called her on the phone for the pre-interview interview, they asked her about her experience. And she said it was entirely positive, and she really was happy, and when she said that, they did not want to interview her. (Director, Northern California Agency)

This agency decision-maker was criticizing the magazine for failing to present a fair portrait of collaborative reproduction by representing the happy endings as well as the problematic relationships.

Negative media tarnishes the reputation of the business of egg donation, which in addition to incurring society's judgment, can also scare away potential donors.

A [television] series produced by MTV called *Generation Cryo* [in which a group of donor-conceived children track down their shared sperm donor], and I would say as a direct result of that show, recruitment of donors dropped, I want to say about thirty percent in the month that show aired.... So I think that's basically what scared a few of our donors off. So they saw this show and they thought, what's stopping anyone else from doing that? (Director, Northeastern Agency)

In addition to the fear of identification after participating in a supposedly anonymous egg donation cycle, the media has instilled potential donors with fear for their health.<sup>506</sup>

A few years ago, Jennifer Lahl put out a movie called *Eggsploitation* [in which four donors who experienced medical complications as a result of donating their eggs tell their stories, which are in turn portrayed sensationally and treated as evidence that egg donation

<sup>&</sup>lt;sup>506</sup> One recent major example is the documentary *eggsploitation*, a movie directed by Jennifer Lahl of the conservative organization The Center for Bioethics and Culture, available from www.cbc-network.org; Internet; Accessed 10 September 2014.

is universally dangerous].<sup>507</sup> ... And she did a campaign. She did like a tour of ... the top tier schools, and she showed this video to people and made these four little anomalies the way it is in this industry, and she painted a picture that was really slanted. In doing so, these are young impressionable women. Granted, they're very intelligent, but still, that's all the information they're getting, and the picture that's painted isn't favorable. So why would a woman put herself in that position, even it if is only a small chance that could happen? Why would I do that to myself? It's not worth it. (Director, Southern California Agency)

Agency decision-makers experience societal pressure as a result of negative media coverage of egg donation. That pressure can take the form of generalized judgment from society at large on issues such as commodification and perceived exploitation, or the decline of willing egg donor recruits. Both of these effects pressure agencies to assert their legitimacy, both to be accepted as a valid business in society, and to ensure that there will be enough young women willing to donate their eggs to enable agencies to remain in business.

#### The Few: Very Bad "Bad Guys"

Another source of pressure on agencies is other agencies, in particular when they behave criminally, as discussed below. The misbehavior of others in the industry reflects poorly on agencies that are trying to run an ethical business, brings down the judgment of society on the industry as a whole, and invokes the fear of well-intentioned but ultimately harmful regulation. Agency decision-makers' concern for the legitimacy of the industry, and for egg donation in particular, as well as the damage done to vulnerable intended parents, are the driving force behind their harsh criticism of agencies that defraud clients, donors, and surrogates, or otherwise behave criminally. My interviewees wanted to distance themselves and their agencies from these unethical members of the field:

<sup>&</sup>lt;sup>507</sup> The donors featured in *eggsploitation* suffered horrific complications, including a stroke leading to paralysis and brain damage, death from colon cancer four years after donating, and a hemorrhage during egg retrieval. While these stories are terrible, no doubt, they are not generalizable to the experience of egg donors, most of whom remain healthy after donating, at least in the short term (and for whose long term health evidence is lacking). Furthermore, some of these complications, such as the cancer, may or may not be related to the egg donation; we simply have no way to know. It is important to recognize that terrible complications are possible, and to communicate that possibility to donors. Even more, we need studies about the likelihood of such complications, so that true informed consent is possible.

Either you're reputable and you do things right, or you just don't. (Director, Southern Agency)

Several agency decision-makers expressed a general dissatisfaction with the state of business in egg donation.

I learned pretty much all of the agencies in the Bay Area; I learned about them, and how they operated, and was pretty unhappy. (Director, Northern California Agency)

One Southern agency director started her agency (after working for an in-house program) in part because:

I also knew that I didn't trust anybody in the industry I worked in, so I—no, I didn't, I really didn't. I had seen so much horrible stuff. (Director, Southern Agency)

Another agency decision-maker was dismayed by the standard practices of egg donor agencies and in-house programs:

There are a lot of things that agencies out there do that just—and not even agencies only, it's often clinic-based programs, too—that just have been very difficult for me to watch. It's kind of like it is what it is. (Director, Southern Agency)

A Southern California agency director blamed a lot of the unethical behavior on agencies' lack of communication with one another about ethical issues:

And on the flip side, I think it [agencies' failure to communicate with one another] also left certain agencies—and fortunately, I don't think there's too many of them—that it did leave certain agencies open to be able to do incredibly unethical business practices and have nobody, not even their peers, being able to really say anything because everybody was in it for themselves. (Director, Southern California Agency)

One topic on which agency decision makers agreed was that there should be some means of preventing agencies from engaging in behavior so reprehensible as to be criminal, such as "baby-selling" and fraud. In one instance of criminal behavior, an attorney and agency owner, Theresa Erickson, along with a few conspirators, sent U.S. surrogates to the Ukraine to be impregnated with embryos from anonymous donors.<sup>508</sup> The resulting babies were sold to unsuspecting intended parents for more than \$100,000 each.<sup>509</sup> Erickson pled guilty to conspiracy to commit wire fraud in 2012, and was sentenced to five months in prison, nine months of home confinement, and a \$70,000 fine.<sup>510</sup> Agency decision-makers were understandably horrified at the revelations of Erickson's baby-selling ring:

<sup>509</sup> See previous note.

<sup>510</sup> See note 508.

<sup>&</sup>lt;sup>508</sup> In California, all parties must agree to a surrogacy arrangement before an embryo transfer takes place: "The parties to an assisted reproduction agreement for gestational carriers shall not undergo an embryo transfer procedure, or commence injectable medication in preparation for an embryo transfer for assisted reproduction purposes, until the assisted reproduction agreement for gestational carriers has been fully executed as required by subdivisions (b) and (c) of this section." California Family Code § 7962(d). Theresa Erickson, along with her co-conspirators, surrogate Carla Chambers and Maryland attorney Hilary Nieman, recruited U.S. surrogates and sent them to Ukraine to be impregnated with embryos created from anonymous egg and sperm donors. The surrogates were under the impression that intended parents already existed for these babies, but Erickson and her co-conspirators only found intended parents after a pregnancy was underway. The intended parents believed that they were legally adopting an unwanted baby whose original surrogacy agreement had fallen through. According to one surrogacy attorney, Andrew Vorzimer, Erickson also attempted to create the "most marketable baby available," with blonde hair and blue eyes. Erickson pleaded guilty to wire fraud and admitted to filing false applications on behalf of her surrogates to secure state medical insurance coverage for their medical costs associated with pregnancy. Erickson and Chambers served just five months in federal prison, followed by nine months of house arrest. Nieman received five months in prison and seven months of house arrest. The defendants were ordered to pay over \$731,000 in restitution to their victims. See Associated Press, "Surrogacy Lawyer Theresa Erickson Pleads Guilty," SF Gate, 25 February 2014, available from www.sfgate.com/crime/article/Surrogacy-lawyer-Theresa-Erickson-pleads-guilty-3360450.php; Internet; Accessed 22 September 2014; Rory Devine and R. Stickney, "Convicted Surrogacy Attorney: I'm Tip of Iceberg," NBC San Diego, 29 February 2012, available from www.nbcsandiego.com/news/local/Theresa-Erickson-Surrogacy-Abuse-Selling-Babies-140942313.html; Internet; Accessed 22 September 2014; Nancy Dillon, "Noted Surrogacy Lawyer Theresa Erickson Sentenced for Her Role in Baby-Selling Scheme," NY Daily News, 24 February 2012, available from www.nydailynews.com/news/crime/noted-surrogacylawyer-theresa-erickson-sentenced-role-baby-selling-scheme-article-1.1028320; Internet; Accessed 22 September 2014; Federal Bureau of Investigation, "Baby-Selling Ring Busted," FBI Website, San Diego *Division*, 9 August 2011, available from www.fbi.gov/sandiego/press-releases/2011/baby-selling-ringbusted; Internet; Accessed 22 September 2014; Alyssa Newcomb, "Two San Diego Women Sentenced in Baby Selling Case," ABC News, 24 February 2012, available from abcnews.go.com/US/san-diego-womensentenced-baby-selling-case/story?id=15785854; Internet; Accessed 22 September 2014; Andrew Vorzimer, "Government Seeking More that \$731,000 in Restitution from Defendants in Baby Selling Case," The Spin Doctor (blog), 22 February 2012, available from www.eggdonor.com/blog/2012/02/22/ government-seeking-731000-restitution-defendants-baby-selling-case/; Internet; Accessed 22 September 2014; Julie Watson, "Theresa Erickson to be Sentenced for Baby Trafficking Ring," Huff Post Crime, 24 February 2012, available from www.huffingtonpost.com/2012/02/24/theresa-ericksonsentneced\_n\_1299434.html; Internet; Accessed 22 September 2014.

Because there are those moments when you find out that something terrible has been going on, like Theresa Erickson, which—and you kind of go 'oh my gosh, why am I even in this field?' (Director, Northern California Agency)

Two Northern California agency directors were more succinct:

Well, whatever that Theresa whatever-her-name-is, what she did? Oh my god. (Director, Northern California Agency)

Yeah, right. Selling babies, not a good thing. (Director, Northern California Agency)

These agency decision-makers wanted to distance themselves from the actions of Theresa Erickson, and so condemned both the baby-selling itself, and Erickson's place in the collaborative reproduction industry.

Baby-selling is especially horrifying, but much more common among egg donor agencies is fraud. Several agency decision-makers were dismayed by the relatively frequent revelation of agencies that have been defrauding their clients, donors, and surrogates.

Every two to three years, we have a big scandal. (Director, Southern California Agency)

There have been several such scandals in the last few years, but three names in particular came up in the course of my interviews: SurroGenesis, B Coming, and Miracles Egg Donation, Inc.<sup>511</sup> In 2012, Tonya Collins, owner of SurroGenesis, was convicted of wire fraud and sentenced to five years, three months in federal prison after defrauding intended parents and surrogates out of millions of dollars, which she used

<sup>&</sup>lt;sup>511</sup> SurroGenesis, www.otheroom.com/archive/surrogenesis/index.html; B Coming, www.b-coming.com (website now defunct); and Miracles Egg Donation, Inc., www.miraclesinc.net/.

without permission for personal purchases.<sup>512</sup> One Southern California agency director was very concerned about the effect of the SurroGenesis scandal on her agency and agencies in general:

Like there's been fraud in our industry, and that scares me because one of the places—one of the agencies was called SurroGenesis ... we were like, wait a minute, this is so wrong. And with SurroGenesis, it was two to three million dollars. (Director, Southern California Agency)

In the 2009 B Coming scandal, owner Rosa Balcazar allegedly defrauded intended parents of hundreds of thousands of dollars by failing to provide the promised egg

<sup>&</sup>lt;sup>512</sup> Tonya Collins functioned as the owner of both SurroGenesis and the Michael Charles Independent Financial Holding Group, which purported to serve as a third party escrow company that would hold clients' funds in trust and pay them out for legitimate expenses associated with their surrogacies. Collins directed clients toward the Michael Charles Independent Financial Holding Group, but concealed her ownership of it and created fictitious employees to make it appear that the company was independent and had its own staff. Collins then used clients' funds for personal purchases such as cars, houses, jewelry, clothing, and vacations. As a result, SurroGenesis was unable to pay surrogates' expenses. She embezzled two million dollars in client funds and was sentenced on four counts of wire fraud to five years, three months in federal prison. See Federal Bureau of Investigation, "Modesto Surrogate Parenting Agency Owner Pleads Guilty in \$2 Million Fraud Scheme," FBI Website, Sacramento Division, 19 February 2013, available from www.fbi.gov/sacramento/press-releases/2013/modesto-surrogate-parentingagency-owner-pleads-guilty-in-2-million-fraud-scheme; Internet; Accessed 22 September 2014; Carlos Saucedo, "Modesto Woman Gets Five Years in Prison for Surrogacy Scam," ABC30 Action News Fresno, 13 May 2013, available from abc30.com/archive/9100956/; Internet; Accessed 22 September 2014; Stephanie Saul, "Would-Be Parents Find Surrogate Agency Closed," The New York Times, 20 March 2009, available from www.nytimes.com/2009/03/21/us/21surrogate.html?\_r=0; Internet; Accessed 22 September 2014; "SurroGenesis Scams Women Wanting Children," CBS Sacramento, 20 April 2012, available from sacramento.cbslocal.com/2012/04/20/surrogenesis-scams-women-wanting-children/; Internet; Accessed 22 September 2014; Andrew Vorzimer, "SurroGenesis Owner Tonya Collins Pleads Guilty to Wire Fraud," The Spin Doctor (blog), 19 February 2013, available from www.eggdonor.com/blog/2013/02/19/ surrogenesis-owner-tonya-collins-pleads-guilty-wire-fraud/; Internet; Accessed 22 September 2014; Andrew Vorzimer, "SurroGenesis Update: Tonya Collins Arrested and Indicted on 30 Felony Counts," The Spin Doctor (blog), 20 April 2012, available from www.eggdonor.com/blog/2012/04/20/surrogenesisupdate-tonya-collins-arrested-charged-30-felony-counts/; Internet; Accessed 22 September 2014.

donation and surrogacy services.<sup>513</sup> She has not been charged with criminal conduct.<sup>514</sup> But even just the complaints reflect badly on the field:

There's one that's called B Coming, I don't even know if they're still out there, but... that's the sort of thing where it's like, UGH! It just makes my skin crawl. (Director, Northern California Agency)

A Southern California agency director describes the specifics of a defrauding scheme by an agency called Miracles Egg Donation, Inc.:

<sup>514</sup> See previous note.

<sup>&</sup>lt;sup>513</sup> Balcazar's clients complained that they paid her \$80,000-\$100,000 apiece, and surrogacy services were not provided. Balcazar responds that services were provided, but her clients are angry that a pregnancy did not result in their cases. According to an article in the Los Angeles Times, Balcazar stated that the majority of her clients come from Spain; when Spanish clients complained to Beverly Hills police, the police responded by trying to determine whether or not they had jurisdiction. Balcazar filed for bankruptcy in 2007, in October of 2008, the California Secretary of State revoked B Coming's business license, and in November of 2008, the insurance company Health Net sued B Coming for fraud, misrepresentation, and breach of contract for passing off a client and a surrogate as B Coming employees in order to secure health insurance for them. Kimi Yoshino and Alan Zarembo, "Beverly Hills Surrogacy Firm Accused of Fraud and Theft," Los Angeles Times, 26 March 2009, available from articles.latimes.com/ 2009/mar/26/local/me-surrogate26; Internet; Accessed 23 September 2014. Dean Masserman, an attorney working on behalf of some of the client victims said there was much more to it: "The six couples from Spain wired over \$500,000.00 to at least four different bank accounts in the name of B Coming or Rosa Balcazar. Not a single one of those couples had a surrogate who even got pregnant, let alone had a child. The claim by Ms. Balcazar in the article that she provided a service for which she should be paid is laughable. Aside from the point you make regarding earned fees as opposed to monies held in trust, my clients would dispute she even earned those alleged fees because she did not actually provide them any services. She shopped the same surrogate to different couples, she charged them for egg donors and appurtenant medical expenses when they never sought ova donation in the first place. She lied about the medical history of the surrogates and failed to properly screen them. As a result, surrogates would skip doctor appointments, fail medical screenings or simply disappear. That would be followed by a promise from Ms. Balcazar to the couple that she would find them another surrogate, only to have the same thing happen again, or she would simply fail to follow up at all, keeping all of their funds and not refunding a dime.... The remaining couples from Spain all have similarly tragic stories of failed surrogates, demands for more money, improper accounting, lost money and shattered dreams. Rosa Balcazar spoke their language, traveled to their country, shared meals with them, took their life savings, and then stole everything from them. She has single handedly ruined lives, cost honest people and businesses to collectively lose in excess of one million dollars, and stained an otherwise reputable industry. This is not a systemic industry problem. These are the acts of a few criminals who have preyed upon people at their most vulnerable moments." Quoted in Andrew Vorzimer, "BeComing a Poseur," The Spin Doctor (blog), 26 March 2009, available from www.eggdonor.com/blog/2009/03/26/becoming-a-poseur/; Internet; Accessed 22 September 2014. Additionally, Balcazar failed to secure legal representation for her clients, leading to surrogacies taking place in states unfriendly to them, and surrogates and their families being threatened with legal parentage. Andrew Vorzimer, "The Depravity of B Coming & Rosa Balcazar," The Spin Doctor (blog), 9 April 2009, available from www.eggdonor.com/blog/2009/04/09/the-depravity-ofb-coming-rosa-balcazar/; Internet; Accessed 23 September 2014.

There's a place called Miracles that—at least, they were under scrutiny ... they would create fake donor profiles of amazing donors that anyone would [want to] match with, but then that donor either would long since have been dropped out of that [agency], wouldn't be available, one thing or another, but obviously people were matching with these donors because they were the highly sought after, incredible donors. They would sign with the agency and then the agency would come back a month or two later and say, 'Oh, unfortunately, something came up and this donor is no longer available.' ... Or three people might have been matched to the same donor at the same time, and no one else knew, and it's hard to say if she even existed, or if she even had known about the other couples [intended parents]. But it didn't matter, because they [intended parents] signed the contract and per the contract, they don't get a refund. And so then they're forced to either walk away with the money lost, or choose another donor in that agency.... which they no longer trust, and in addition to that, there may not be any other donors they were interested in. Especially if they [chose the agency because of] fluffed up, false profiles. (Director, Southern California Agency)

In fact, Miracles Egg Donation, owned by Allison Layton, was sued in May 2014 by an intended parent for defrauding the plaintiff of money paid to reserve a donor who, the plaintiff claims, did not exist in the first place, or was patently unavailable.<sup>515</sup>

Some agency decision-makers emphasized the ill effects of criminal agencies' actions on intended parents, as well as on the industry as a whole.

The one thing that really I find scary is the agencies that just can pop up out of nowhere and they're run out of their homes, and they take advantage of intended parents, and they take their money and they run. That scares me from an industry standpoint because, number one, that can bring on regulations that are not favorable. Then also it takes advantage of a group of people that already are in a position of vulnerability, so just ... as a human being, that just makes my skin crawl. (Director, Southern California Agency)

Another Southern California agency director was also concerned about the defrauding of vulnerable intended parents:

We've heard a few agencies have closed after taking, running off with intended parents' money; very, very concerning. These people

<sup>&</sup>lt;sup>515</sup> Allison Layton, founder of Miracles Egg Donation, Inc., allegedly defrauded an intended parent of \$19,500 by offering her a nonexistent donor, and used the money to pay off other clients and donors she had cheated. She was accused of embezzling intended parents' trust funds. See Corinne Donnelly, "Miracles Egg Donation Update: Fraud Alleged in Human Eggs," The Spin Doctor (blog), 5 May 2014, available from www.eggdonor.com/blog/2014/05/05/miracles-egg-donation-update-fraud-allegedhuman-eggs/; Internet; Accessed 8 September 2014; Andrew Vorzimer, "New Allegations Against Miracles Egg Donation & Surrogacy," The Spin Doctor (blog), 14 February 2012, available from www.eggdonor.com/blog/2012/02/14/allegations-miracles-egg-donation-surrogacy/; Internet; Accessed 8 September 2014; Andrew Vorzimer, "Miracles Egg Donation Has Closed Its Doors-Or Has It? [Updated]," The Spin Doctor (blog), 29 August 2011, available from www.eggdonor.com/blog/ 2011/08/29/miracles-egg-donation-closed-doors/; Internet; Accessed 8 September 2014; Andrew Vorzimer, "Serious Allegations of Misconduct Leveled Against Miracles Egg Donation and Surrogacy, Inc.," The Spin Doctor (blog), 27 July 2011, available from www.eggdonor.com/blog/2011/07/27/ allegations-misconduct-leveled-miracles-egg-donation-surrogacy/; Internet; Accessed 8 September 2014. A number of affected surrogates took to the web to write about their negative experiences with the agency. See, e.g., Ashley, "My Surrogacy Agency and Legal Issues..." Life After Someone Else's Buns Were in *My Oven!!* (blog), posted 14 February 2012, available from www.notthema.blogspot.com/2012/02/mysurrogate-agency-and-legal-issues.html; Internet; Accessed 8 September 2014; and "To All IPs, Donors, and Surrogates with Miracles Egg Donation and Surrogacy in CA," Surrogate Mothers Online, LLC (thread in online discussion forum), posted 30 July 2011, available from www.surromomsonline.com/support/ showthread.php?179568-To-All-IPs-Donors-and-Surrogates-with-Miracles-Egg-Donation-and-Surrogacyin-CA; Internet; Accessed 8 September 2014. Although Allison Layton has reportedly absquatulated to Idaho, as of September 2014, the Miracles Egg Donation, Inc. website is still up: www.miraclesinc.net.

have been through so much already, and for somebody to take advantage of them like that is just heartbreaking. (Director, Southern California Agency)

Agency decision-makers and the media alike are in agreement that agencies which defraud their clients, donors, and surrogates, or which engage in baby-selling, should be ferreted out and punished. The ABA Model Act Governing ART Agencies contains a provision specifically prohibiting fraudulent behavior:

Affirmative Duties and Obligations [of agencies]: ... Respect the autonomy of Participants by not engaging in coercion, fraud, misrepresentation, or unethical behavior.<sup>516</sup>

Agency decision-makers expressed explicit concern about the impact of these scandals on the legitimacy of their own agencies and the field as a whole—and on the financial and emotional circumstances of victimized intended parents. Major scandals such as baby-selling and fraud function to exert a significant amount of pressure on the industry, and compel agencies to make decisions that will illustrate to potential clients, donors, and surrogates, as well as to the media and society at large, that their agency, and their field, can be practiced responsibly, ethically, and with positive outcomes.

# The Many: Sub-Criminal Lack of Ethics

Although several agency decision-makers expressed their deep concerns about the effect of criminal agencies on intended parents and the industry as a whole, far more ninety percent of my interviewees—criticized what they saw as the unethical practices of other agencies that failed to rise to the level of criminality. Although not overtly criminal, these various practices, including agencies' financial policies, egg donor screening standards, and management of donors, were still of concern to agency decision-makers for their potential to threaten the legitimacy of the business of egg donation.

The director of a Midwestern agency felt that although the egg donation industry is unregulated, that didn't necessarily mean that agencies were behaving unethically; she saw a wide range of behaviors as ethically acceptable:

<sup>&</sup>lt;sup>516</sup> ABA Model Act Governing ART Agencies (DRAFT) § 302.2.

I think like any industry, perhaps [rules within the industry fail to keep up with actual practices], but this [egg donation] just happens to be far more provocative. People love to look at an industry that has no regulation, and if people are sort of operating as an outlier in any way, they are looked down upon. That's not to say that what they're doing is necessarily wrong or unethical, it's just perhaps evolved into a different space in the industry and guidelines that were written fourteen years ago just haven't kept pace. (Director, Midwestern Agency)

This agency decision-maker's opinion, however, was in the minority, and the vast majority of my interviewees denounced a number of unethical practices at other agencies as threats to the legitimacy of egg donation, including certain financial practices, incomplete donor screening, and unfair management of donors.

## **Unethical Financial Practices**

Many of the practices that my interviewees criticized seemed to have their basis in financial gain for the agency engaging in them. One agency decision-maker was distressed that, in her opinion, the industry is focused on money rather than ethical conduct:

When I grew up, there was a business culture of the way that you build a successful business is to provide a good service, treat your customers with respect, and conduct yourself with integrity. And that is the definition of a successful business. And I feel like unfortunately, we've moved into a culture where it's get as much as you can, squeeze every last drop of blood, and that is a successful business. (Director, Northern California Agency)

Several agency decision-makers complained about other agencies requiring that intended parents pay all fees up front, with no guarantee of finding a donor and no refund available.

I think there's so much out there that people come to me and say, 'oh, I lost all this money and they [other agency] made me sign up and pay all this money before I found anybody [a donor]. (Director, Southern California Agency) There's a lot of agencies that lock people in on the front end. They require all the money up front and they don't refund or they only refund a little bit, and that locks in a couple [intended parents] to choose a donor with them [the other agency], you know, even things as much as the donor's compensation. 'Well, you've already paid that to us, so either you lose it or you pick a donor that we can pay it to [within the other agency]. (Director, Southern Agency)

Some agency decision-makers criticized other agencies for unfairly keeping intended parents' money by not offering a reasonable refund policy for when an intended parent changes their mind or when a cycle goes wrong.

I think the thing that annoys [me] the most about the other agencies is the fact that they don't refund money if something happens with the donors. I mean, that's my biggest pet peeve, honestly. (Director, Southern California Agency)

Another Southern California Agency director thought that intended parents who had not yet chosen a donor or started a cycle should get most of their money refunded, but found that most agencies did not offer such a policy:

> I'm talking about if you walked away from the process and there's —they don't give you any money back. At all. I mean, if you just say, I'm going to go adopt and thanks but no thanks.... Most people [agencies] give you back nothing.... I just think it reflects badly on the business. (Director, Southern California Agency)

Another financial practice that my interviewees found unethical and avaricious is setting agency fees based on the egg donor's fee, in which case the agency takes a percentage of the donor's fee.<sup>517</sup>

I don't think agencies should take a percentage of what the donor's fee is.... I think that's very wrong. (Director, Southern California Agency)

Another Southern California Agency director felt that this practice artificially drives up egg donor compensation:

<sup>&</sup>lt;sup>517</sup> None of my interviewees' agencies charged a percentage of their donors' fees, or claimed not to. Since several of them mentioned the practice, however, I conclude that it is a business practice in which agencies that were not willing to speak with me might be engaged.

I also really don't like taking a percentage of the donor fee because a lot of agencies do that.... It drives up the fee of the donor. They normally might say a donor's \$7500, but now they'll make her fee \$10,000 and she has to give 5% and they also take an agency fee. So I think that's a little slithery. (Director, Southern California Agency)

Finally, some agency decision-makers criticized other agencies for compensating for referrals from clinics.

We've had other agencies who [we] found out that they are bribing nurses by sending them iPads to get referrals. Which we were not necessarily thrilled about. (Director, Northern California Agency)

Another Northern California agency director criticized the closed circle of clinics one agency has built via the owner's referral system:

It's just frustrating to me that ... she [the other agency owner] has her cadre of doctors that she will refer to. And you scratch my back I scratch yours. So it's a referral system. (Director, Northern California Agency)

Almost half of my interviewees criticized other agencies for their unethical and unfair financial practices, and the effect of those practices on public perceptions of the business of egg donation.

## **Incomplete Donor Screening**

In addition to unethical financial practices, almost half of my interviewees criticized the screening standards of other agencies. They felt that a complete screening must of necessity include an interview, that there were gaping holes in other agencies' donors' medical or family histories, or that these other agencies continued to list in their databases donors with troubling genetic histories—donors that my interviewees would never accept in the first place.<sup>518</sup> Not all agencies perform substandard screening of egg donors, according to a Northern California case manager, but some do:

<sup>&</sup>lt;sup>518</sup> Gaps in a donor's history may include a donor's lack of information or reporting about her own medical history, as well as incomplete medical histories of relatives that a donor either didn't know or about whom she cannot access information.

Agencies are hit-or-miss. Some are very good and good at vetting [egg donors], and take care and time in finding great gals with great health histories. Other agencies [are] just looking for girls. You can tell the difference. (Case Manager, Northern California)

One agency decision-maker felt that by implication, agencies with very large donor pools must not be screening their donors appropriately.<sup>519</sup> Commenting on the pride of a case manager at a very large agency, this Southern agency director said:

We [at interviewee's agency] go through so many donors to find one. How could you possibly have [thousands] of donors in your donor pool? You haven't done shit if you have [thousands of] donors in your donor pool, you should not be proud of that. Do not stand up there and say that's a good thing. I get exasperated. Yeah, [thousands of] donors she had. She was so happy about it. (Director, Southern Agency)

Agencies who fail to interview egg donor candidates in person are lax in their screening standards, according to some agency decision-makers.

I just talked to a donor who did a cycle in Southern California, and ... I don't even think she met the person that was interviewing her. And so that's something that I think should be mandated, there should be a face-to-face interview. With a written report. And they don't let the donor see it. (Director, Northern California Agency)

Similarly, a Northeastern agency director singled out an agency for failing to interview its candidates:

I know for a fact that some very big agencies, like [prominent Northeastern agency], for example, do not ever meet their surrogates in person, nor their donors, egg donors. So they never actually have an in-person meeting with them, they basically don't know anything about them. (Director, Northeastern Agency)

A Southern agency director told some harrowing tales about the gaps in many other agencies' donor profiles. Between her time working at an in-house program and the

<sup>&</sup>lt;sup>519</sup> According to my interviewees, a large donor pool is more than about one hundred and fifty current egg donors populating the donor database.

profiles from other agencies hopeful intended parents have brought to her for evaluation, she has seen a lot of

gaping holes in these applications. I could never accept a donor with those kind of holes. No information. I mean it's like horrible. (Director, Southern Agency)

She gave three examples of the problems that can arise if donor screening is incomplete:

1) I [saw] one donor who donated, I think, three or four times [at another agency], who then came to me and I discovered in rescreening her that two of her aunts had very, very serious bulimia, and one had died and that was not on that application anywhere.

2) [At her old in-house program], we had one donor who had donated to a family and that family had three beautiful little boys.... And when I rescreened that donor, I discovered that her five siblings were all drug and alcohol addicted, and the family had never been told about it.

3) Another one of my donors ... was the child of a man who had murdered her mother. (Director, Southern Agency)

She also said that some donors simply cannot be screened completely, but that doesn't stop unethical agencies from accepting them:

There are agencies out there who I've seen accept donors with an adoptive parent, which just makes me want to vomit.<sup>520</sup> (Director, Southern Agency)

For this agency decision-maker, incomplete screening is the biggest ethical issue in other agencies' practices.

<sup>&</sup>lt;sup>520</sup> This agency director sees adoptive parents as problematic when screening egg donors because it is very unlikely that the donor will have complete medical history information about her biological parents, which makes it impossible for agencies to perform a complete screening. For example, evidence of a mental health problem or learning disability that might have a genetic component could become apparent upon examination of the donor's family medical history (but would not evident in standard medical testing or the donor's own medical history); if the donor lacks information about her biological parents, this information would simply be unavailable.

A Northern California agency director expressed her disbelief that some agencies list donors in their databases who have clearly disqualifying medical or genetic conditions.

Many of her [another agency's donor] candidates have some underlying health issues, that it's like I can't imagine why she has them on there [in the donor database].... I feel like I've had ethical issues with her, and she continues to keep those donors on there, even though there have been some pretty serious issues that have come up. So that's something that I'm like yeeeeaaaah, I don't know about that. (Director, Northern California Agency)

Another Northern California agency director agreed:

They put donors up that are carriers for things that I consider to be big red flags. (Director Northern California Agency)

If listing donors that should be disqualified is a recurring problem, that speaks to the ethics of the agency owner. However, such listings can come about in another way, as described by a genetic counselor:

Many clinics are still not screening their donors by family history and so what they're doing is they're [donors are] filling out a questionnaire; the physician's reviewing it. The physician doesn't usually have training in medical genetics, but they're reviewing it and going, 'yeah, yeah, should I worry about that?' ... They're making judgment calls about genetic risk and the recipients don't really know the difference. They're not questioning their doctor's ability to do this, but I think they could let a lot of genetic risk come in without having the idea that they're taking any unnecessary risk, and so I've been strongly pushing physicians to think you really need to have somebody on this side of things to look at that [genetic] risk. (Genetic Counselor)

It's not just genetic screening that can be problematic, according to agency decisionmakers. If other agencies are making use of the wrong professionals, or the "right" professionals fail to agree on screening standards, donor screening remains incomplete. A Southern California agency director felt that all psychological evaluations of potential egg donors should be carried out by psychologists:<sup>521</sup>

I know some agencies, they don't use licensed psychologists. They use social workers to do [donor] testing. They do testing over the phone. (Director, Southern California Agency)

A mental health professional had a similar concern, that not all mental health professionals conducting donor evaluations are qualified to do so:

I know that the thought leaders in our field that are part of the Mental Health Professional Group [of the ASRM] are pretty much in agreement about what we [mental health professionals] do and how we do it and what we say. But I think there are a lot of agencies that are screening donors with people that are not as competent and/or as well versed in the field. (Mental Health Professional)

Almost half of my interviewees expressed concern specifically about egg donor screening standards, and the unethical practices of incomplete screening at agencies other than their own. Their criticism of these other agencies' screening standards implies a concern with the legitimacy of the industry as a whole.

# Unfair Management of Donors

A final category of criticism is, generally, the unfair management of egg donors by agencies, including bidding wars, misrepresenting donors, and bait and switch practices.<sup>522</sup> Half of my interviewees mentioned these practices, describing them as abusive of intended parents and donors alike, and reflecting poorly on the business of egg donation.

My interviewees described two different ways in which an unethical agency might monopolize a particular donor. One agency decision-maker said that sometimes donors

<sup>&</sup>lt;sup>521</sup> There are a number of different types of mental health professionals, all with different education and licensing requirements. These include: psychiatrists, clinical psychologists, clinical social workers, licensed professional counselors, mental health counselors, and marital and family therapists.

<sup>&</sup>lt;sup>522</sup> I cannot say with what regularity such practices take place among all egg donor agencies, but these particular practices were those that my interviewees were most likely to mention.

are contracted solely to work with a single set of intended parents, and are compensated very well for their agreement. This agency decision-maker wasn't sure whether this was clearly unethical or not, but the practice made her uncomfortable:

I've also seen other places where they say, 'oh, this donor can only donate to these parents, and so she's under like a contract to work with these parents for the next ten years.... If that's something they've all come up with and they all agree on, I guess that's fine. But that's strange to me. I don't know. (Director, Southern California Agency)

Another Southern California agency director criticized agencies for lying to their donors about being matched with intended parents, in order to prevent the donors from engaging in a cycle through a different agency.

> When agencies find out that the donor signed up with one or two other places [agencies], the agency will falsely tell them they're matched ... so other agencies will call her with a match and she'll be like, 'oh, I'm matched.' And then it started to turn out—we'd hear from that donor a month or two later and nothing's happened, and they [the donor] haven't heard from them [the other agency], and I've called and the coordinator [at the other agency] didn't know what I was talking about. And again, it's kind of the same companies just saying, 'oh, you're matched, so don't cycle with anyone else.' ... A lot of it is not in the best interest of the donors, and it's not really fair, ethical, free market practice, either. But it's legal. (Director, Southern California Agency)

The agency organization SEEDS has created a standard that it hopes will be adopted by the field, prohibiting this practice of monopolizing donors:

Should a donor apply to a second or third agency and is honest about having previously applied to competitors, the agency(ies) should not tell the donor she is currently matched, when she is not, in order to keep her from being matched elsewhere.<sup>523</sup>

Agency decision-makers also criticized other agencies for misrepresenting donors on their websites. One Southern California agency director stated that some agencies deliberately omit important information from their donors' profiles.

<sup>&</sup>lt;sup>523</sup> "Donor Matching," SEEDS Standards.

The ones [unethical practices] that I find the most cringe-worthy are purposely leaving out important medical information, psychological information; important information about the donor that needs to be shared in order to keep the match. (Director, Southern California Agency)

A Northern California agency director criticizes another agency for airbrushing their donors' profile photos:

The photos she uses on her site are airbrushed. And she does say that on there, but the thing is, it's misleading, because intended parents go, 'she's so beautiful, and she's so smart.' (Director, Northern California Agency)

This agency director notes that the airbrushing agency does disclose the practice, but implies that that is insufficient to make the practice ethical, because the first impression of the donor is her photo—so the first impression of the donor on the intended parents is inaccurate.

Another way in which agencies misrepresent their donors is by playing "bait and switch" with database listings: listing either donors who are real but not currently available because they are in cycle, or donors whose donation career is long over. Several agency decision-makers complained about this practice.

On websites, don't put up donors who are currently in cycle, we don't do that.... I think people do that as a bait and hook a lot. (Director, Southern California Agency)

Even more upsetting is evidence of agencies using "false" profiles. Some agencies give others the benefit of the doubt:

I get frustrated with agencies quite often ... I don't think they mean to be misleading, but they will keep donors up there that really aren't actually available, or that just keep their inventory looking kind of good. (Director, Northern California Agency)

Several agency decision-makers, however, believed that the agencies that posted false profiles did so on purpose:

They do a little bit of a bait and switch, where they have an awesome donor, but somehow she never cycles.... [An intended

parent] see[s] the girl [who] goes to Harvard, of course, 'Sure, I want the Harvard grad.' For some reason, all the matches that have [been] made, we haven't actually seen anybody go to cycle with these [Harvard] gals: 'What's the deal here?' (Case Manager, Northern California Agency)

The Miracles Egg Donation lawsuit mentioned in the previous section is an instance of misrepresentation of donors taken to a criminal level,<sup>524</sup> but with many such misrepresentations in donor databases, agency decision-makers only suspect unethical practices at work:

Because I work with a lot of people who are looking for very highly educated donors, I had at least five couples over a year period, who would talk to me about, 'Oh, there's this donor who's a doctor, and she's beautiful, and she has all these wonderful characteristics' ... but each one, something would happen, where they would miss out on working with that donor. And so after hearing this story several times—and I'd always say, 'Oh, can you send me her profile, I'd like to see who that is,' or I'd look them [the donor] up. She [other agency owner] would change the profile ... number ... or she [the doctor donor] wouldn't be on the site, she'd be sent out separately [by the other agency]. And I just felt like, there's something wrong here, I may have no proof, but I just felt like it was a bait and switch. You know, we get you [intended parent] all interested in this [doctor donor] and then, 'Oh, sorry, she got pregnant, she changed her mind.' And all of these different things where she couldn't go to cycle. And when that comes up that many times, you kind of go hmm. (Director, Northern California Agency)

In addition to monopolizing and misrepresenting their donors, agencies may also manage their donors unfairly by engaging in "bidding wars" over donors with other agencies. My interviewees who had experienced this phenomenon were clear that they considered the practice to be highly unethical, as well as disadvantageous for both the agency and the intended parents unfortunate enough to be subjected to them.

I have been the unfortunate victim of one of those, yes. (Director, Southern California Agency)

<sup>&</sup>lt;sup>524</sup> See note 515.

Sometimes the egg donors themselves are the source of a bidding war, but often an agency is the driving force behind it, and, critically, each agency has the power to stop it. A Southern California agency director describes how a bidding war occurs:

Donors can sign up with multiple agencies. There's no law keeping them from doing such. So, for instance, if we call a donor and she says, 'Oh, so-and-so [other agency] just matched me, but my fee is \$6500. What are you willing to give me?' We'll say, 'Nothing. Finish your match, come back to us, we'll give you a higher fee when you come in.' ... Unfortunately, other agencies would say, 'OK, we'll give you \$7500,' or 'We'll give you \$8000.' And so then that donor drops the person she already promised—the agency and the client [intended parent]—and she goes to the other agency.... I would like to think the majority of agencies do what I do. Unfortunately, there are a handful—and they're very well known to do it—and it happens many times, and we remove these donors [from the agency database] permanently. (Director, Southern California Agency)

If an unethical agency has found an intended parent willing to pay double (or more) a donor's agreed-upon fee at another agency, there is not much that an ethical agency can do to prevent their donor from jumping ship.

We've also had situations ... where they [other agencies] know that the donor is listed with multiple agencies and they'll contact the donor and say, 'Hey, I've got a cycle for you.' And the donor will say, 'Well, I just committed to doing a cycle with XYZ Agency.' And then they'll come back and say, 'Well, what if we doubled your fee?' ... And then, of course, yeah, the donor gets additional money from the same cycle, but now we've either created a bidding war, or we've screwed the intended parents that originally booked her from their place in line, because they can't afford to come back with the higher amount that she wants. (Director, Northern California Agency)

Or even more difficult for a donor to resist:

I don't like it when agencies will bid for donors. So say, for example, we match one of our donors and she is working with two agencies. She works for our agency and another agency B. And we match her with an intended parent. The other agency goes, 'Oh, you know, we have an intended parent who really, really loves you, and they are wealthy. And so they are going to offer you \$50,000 to do a cycle, although you're only asking for \$6000.' So all of a sudden, the donor is like, 'Well, if I'm going to be doing the same thing, and I don't know these people, they're just people that I'm supposed to be matching with, why would you—OK I'm going to go with intended parent B.' Our agency, we would never do that.... And there are some agencies that don't have any problem and are notorious for doing that. So they will offer huge amounts of money, and it's just not fair. (Director, Southern California Agency)

Even within a single agency, bidding wars can take place:

I have a lot of issues with [a prominent agency owner], because she can be very difficult for intended parents to work with, and because ... she will match the donor with the highest bidder [within the agency].... And that leaves a bad taste. (Director, Northern California Agency)

The negative impact of bidding wars on the legitimacy of egg donation is significant enough that the agency organization SEEDS has two standards that address bidding wars between and within agencies.

> Agency Boundaries: Agencies should not visit sites of their competitors or work with intended parents who have access to competitor donor profiles with the intent of finding information out about the donor and contacting them independently.<sup>525</sup>

And:

Donor Fees: In order to maintain good business practices among agencies on behalf of the families we work with, SEEDS Ethical Standards suggests that the following business practices among agencies should not be used: 1) Offering a donor who is currently matched with another agency a higher fee if she switches agencies; 2) Creating a "bidding war" between intended parents for the same egg donor to see who is willing to pay the highest fee;

<sup>&</sup>lt;sup>525</sup> "Agency Boundaries," SEEDS Standards.

3) Encouraging a donor to request or accept a fee higher than other agencies she has applied with.<sup>526</sup>

Half of the agency decision-makers with whom I spoke denounced practices by other agencies that they saw as unethical management of donors, including monopolizing donors, misrepresenting donors, and engaging in "bidding wars" for donors. These practices were among those unethical business practices that agency decision-makers felt reflected poorly on the field of egg donation as a whole.

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Nearly all of my interviewees expressed some criticism of unethical practices by other agencies. These practices included unethical financial practices, incomplete donor screening, and unfair management of egg donors. Agency decision-makers wished to distance themselves from what they judged to be unethical practices, often asserting that their agency would "never do that," but that they had witnessed or heard rumors of the poor practice at other agencies. The displeasure expressed by agency decision-makers is evidence that they experience pressure to make ethical decisions about their business practices, as distinct from the agencies they criticized, in order to shore up the legitimacy of the field in which they work.

#### The Market, aka Intended Parents

Another source of pressure on the behavior of egg donor agencies is their customer base, intended parents. Intended parents are often highly educated, savvy consumers, and they know to shop around for a "good" agency.<sup>527</sup> With the advent of social media, online review sites, and internet discussion forums, it is easy for intended parents to talk to one another anonymously, discussing the relative merits of one agency over another, and the well informed intended parent will reject agencies with poor reputations.<sup>528</sup> Half of my interviewees named "word of mouth" as a major source of business:

<sup>&</sup>lt;sup>526</sup> "Donor Fees," SEEDS Standards.

<sup>&</sup>lt;sup>527</sup> They are also organized; the nonprofit organization Parents via Egg Donation (PVED) educates and represents intended parents within the industry, and since its founding in 2008, it has gained considerable influence. See the PVED website at www.parentsviaeggdonation.org/.

<sup>&</sup>lt;sup>528</sup> See, e.g., Fertile Thoughts, www.fertilethoughts.com/, and IVF Connections, www.ivfconnections.com/.

Our bigger source is word of mouth referrals. (Director, Southern California Agency)

It's all word of mouth. (Director, Southern California Agency)

Word of mouth. (Director, Southern Agency)

I would say about eighty percent of our clients are referral clients ... referrals from other parents. (Director, Northeastern Agency)

The savvy consumer client base of egg donor agencies translates into economic market pressure on agencies to make decisions in such a way that intended parents will be satisfied with their agency experience.

This market pressure is evident in the criticisms of agency decision-makers about their less ethical colleagues. As one Southern agency director lamented,

It's a very predatory community, I will tell you that. There are some very wonderful people out there, who are doing things right and as many people as there are who are wonderful, there are probably ten times the amount of people who just should be put away somewhere. (Director, Southern Agency)

One complaint was the lack of customer service apparently provided to intended parents by many agencies.

I have a lot of concern, because I think from what people tell me that agencies—not all, not good ones—but a lot of agencies kind of take their fee and then that's it, you're on your own. (Director, Southern California Agency)

A Northern California agency director criticized the customer service practices of the agency in which she was formerly employed:

It was kind of one of those things where if you called the phone number, it would go to a random location in [major U.S. city], so that they could get [major U.S. city] presence, and then someone would eventually call you back in forty-eight to seventy-two hours. The problem with that is that when you're dealing with egg donations and things like that, it's very time sensitive and it was causing a lot of frustration for people. (Director, Northern California Agency)

When this agency decision-maker started her own agency, she said she adopted a much more supportive customer service protocol, the basics of which included answering the phone and providing quick answer to clients' pressing questions.

Customer service issues are experienced by both intended parents and egg donors—a mental health professional, who hears opinions from both sides, claimed that nobody is happy:

It's very interesting, because a lot of intended parents complain to me that they feel like their agency is really only concerned about the donor, and they don't really care about us [intended parents], even though we're the ones paying the bill. And the donors will very often say, 'Well, clearly they're the ones paying the bill, and they're the ones that everybody cares about.' So it's unfortunate that it's so divided like that, but it very frequently is. (Mental Health Professional)

Agency decision-makers also observed *clinics* taking advantage of intended parents by performing (in the decision-makers' eyes) unnecessary medical treatment and testing.

It does feel like we hear this repetitive story of when you [intended parents] get into six or seven rounds of IVF and then they [physicians] finally say, 'Maybe you should consider a donor egg.' Could that conversation have happened after the third round? (Case Manager, Northern California Agency)

This case manager was concerned about clinics that encourage intended parents to pursue futile medical treatments, to their financial and emotional detriment. Another agency decision-maker criticized an in-house donor egg program for requiring intended parents to pay for a psychological evaluation for their donor, even if she had had such an evaluation for another cycle a short time previously.

> Some of these agencies, like [prominent in-house program], even though the donor did a cycle, like, three months ago or so, and then she's selected again, they want another phone consult with the therapist. And I think that ... they're just trying to generate more money. There's no significant changes in the donor's life. (Director, Northern California Agency)

Agency decision-makers complained as well about other players in the egg donation business deliberately misleading intended parents, so that they cannot make informed decisions about their medical care, their agency choice, or their donor choice.

> Sometimes people come to me and it seems to me that their fertility physicians have not been giving them really accurate information. And that's frustrating. I mean, people think that it's a sure thing. And it's definitely not. (Director, Northern California Agency)

This agency decision-maker was concerned that intended parents would invest in medical treatment that was significantly less likely to be successful than their physicians had led them to believe. Another agency decision-maker criticized other agencies for misrepresenting their services, specifically, for implying that medical testing is included in their agency fees.

> I have specifically read agencies' websites that say ... in their fee is included, they call it 'genetic screening,' when in reality it's a genetic consultation with a geneticist, who talks to the donor and then requests the tests that they deem necessary. But you know, agencies are calling it genetic screening—or even if they are calling it a genetic consultation, they're not explaining to the intended parents really what that means [i.e., the agency fee does not include medical tests on donor chromosomes]. (Director, Southern Agency)

A Southern agency director excoriated a company that offers to find the egg donor with the best phenotypic match to the intended mother.

I get to share what I register as beyond nauseating to me. There's a new company out there. Now, this is just horrible.... [It] is offering recipient families facial recognition matching.... They take the mom's picture and they run her picture through all these different agencies' egg donors, and they then tell her who the closest match is to her. (Director, Southern Agency)

The reason this agency decision-maker is so upset by this company is that she feels that phenotype should be the least of an intended parent's concerns; that instead, they should focus on family health history (aka genetics) and personality.

Instead of saying to them, you know, your desire to have a donor who looks like your twin sister is absolutely bullshit, because even if I find you your twin sister, your kids are not going to look like you, because you've just gotten an entire family pool of genetics, not—instead of clarifying the misperceptions that families have, they just jumped in there. (Director, Southern Agency)

The facial feature matching company is, in this agency director's opinion, taking advantage of intended parents by reinforcing commonly held incorrect beliefs about heritable traits, thus propagating and profiting from misinformation.

Finally, agency decision-makers criticized other agencies and clinics for patronizing intended parents. A Northern California agency director was upset when she discovered that one of her clients' physicians had insisted that the client transfer one embryo, when they had decided beforehand to transfer two:

This is the part that really burns me up. I went over all these numbers [cycle success rates] with the couple, before their first transfer. They wanted to transfer two fresh embryos, and their physician basically treated them like it wasn't their decision. It was the physician's decision. I had smoke coming out my ears when I heard that. (Director, Northern California Agency) Another Northern California agency director also criticized physicians for encouraging single embryo transfers, and taking the choice away from intended parents, when in her opinion, single embryo transfers are not medically superior:<sup>529</sup>

I don't get what the push [for single embryo transfers] is.... OK, a twin pregnancy is automatically put in the high risk category, but that only means, you know, that you monitor them more carefully and if there's a problem, you deal with it. And yes, they have mostly scheduled c-sections. That's not a big deal. They have a higher incidence of gestational diabetes. That's totally manageable. A lot more manageable than never having a baby, which is the alternative. (Director, Northern California Agency)

Several agency decision-makers disparaged clinics and agencies that fail to grant intended parents their choice of donor.

I had one doctor ... say, 'can you believe these families who think that they get the—they could be that picky about who's donating their eggs to them?' And I'm looking at him like—yes, it's true that when you use your own genetics, you don't get to pick ... But

<sup>&</sup>lt;sup>529</sup> Responsible reproductive endocrinologists have advocated single embryo transfers as a means of reducing the number of multiple births. There is some evidence that single embryo transfer can approach the success rates of double embryo transfer: P.A. Saunders et al., "Single Embryo Transfer (SET) at Blastocyst Stage is as Successful as Double Embryo Transfer (DET) at Cleavage Stage," Fertility and Sterility 100, no. 3 (Sept. 2013): S84. Physicians who advocate for single embryo transfers tend to see multiple births (twins, triplets, or higher order multiples) as less than successes, since multiple births increase the medical risks to both mother and babies. Multiples are likely to be born premature, which puts them at risk for low birthweight, cerebal palsy, intellectual disabilities, and vision and hearing loss, and mothers of multiples are more likely to suffer from preeclampsia (high blood pressure) and gestational diabetes. See March of Dimes, "Multiples: Twins, Triplets, and Beyond," March of Dimes website, www.marchofdimes.org/pregnancy/multiples-twins-triplets-and-beyond.aspxT; Internet; Accessed 31 October 2014. (March of Dimes is a major nonprofit research and advocacy organization whose mission is to "help moms have full term healthy pregnancies and research the problems that threaten the health of babies." "Mission," March of Dimes website, www.marchofdimes.org/ mission.aspx; Internet; Accessed 31 October 2014.) One option for an intended mother who becomes pregnant with multiples is a procedure called "selective reduction," or "multifetal pregnancy reduction," in which one or more of the fetuses is terminated in utero in the first or early second trimester in order to give the remaining fetuses a better chance at a healthy birth. This procedure is highly controversial for obvious reasons, but in addition to any anti-abortion arguments that might be made against it, the intended parents are in the position of having created the undesirable situation in the first place. See The Committee on Ethics of the American College of Obstetrics and Gynecology, "Multifetal Pregnancy Reduction," Committee Opinion no. 553 (February 2013): 1-6. (The American College of Obstetrics and Gynecology is the professional organization for obstetricians and gynecologists; these specialists are the physicians who perform selective reduction procedures.)

when you have a family who's been led to this, they do. They get to pick. (Director, Southern Agency)

Another agency decision-maker criticized in-house egg donor programs that don't allow intended parents any choice of donor at all:

The clinics themselves would match the couples. They couples didn't have any say in the matter. That, to me, is mind boggling. It's like, this is not a kidney. This is not a blood transfusion. This is the genetic map for my child. (Director, Northern California Agency)

Some agencies are guilty of patronizing intended parents about their egg donor choice as well, according to a Southern California agency director:

And there are other agencies where I've heard agency owners say, 'Well, you know, I decide who matches with who.' And that, to me, is like playing God to a certain extent, and I don't like that. It makes me cringe. (Director, Southern California Agency)

Agency decision-makers' criticism of the unethical practices of other agencies and clinics is evidence that they feel pressure as a result of these unscrupulous organizations' actions and their effect on the satisfaction of intended parents with the egg donation process. Whether a result of poor customer service, unnecessary medical treatment and tests, misinformation, or patronization of intended parents with regard to medical decisions or donor selection, dissatisfied intended parents can spread the word to other potential intended parents, threatening egg donor agencies' legitimacy in the marketplace and causing agency decision-makers to seek means of bolstering the legitimacy of the field.

### **Grasping Legitimacy**

### Ethics, Clearly

Agency decision-makers respond to the various pressures on their agencies and their industry by making several different kinds of claims of legitimacy.<sup>530</sup> Several of my

<sup>&</sup>lt;sup>530</sup> This is an example of coercive isomorphism. See DiMaggio and Powell, "The Iron Cage Revisited," 74. See also the Pache and Santos account of how "hybrid" organizations incorporate elements from the social logic in order to gain legitimacy. Pache and Santos, "Inside the Hybrid Organization."

interviewees discussed their desire for a greater level of transparency in agency practices as a fundamental basis for legitimacy of egg donation, and as a means of preventing criminal and unethical agency practices. Transparency is important, these agency decision-makers felt, in the exchange of information between agency, client, and donor, as well as among agencies:

> Transparency of information, I believe with my whole heart, is incredibly important for this industry. (Director, Southern California Agency)

It is also important in the context of the new egg freezing technology, and within frozen donor egg cycles:

So it's just transparency. That's what I'm worried about [with regard to frozen donor egg IVF cycles]. (Director, Southern California Agency)

And transparency is the mental health profession standard when it comes to sharing identifying information between a donor and intended parents, and disclosure to donor-conceived children:

I think the overall consensus is [that] complete openness and transparency is better for all involved, if you feel that that's something that you can wrap your head around. (Director, Southern California Agency)

The majority of the agency decision-makers with whom I spoke emphasized their own agencies' fair, ethical practices in the same breath as their criticism of the practices of other agencies and clinics. Specific examples included not giving any money for referrals, not engaging in bidding wars for donors, and, sometimes, cooperating with other agencies to find the "right" donor for a particular client. More than four out of five of my interviewees' agencies have statements about their ethical policies on their websites; many of which point out that other agencies don't share their own high ethical standards. These prevalent claims to elevated ethical standards are evidence of agencies' response to the media, social, and market pressures that threaten their legitimacy, as well as the legitimacy of the field as a whole.<sup>531</sup>

<sup>&</sup>lt;sup>531</sup> Egg donor agencies incorporate an element from the social institutional logic—high ethical standards —in order to establish their legitimacy, which is low to start because of their origination in a market logic. See also DiMaggio and Powell, "The Iron Cage Revisited," 74.

Agency decision-makers also claim legitimacy for their own agencies and for the field in other ways. They take advantage of their necessary relationship with infertility clinics, which, being medical establishments, enjoy the legitimacy of their well-established profession.<sup>532</sup> Agencies also affiliate themselves with other professions, including mental health professionals and attorneys, and organizations, especially infertility support organizations, in an effort to siphon some of those professions' and organizations' legitimacy to the world of egg donor agencies. Since some of the media attention the industry receives helps to stigmatize the practice of egg donation, from those who donate their eggs to those who receive them, and everyone in between, agency decision-makers also attempt to claim legitimacy by subverting the shame that is attached to egg donation in the popular imagination.<sup>533</sup> The primary way in which they do so is by encouraging disclosure to children about the way they were conceived, and, to a lesser extent, encouraging contact between intended parent and donor.

All of these agency actions are ultimately intended to secure the legitimacy of not only the agency run by the decision-maker, but also of egg donor agencies as a group. They are the ways in which agency decision-makers claim legitimacy that fall short of an effort to professionalize egg donor agencies—an effort that is discussed in the following section.

### Riding the Coattails of Medicine

Medical infertility treatment clinics, which retrieve the eggs from one woman, fertilize the eggs in vitro, and then transfer the resulting embryos into another woman, form the foundation of the business of egg donation agencies. Because infertility clinics are part of the larger profession of medicine, they enjoy the legitimacy borne from the status of a well established profession, consisting of formal entry requirements (medical school, residency training, board exams, licensing by state medical boards), professional organizations (The American Medical Association and The American Society for Reproductive Medicine, among others), and strict codes of conduct (state boards of medical examiners, Hippocratic oath, professional ethics standards).<sup>534</sup> Professional organizations like the ASRM establish and publish practice guidelines which, while not rising to the level of law, exert significant influence over the conduct of the relevant

<sup>&</sup>lt;sup>532</sup> Starr, Social Transformation of American Medicine, 79 et seq.

<sup>&</sup>lt;sup>533</sup> For examples of criticism of egg donation in the media, see note 494.

<sup>&</sup>lt;sup>534</sup> DiMaggio and Powell, "The Iron Cage Revisited;" Larson, *The Rise of Professionalism*, 49-52; AMA, amaassn.org/; ASRM, www.asrm.org.

physicians; if a reproductive endocrinologist wishes to share fully in the legitimacy of his or her profession and speciality, they must abide by the ASRM guidelines.<sup>535</sup>

Egg donation agencies of necessity have a close relationship with the clinical side of egg donation; they provide the donors whose eggs will enable clinic patients to become pregnant. Because of that relationship, they are able to share in the legitimacy of the medical profession, in essence riding the coattails of the reproductive endocrinology medical speciality and deriving some legitimacy through proximity with an established profession. Agency affiliations with other professionals and professional organizations are a means of ensuring the appearance of legitimacy; medicine has its own sets of standards that, to some extent, the agencies can rely on as proxies for their own (as yet nonexistent) field-wide standards.

# Deferral to Medical Professional Guidelines and Clinic Standards

In order to take advantage of the medical profession's legitimacy, agency decisionmakers defer judgment to clinics and physicians on some issues (including medical screening, psychological screening, genetic screening, and donor education) and follow the ASRM guidelines, even though those guidelines have no professional power over the agencies.<sup>536</sup> Agency decision-makers also attempt to "fix" problems that they see with clinics—in particular, clinic interactions with their clients/patients—which is also an attempt to shore up the legitimacy of the field as a whole. Finally, agency decisionmakers try to maintain good working relationships with clinics, so that they will have a wide professional network and in turn receive client/patient referrals from clinics.

Agency decision-makers defer to clinics on issues that have both medical and social components. In part, this is a practical strategy; if agencies fail to comply with clinic standards, clinics will refuse to work with them. In addition, however, agencies that fail to comply with clinic standards cannot take advantage of existing clinic legitimacy.

<sup>&</sup>lt;sup>535</sup> See ASRM Practice Committee and SART Practice Committee, "Recommendations for Gamete and Embryo Donation," 47; ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305; ASRM Practice Committee, "Repetitive Oocyte Donation," S194; ASRM Ethics Committee, "Misconduct in Third-Party Assisted Reproduction," 38; ASRM Ethics Committee, "Interests, Obligations, and Rights in Gamete Donation" (2014), 675; ASRM Ethics Committee, "Oocyte or Embryo Donation to Women of Advanced Age," 337; ASRM Ethics Committee, "Informing Offspring of Their Conception by Gamete or Embryo Donation," 45.

<sup>&</sup>lt;sup>536</sup> See previous note.

One such issue is age limits for intended parents. While clearly the age of a patient intending to become pregnant has medical implications, it is a social issue as well, as more and more older parents have children, and then die earlier in the children's lives, sometimes before the children are launched into society.<sup>537</sup> There is a general sense among agency decision-makers that they would prefer not to work with much older parents (older than fifty or fifty-five years):

I try and shy away from intended parents who are on the older [over fifty-three] side.... I basically do a gut check. (Director, Northern California Agency)

Yet most agency decision-makers deferred to clinic guidelines and individual physicians' decisions about intended parent age:

The general rule of thumb—it's really based on the doctor's office is one hundred and ten as far as combined age of the recipients.... But we make that more of a clinic thing, not an 'our' thing. (Director, Southern California Agency)

Most doctors' offices have a fairly strict requirement of who people that are of advanced age usually get turned down by the medical facility long before they come to us. (Director, Southern California Agency)

But at this point, most, the vast majority of doctor's offices have a cutoff for intended moms of fifty to fifty-five, or [for] the couple together. (Director, Southern California Agency)

If they've been accepted by a reproductive endocrinologist, then I'm fine with that. (Director, Northern California Agency)

Some fertility centers say, 'you know what, so we don't have to make those kinds of judgment calls, we're just going to cut it off at fifty.' And I think that's just an easy way of saying, 'we can't deal with.' (Director, Midwestern Agency)

<sup>&</sup>lt;sup>537</sup> For a good overview of the issues raised by the increasing age of new parents in the United States, see Judith Shulevitz, "How Older Parenthood Will Upend American Society," *The New Republic*, 6 December 2012, available from www.newrepublic.com/article/politics/magazine/110861/how-older-parenthoodwill-upend-american-society; Internet; Accessed 23 September 2014.

That's not for me to say. That's [intended parent age limits are] the fertility clinics' thing. (Director, Northern California Agency)

Right. Correct. We let the clinic make that decision [about intended parent age limits], yeah. (Director, Southern California Agency)

Agency decision-makers also rely on infertility clinics to make the final decision about whether a particular egg donor is medically acceptable. Agencies screen donors, but if they fail to pass medical screening, they are automatically disqualified.

They [egg donors] have to pass a medical record review by the fertility physicians. (Director, Northern California Agency)

The standards of the medical profession support the agencies' claim to legitimacy:

A lot of the stuff that we do as a business, the decisions a lot of times fall with the medical doctors. So if we're working with a surrogate or an egg donor, we have to rely on the medical field to say, do they pass medical screening? (Director, Southern California Agency)

Agency decision-makers also defer to clinics about whether or not a particular set of intended parents will ultimately make good parents. This deferral is convenient because it enables the agencies to accept any clients that come their way without compunction. Interestingly, the agency decision-makers note that the clinics are themselves relying on opinions from mental health professionals.

Because they [intended parents] go through the actual professionals. It's not just me having a conversation or another case manager having a conversation. They actually have a medical professional and a psychologist evaluate them and making sure that they are fit to be parents, so to speak. (Director, Southern California Agency)

Similarly:

When they [intended parents] come to us, regardless of how they find their way to us, ultimately, you see, they need to be working with an established and reputable IVF center.... They're subject to FDA intrusions [mandated infectious disease testing] and screenings and looking in. So IVF clinics have to have these protocols in place, so it's not as if I can be in a situation where I can say, 'I really don't like you [intended parents].' I mean, if they've been through all the medical workup that they have, if they have the psych social screening, the medical center is going to weed them out if there's really a problem. (Director, Midwestern Agency)

Still, sometimes, agency decision-makers have concerns about working with a particular set of intended parents—even when that set of intended parents has been "approved" by a clinic—when the intended parents have given some indication that they will not be good parents, and to allay those concerns agency decision-makers double-check with the professionals:

Usually if they're [intended parents are] coming to us from a clinic we kind of feel like the clinic's pretty much vetted them, and feel like if they're [the clinic is] going to work with them [intended parents], we don't have any reason not to. There might be some concerns that would come up in individual cases, and I would call the clinic and just maybe clarify with the person that I talk with at the clinic. (Director, Southern California Agency)

And occasionally, an agency decision-maker will seek a second professional opinion themselves:

Well, the clinics require psych screenings. So if the clinic is fine to work with them, we just make sure if it's too much, then we would ask for a second evaluation just to again make sure that we're not putting a child in a dangerous home or anything like that. (Director, Southern California Agency)

Another way in which agencies strive for legitimacy is through affiliation with professional organizations. They appeal to the authority of the ASRM (the primary professional organization for reproductive endocrinologists), for example, when explaining to donors and intended parents the logic behind limiting the number of cycles in which a donor can participate, the age limits for donors, and (for those who follow the ASRM guidelines on donor compensation), the cap on donor compensation

of \$10,000.<sup>538</sup> Almost two thirds of my interviewees discussed why they follow other professional organizations' guidelines, and a few even stated explicitly that it was in order to make use of the presumptive authority of an established profession.

Some agency decision-makers follow other professional organizations' guidelines because they feel they are required to in order to maintain their working relationships with clinics.

There's actually a process that you go through to be certified by ASRM [as an ethical egg donor agency] and I have not done it. I mean, I do follow the guidelines, because basically the clinics do, and I do whatever the clinics want me to do. (Director, Northern California Agency)

Others see it as an ethical necessity, part of doing their best to ensure that their own practice is ethical, even though they know they are not required to follow other professions' guidelines:

We adhere to all of the ASRM guidelines, the AAARTA guidelines, we work with RESOLVE. So even though essentially I don't have to —I'm not legally required to follow any guidelines, ethically I make sure that I stick to all of them.<sup>539</sup> (Director, Northeastern Agency)

Some agency decision-makers will disobey the ASRM guidelines, but only with the permission of a physician:

We really pretty much follow the guidelines, and I say 'pretty much,' but if we have someone who's donated six times, and the

<sup>&</sup>lt;sup>538</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305. Agency decision-makers primarily follow the ASRM guidelines, though they might also follow particular mental health professional guidelines or legal ethical guidelines from, for example, the American Academy of Assisted Reproductive Technology Attorneys. American Academy of Assisted Reproductive Technology Attorneys (AAARTA), www.aaarta.org.

<sup>&</sup>lt;sup>539</sup> The ASRM guidelines address topics such as egg donor compensation, how many times an egg donor should be permitted to donate, and general guidance on egg donor qualifications, such as minimum and maximum age. See note 535 for citations. AAARTA (The American Academy of Assisted Reproductive Technology Attorneys) provides a code of ethics by which its members must abide. The AAARTA Code of Ethics contains provisions addressing attorney conflict of interest and the attorney's obligation to ensure that his or her clients are educated as to their legal rights and responsibilities with regard to a reproduction arrangement. RESOLVE is a nonprofit infertility support organization which does not publish guidelines for professionals, but does advise infertility patients on how to navigate the complex world of collaborative reproduction arrangements.

first or second couple she donated to wants a sibling from the same donor, almost every doctor I know would be willing to do it because I think there are exceptions. (Director, Southern California Agency)

And others follow the guidelines even when physicians—to whom the guidelines actually apply—do not:

Right now, you know the six ASRM guidelines, doing six retrievals.... It's not really based on any true research; we really need to do more research. But if that's all we have, then I think we should kind of maybe stick to that, six rules. I have seen other agencies where donors have done twenty retrievals, and I don't know. I'm not a medical doctor, so if the medical doctor is approving them all the time, then I guess that's fine. But [at my] agency, once you hit six [egg retrievals as a donor], I remove you from the database. (Director, Southern California Agency)

One agency decision-maker pointed out that some of her staff are in fact subject to various professional guidelines, and of course they follow those guidelines, as well as the ASRM guidelines that do not affect the agency directly.

Of course we follow a lot of guidelines, not just published, but in terms of what we as professionals, including the professionals on staff who are licensed in their particular profession. We follow all of those ethical guidelines. For instance, I'll just give you an example, we have licensed mental health professionals on staff, and they have to follow all of the criteria necessary for that licensure. Including getting continuing education along the way so, yes, we adhere to all of that. (Director, Midwestern Agency)

For this agency director, following both guidelines that apply directly and those that do not increases her legitimacy.

Finally, some agency decision-makers deliberately reflect other professional organizations' guidelines in their own internal policies, as a means of claiming legitimacy for their own business:

We have our own set of guidelines, as well as there is a structure from American Society for Reproductive Medicine, ASRM. So there's a set of guidelines that they put out that we also follow, that's kind of our internal ones as well, mirror those guidelines. (Director, Southern California Agency)

One agency decision-maker stated that her agency appeals to the ASRM guidelines when reasoning with clients and donors, as a source of ultimate authority for her agency's practices:

I'm actually glad the ASRM put together a list of guidelines. And I actually like the ones that they put out, even though I think there are exceptions to most rules.... But here's the thing: having those guidelines out there and having people—to the best of their ability —stick to them, gives us a basis and a sounding point when we're saying, talking to donors. When they're saying 'I want fifty grand,' and it's like, 'Well, here's the problem,' you know? (Director, Southern California Agency)

This logic is a form of legitimacy by proxy, with the agency riding on the legitimate coattails of the medical profession.

Agency decision-makers rely in part on the professional legitimacy of the organizations with which they interact in the course of their business. By deferring to clinic decisions and norms on issues that have a social component, and by following medical professional organization guidelines, or mirroring such guidelines in their own agency policies, agency decision-makers attempt to claim some of the legitimacy of the well established profession of medicine, and to a lesser extent, the mental health profession.

### **Bad Apples Spoil the Barrel**

Egg donor agencies' endeavor to gain legitimacy from their affiliation with infertility clinics is not merely a passive following of clinic norms and medical professional guidelines. Agency decision-makers also make efforts to bolster the legitimacy of the clinics themselves by mediating the problems that they observe between clinics and the agency clients, intended parents. Typically, this involves agency decision-makers taking on the role of educators when clinics fall short of their profession's ideals, such as when a clinic consistently has poor outcomes, when the agency decision-maker feels that a clinic has somehow misinformed the intended parents, or when agency decision-makers makers perceive that a clinic is otherwise taking advantage of vulnerable intended

parents.<sup>540</sup> Interestingly, agency intervention between a clinic and its patient would appear to undermine the legitimacy of the clinic and its underlying profession, but in paradoxical relationship with agency deference to medical professional codes, it is part of a (likely unconscious) agency effort to maintain the legitimacy of the medical profession, from which they themselves benefit. In effect, agencies improve upon the legitimacy of the medical profession by pointing out to intended parents the "bad apples" as anomalies within the profession as a whole, and thus prevent the influence of these bad apples from spreading within the medical profession. In this way, agency decision-makers seek both to preserve the legitimacy of the established professions with which they are affiliated, and command the benefit of that legitimacy for their own part of the field of egg donation.

One way in which agency decision-makers attempt to prevent clinics that are poor representatives of their profession from eroding its legitimacy is by educating parents when their chosen clinic has poor success rates—low pregnancy and live birth rates per IVF cycle.

It's really hard when someone comes to me from a doctor's office that I know is not the greatest, you know. If I know that—at least with us, I know that their stats are a lot lower because we keep track of that. So you know, you sort of want to be protective of them.... We always intervene and try to help. (Director, Southern California Agency)

This type of intervention, is, however, tricky, because intended parents need to trust in their physician in order to feel confident entrusting them with their health and their money.

I feel very strongly that in terms of educating families, that means I have to tell them about statistics, and it's a little bit—that's a moral dilemma. That's a sticky one for me. If it's a physician who doesn't have good numbers who sends the patient to me, and then it's really complicated, but I still find a way to educate the family because, you know what? I'm not here for the doctor, I'm here for the patient. (Director, Southern Agency)

<sup>&</sup>lt;sup>540</sup> My interviewees' opinions about clinic success rates appeared to be partly based on the official SART data (SART, Clinic Summary Reports 2003-2012) and partly based on their own anecdotal experience with a particular clinic.

If necessary, agency decision-makers want to see intended parents switch to a clinic with higher success rates, to improve their chances of bringing home a baby, and to prevent intended parents' views of the industry from being warped by a poor experience with a poor clinic—and, presumably, to enhance their own success rates.

Agency decision-makers will also intervene when they feel clinics have given intended parents inaccurate or misleading information about their chances of success. This, too, is a tricky proposition:

People don't want to hear ... their egg donor agency contradicting their physician.... Doing anything to undermine a parent's confidence in their physician ... is a very risky business. (Director, Northern California Agency)

But it is a necessary intervention, according to some agency decision-makers, who have seen the effects of such misinformation after the fact:

So many women come to us after multiple IVF rounds, even with DE [donor egg], and they come back, and they're like, 'I don't know what kind of information I've been getting from clinics.' (Case Manager, Northern California Agency)

These intended parents are disillusioned with their clinics, which undermines the legitimacy of the clinic, which in turn undermines the legitimacy of the industry as a whole, including egg donor agencies.

Agency decision-makers also tackle other ways in which they perceive clinics to be taking advantage of their patients (aka agencies' clients). One agency director complained about clinic shared risk programs, in which intended parents pay a higher than standard fee for a cycle, and in return receive an extra cycle or two if the first cycle fails. She thought that intended parents could decide about such programs, but needed to be educated by agencies, as well as clinics, in order to do so.

So I know that there are some IVF centers who are doing the guaranteed programs, and those sometimes I wonder—I don't know. I don't know if those are the best, because you're really raising the parents' expectations and hopes in saying, 'I'm going to guarantee you a child.' And there are different fees and it gets more and more expensive because you're paying more money into it. But ... I think that as long as agencies and clinics are just properly

educating the parents, we have to trust that the parents can make their own decisions. (Director, Southern California Agency)

Another agency decision-maker tried to keep her clients away from clinics that she perceives to be unethical or unsafe.

If I think somebody [a clinic] is like being—is doing things that are unethical, unsafe, I would [not work with the clinic]. I have a clinic that we worked with that has great numbers, but I don't pursue working with him because he does very stupid things, and if I work with him, it's a lot of energy for us to micromanage his care. (Director, Southern Agency)

Agency decision-makers, counterintuitively, sometimes engage in criticism of clinic practices to intended parents in order to protect intended parents from the bad apples in the industry. Together with deferring to medical professional guidelines and clinic norms that they deem sound, agency decision-makers, by protecting their clients from experiences with poor representatives of the medical branch of egg donation, also protect the legitimacy of the profession, and their own share in that legitimacy.

# Working Relationships

A final way in which agency decision-makers try to claim some of the medical profession's legitimacy for themselves is by maintaining positive working relationships with a variety of clinics. Half of my interviewees emphasized their working relationships with clinics as vital to their success as a business—and by implication, their legitimacy within the field of egg donation.

Good working relationships with clinics benefit agency clients, by providing intended parents the ease of a smooth bureaucratic process and the comfort of quality medical care and education about the process.

There's some [clinics] we work with more than others, and so we will target the cities [with which] we have the most relationships and the most referrals from because having local donors and local donor choice is obviously going to benefit the intended parents, because then they're not paying for travel, and so on and so forth. (Director, Southern California Agency) If intended parents are pleased with their experience, their positive opinions will help to build the legitimacy of egg donation agencies. Many agency decision-makers cultivate relationships with particular clinics with this aim in mind:

> Obviously, if we already have a relationship with the nurses and the doctor and whatnot, it makes the intended parents feel very comfortable and confident that they're going to be in good hands. (Director, Southern California Agency)

It can behoove agencies to pick and choose among clinics, in order to feel confident sending their intended parents to their affiliated clinics, and, in return, the clinics are comfortable and familiar with the agency.

I have a list [of clinics] that I like to work with. When I first started, I sent my information out to basically all the major clinics in the Bay Area, and I think I've worked with probably a total of somewhere between twelve and fifteen. And out of that, I've reduced [the list] down. (Director, Northern California Agency)

The power of opinion goes both ways—agencies also attempt to bolster their legitimacy by garnering the good opinion of the clinics themselves, in order to ensure that clinics will refer to them, thus ensuring good business, and by implication, buttressing the legitimacy of egg donor agencies. One agency director created relationships with clinics

> usually from—if it's not just cold calling—walking in their door saying, 'Hey, can I tell you about our program?' Which of course initially, that's how a lot of our business came, but also if a donor was being monitored somewhere and we did a good job, then they'd be open to hearing more about our program and referring to us. (Director, Southern Agency)

Another agency decision-maker felt that the basis of her agency's good relationships with physicians was to make the physicians' jobs easier: her agency's services

really helped them [an infertility clinic] help their patients, and I learned early on that one of the keys to doing this is to take some of the onus and pressure off the doctor's offices. (Director, Southern California Agency)

In fact, agencies' main source of business is clinic referrals. Eighty-five percent of my interviewees stated that clinic referrals were their primary or a major source of business:

The clinics refer them [intended parents] to me. (Director, Northern California Agency)

They're referred to me by the fertility clinics. (Director, Northern California Agency)

We're referral based only. (Director, Northern California Agency)

We certainly get a lot of referrals from doctors. (Director, Southern California Agency)

I'm almost one hundred percent referral based, and the intended parents that come to me have a relationship with a doctor's office. (Director, Southern California Agency)

I would say we're ninety-five; ninety to ninety-five percent referral based. (Director, Southern California Agency)

Intended parents come from clinic referrals. (Director, Southern California Agency)

It's referrals from clinics. (Director, Southern California Agency)

I get them from the clinics that we work with. (Director, Midwestern Agency)

I would say ninety percent are referrals from our doctors that we work with. (Director, Southern Agency)

It's probably about fifty-fifty between internet and referrals through physicians. (Director, Northern California Agency)

The vast majority of my clients come from the reproductive endocrinologists. (Director, Midwestern Agency)

Agencies are dependent on good working relationships with clinics in more than one sense. They must cultivate respect from clinics in order to ensure the influx of referred clients, and they must have confidence in the clinics with which they work, in order to secure the good opinion of intended parents about the whole egg donation process. By maintaining good working relationships with the medical clinics that provide donor egg IVF services, agencies secure for themselves a portion of the legitimacy accorded the profession of medicine.<sup>541</sup>

## **Badging Legitimacy**

In addition to "riding the coattails" of the medical profession, agencies also affiliate themselves with other professions affiliated with egg donation, and with reputable infertility support organizations in order to bolster their legitimacy with potential clients. Over half of my interviewees had badges for national and/or local infertility patient support organizations on their websites,<sup>542</sup> and four out of five stated affiliations with professionals such as nurses, mental health professionals, genetic counselors, and attorneys. This speaks to how agencies desire to portray themselves to the public—as legitimate members of a field that serves infertile people, who are deserving of compassion.

We follow the guidelines of ASRM, we're also involved with RESOLVE, we're also involved with [a local LGBT family organization], which is a gay and lesbian parenting group, unfunded, for gay and lesbian parents. There's a lot of other affiliations that we have. We also follow the strict guidelines of AAARTA.<sup>543</sup> (Director, Northeastern Agency)

The three most commonly "badged" organizations on my interviewees' agencies' websites belonged to The American Fertility Association, RESOLVE, and Parents Via Egg Donation. The American Fertility Association (AFA), which recently changed its name to Path2Parenthood (P2P), is a national nonprofit organization whose purpose is to provide "leading-edge outreach programs and timely educational information. The scope of our work encompasses reproductive and sexual health, infertility prevention and treatment, and family-building options including adoption and third party solutions."<sup>544</sup> Similarly, RESOLVE, which deems itself "The National Infertility

<sup>&</sup>lt;sup>541</sup> For an account of the development of the profession of medicine and its legitimacy, see Starr, *Social Transformation of American Medicine*, 79 et seq.

<sup>&</sup>lt;sup>542</sup> For the purposes of this dissertation, a web badge is an image on a website, typically the logo of an organization, demonstrating an affiliation between the agency and the badged organization.

<sup>&</sup>lt;sup>543</sup> See note 539 for a summary of ASRM, AAARTA, and RESOLVE guidelines.

<sup>&</sup>lt;sup>544</sup> "About P2P," Path2Parenthood website, www.path2parenthood.org/about-p2p/; Internet; Accessed 13 December 2014. The American Fertility Association changed its name to Path2Parenthood on November 3, 2014.

Association," is nonprofit organization "with the only established, nationwide network mandated to promote reproductive health and to ensure equal access to all family building options for men and women experiencing infertility or other reproductive disorders."<sup>545</sup>

While P2P and RESOLVE are organizations dedicated to helping people with infertility in general, Parents Via Egg Donation (PVED) is a nonprofit organization specifically created to support intended parents who have built or intend to build their families through egg donation.<sup>546</sup> Marna Gatlin, its founder, is a mother via egg donation herself, who created the organization "to provide an informational and supportive environment where parents and parents-to-be can learn and share information about all facets of the egg donation process. Our mission is to educate, support, and empower families and individuals at any stage of the process who choose to use egg donation to build a family. We share information about agencies, legal and medical professionals, treatment centers, mental health therapists, pharmaceutical companies, and other resources."547 PVED offers information to intended parents through a variety of means, including a private online discussion forum.<sup>548</sup> PVED's intended audience is the same as egg donor agencies' target business population—people who intend to become parents through egg donation—though PVED also serves those who have achieved parenthood through egg donation. Additionally, Marna Gatlin and PVED are involved in the agency professionalization effort (as discussed below in "The Project of Professionalization"); Ms. Gatlin serves as the SEEDS "Advocate Advisor."549

In addition to the support group badges on many of my interviewees' agencies' websites, eighty percent of the agencies indicate on their websites that they have working relationships with other kinds of professionals, such as nurses, mental health professionals, genetic counselors, and lawyers who specialize in collaborative reproduction arrangements, that serve as a sort of peripheral legitimizing influence.<sup>550</sup> Just as with egg donor agencies' association with the medical profession through

<sup>&</sup>lt;sup>545</sup> "About Us," RESOLVE website, www.resolve.org/about/; Internet; Accessed 14 July 2014.

<sup>&</sup>lt;sup>546</sup> Parents via Egg Donation (PVED), www.parentsviaeggdonation.org/.

<sup>&</sup>lt;sup>547</sup> "About Us," PVED website, www.parentsviaeggdonation.org/about.php; Internet; Accessed 14 July 2014.

<sup>&</sup>lt;sup>548</sup> PVED Forums, forums.pved.org/.

<sup>&</sup>lt;sup>549</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>550</sup> Sometimes these professionals are employees of the agency, sometimes they serve as independent contractors for the agency, and sometimes they simply have a working relationship with the agency in which the agency will refer clients to the professional for particular aspects of the egg donation process (e.g., psychological screening or legal representation).

infertility clinics, their affiliations with other professionals who work in the field serve simultaneously to fulfill the needs of their clients and donors, and also to bolster their legitimacy within the field of egg donation. As with clinics, the fact of a good working relationship between an agency and a field-related licensed professional confers on agencies an intimation of the legitimacy enjoyed by those professionals. Between affiliations with infertility clinics, other field professionals, and nonprofit support organizations, unregulated egg donor agencies have positioned themselves firmly within the legitimate, regulated components of the collaborative reproduction network.

#### Subverting Shame

In addition to claiming legitimacy by proxy through affiliations with infertility clinics (aka the medical profession), other field professionals, and nonprofit infertility support organizations, agency decision-makers try to strengthen their legitimacy within the field by tackling the general view of egg donation as stigmatized and shameful.<sup>551</sup> They do so occasionally by encouraging contact between intended parent and egg donor, but much more often by advocating for disclosure of children's donor origins by intended parents to their children.<sup>552</sup> The shame of infertility, and subsequent need of egg donation, along with fears about how the child will react, are powerful emotions that induce intended parents to keep their disability a secret from friends, family, and their child alike.<sup>553</sup> That secrecy, however, simply furthers the idea that egg donation itself is a shameful act, which in turn undermines the legitimacy of the industry.

<sup>&</sup>lt;sup>551</sup> As evidenced by the reluctance of most parents via egg donation to reveal the means of their child's conception, and as evidenced by many articles online describing how not to make an egg donor feel shamed. See, e.g., Miranda Ward, "What NOT to Say to an Egg Donor," *We Are Egg Donors* (blog) posted 28 May 2014, available from weareeggdonors.com/2014/05/28/what-not-to-say-to-egg-donor/; Internet; Accessed 10 September 2014.

<sup>&</sup>lt;sup>552</sup> Per my interviewees, most of their clients do not intend to disclose to their children that they were conceived through egg donation.

<sup>&</sup>lt;sup>553</sup> As noted previously: "Infertility wreaks inestimable havoc on those who suffer from it.... it tends to produce an emotional reaction akin to major illness." Spar, *The Baby Business*, 16; Domar, Zuttermeister, and Friedman, "The Psychological Impact of Infertility," 45-52.

## Disclosure to Children

Mental health professionals agree that disclosure of their origins to children is healthiest for the children. $^{554}$ 

It's absolutely indisputable that children need to know the truth of their genetic origins.... Doctors everywhere are still sometimes saying, 'This can be your secret and nobody ever has to know.' That concerns me deeply. (Mental Health Professional)

Another mental health professional clarifies that keeping the child's origins a secret fosters shame within the family:

If it were my child, I would tell them, absolutely. I think that by not telling your child, you provide a sense of shame when they do find out. Why wouldn't you tell them? I always encourage parents, if they're going to tell them, make it part of your story from the very beginning. (Mental Health Professional)

The vast majority of my interviewees believed that intended parents should disclose to their children their means of conception. Over eighty percent thought that with very few exceptions, intended parents should disclose, and ninety percent thought that they should at least have the choice. The primary reasons agency decision-makers gave for their support of disclosure was that it was in the child's benefit—that the child had a right to know and/or that any sense of secrecy or shame within the family would be damaging to the child. Only one interviewee, surprisingly, mentioned medical reasons as important for disclosure, and a few felt that disclosure was the only reasonable option because such a secret would be impossible to keep, given the genetic testing technology available to the layperson today.

Some agency decision-makers based their opinion about disclosure on the research of the mental health profession.

I went to one of the presentations [at RESOLVE] by one of the psychologists who'd done a study, and the kids were fine with knowing. She said—the psychologist said, 'Practice with the child as a baby, because it's up to the parents with how comfortable they are with this information to disclose to the child.' ... And it's also

<sup>&</sup>lt;sup>554</sup> Per my mental health professional interviewees, who agreed that there exists consensus in the field that disclosure is best, except for the case of unusual circumstances, such as cultural taboos.

been researched with adoption and, I think, sperm donation, that children who were not told, and discovered, late in life, or were told as adults that they were adopted or came from a sperm donor, those are the children who felt deceived. (Director, Northern California Agency)

I think the consensus among assisted reproduction and adoption as a whole is the more information and knowledge and willingness for people to be open, the better, because it is the child's—it really is. The thought is for the child down the road. (Director, Southern California Agency)

Agency decision-makers were, as a general rule, concerned with the potential damage to children who find out the truth of their conception as adults.

I think they have the right to know, as long as it's done in a healthy way from the very beginning, if it's not something that could be detrimental to the child at all. I think it would be more detrimental if the child was not fully informed, or talked about, and then they find out [when] they're majority or older. I think that would cause more damage. (Director, Southern California Agency)

I would say if it's [disclosure is] done from the very beginning, it's probably the most healthy. I think telling a kid when they're ten, all of a sudden, it's probably not. (Director, Southern Agency)

The general consensus among agency decision-makers seemed to be that telling a child earlier was better:

They [intended parents] have to be respectful of the fact that it is their child's story. And if it's introduced to them at a very young age, at least theory has it, that it's always part of their story, it's always part of their child's life. It's not something that is ever a big, like, 'Oh my gosh, really?' (Director, Northern California Agency)

Some agency decision-makers felt strongly that a child has a right to know their origins, and that not telling them demeans what is otherwise a positive narrative:

And it's not only important for medical reasons, but that's a huge factor. It's also just, I think everyone has a right to their own birth story. And to keep it private, just so you don't have the embarrassment of not being able to procreate on your own without the help of a donor is, I think, really diminishing the birth story itself. (Director, Northern California Agency)

A Southern agency director thought that most intended parents failed to take advantage of the positive aspects of their children's stories.

I was reading an article the other day, and it was just about how you say, 'Yeah, Mommy and Daddy, we weren't able to have a baby on our own, so there was this nice lady that helped us, and you were still in Mommy's tummy,' and that sort of thing.... But I would not say that that's how the vast majority of intended parents do it. (Director, Southern Agency)

Similarly, other agency decision-makers emphasized that telling the child about their origins is a positive story, and being open dispels shame that might attach if the intended parents are secretive about it.

My personal believe, in general, is that openness gives less of a sense of shame or issue with the subject. (Director, Southern California Agency)

Or, as another Southern California agency director put it,

I think it's wonderful to let your child know where they came from. I think if you tell your child, there's not a problem. (Director, Southern California Agency)

A Southern agency director was concerned that keeping the secret of a donor-conceived child's origins was not only damaging to the child, but to the parents as well:

I do think it's important for the parents to have a sense of peace. I think when the parents are in a peaceful place about it, they can help a child feel peaceful about it.... When watching a family who has chosen to not disclose to their children, and who is almost to the point of paranoid, keeping the secret, I don't think it's healthy. I think it takes too much energy from the parents. (Director, Southern Agency) One agency director asserted that keeping a child's origins secret made those origins shameful, and that given the alternative—telling the child that he was conceived in love —there was no question whether intended parents should disclose:

I think that you should tell your children from the very age that they can understand the concept—even if they can't understand the concept. I really think that open honesty is so important. When you hide things ... children, the instinct that they will get, I believe, is you're hiding them for a reason. It's shameful. It's taboo. There's something wrong. And when you do that, you've created this story that is their identity. There's something wrong, so that's why I didn't tell you. And if they find out later on, it's devastating. It's an identity crisis.... I feel like you have a blank slate, and you get to paint this picture any which way you want, and whatever way you paint it, that's going to be the right way. This is their identity.... 'Mommy and Daddy had so much love, but Mommy couldn't have the baby because she was too old, and so then she got the help of a donor. Because of that, Mommy and Daddy now have you, and you were made from love.' As opposed to a more shameful face that the story could take on. (Director, Southern California Agency)

Some agency decision-makers were simply uncomfortable with the idea of keeping such a thing secret:

I personally very much believe in telling your child the truth, and not having it secret. (Director, Southern California Agency)

Others felt that keeping donor-conceived children's origins was literally impossible, given the relative ease of casual genetic testing.

She [intended parent] acts like her kids are never going to figure it out and all I think is, you're out of your mind. (Director, Southern Agency)

And when asked whether intended parents should disclose to their children, a Midwestern agency director said,

Oh! Without a doubt! Absolutely! Absolutely, and anybody that thinks they're hiding it, that is crazy. Now that's crazy. I mean, you can just see on TV, you can swab your cheek and send it into Ancestry.com and learn where you're from. You get into an eighth grade science class, you can prick your finger and find out all kinds of information. Anybody that thinks they're going to keep this under a cloak of secrecy is ... really in another world. (Director, Midwestern Agency)

A genetic counselor agreed with this assessment:

I've always said that you never know when somebody's going to be doing a genetic experiment in school in the next couple of years, or does some kind of recreational genetic testing that's coming on the market, and find out the relationship is not what you've been telling them it is. (Genetic Counselor)

Because the keeping of the secret of donor-conceived children's origins is impossible, discovery, disruption, shame, and crisis will inevitably follow, according to this view.

Only one agency decision-maker thought that it was unnecessary or undesirable for intended parents to disclose to their children.

If you tell kids, and they're too young, I don't think it's necessary to tell them before they're eighteen. If you tell them at all. (Director, Southern California Agency)

Yet she recognized that her opinion was at odds with the consensus of the mental health profession:

But the psychologists believe you should tell them, so. (Director, Southern California Agency)

Some agency decision-makers who believed wholeheartedly in disclosure nonetheless supported a parent's right to choose not to disclose. Sometimes they still tried indirectly to change the mind of intended parents:

I have a lot of intended parents who want to go with the exact same blood type [in their egg donor] or whatever, just so that they can make sure and keep it a secret. And I certainly don't stop them from working with me, and I don't express my—what I hate to say is, but really is, judgments on it. I think it's not a very nice thing to do to a child.... I don't make it very clear, but I do let them know who I refer people to talk to about it, in hopes that I can kind of change their mind without necessarily bringing it up with them. (Director, Northern California Agency)

Several agency decision-makers were more forthright about supporting an intended parent's choice not to disclose, even when they thought it was the wrong decision:

I do also believe in parents' rights, that it's their decision to make. (Director, Southern California Agency)

I make it a really big point that I don't judge people's perspective. I tell them what I think if they ask me, but I will not push my views and my values onto other people, because I don't feel that's my position. (Director, Southern California Agency)

Whatever the parents decide, I completely support. It's up to them. (Director, Southern California Agency)

My feeling about it is that no one on this planet should ever tell a family what's right and wrong in terms of the answer to that question [whether to disclose]. I think each family's unique. I think every family has the right to make that decision on their own. (Director, Southern Agency)

A couple of agency decision-makers felt that some mental health professionals were too aggressive in their belief in disclosure, to the detriment of intended parents' choice.

There are therapists out there who really get very angry and very vehement with couples, that they must disclose, and I don't think we have a right to do that. (Director, Southern California Agency)

There are quite a few of these mental health professionals who are passionate to the point of like craziness about 'you must disclose, there's only one answer.' (Director, Southern Agency)

And a few agency decision-makers believed that intended parents should disclose unless there were specific circumstances which made disclosure a poor idea. Most commonly, they noted that in some cultures, egg donation is socially unacceptable, but that that can be the case within a particular family as well.

There are cultures where sometimes it just can't be done. (Director, Southern California Agency)

I don't think it should be a requirement [to disclose] because I think in some cultures that's much more challenging ... it's not just cultures, either. It might be someone's particular family won't be accepting or open about it, and it can actually become detrimental. (Director, Southern California Agency)

A Northern California agency director spoke about one culture in particular:

There are exceptions, there are certain cultures where it just wouldn't be something that they could do. Because their culture would ostracize the child or the family, and I can understand ... that happens quite a bit, like my Chinese clients, that definitely can be the case. (Director, Northern California Agency)

A mental health professional agreed with these assessments of exceptions to the rule. Though a supporter of disclosure, she recognized both that sometimes it would be a bad idea, and that intended parents should have the final choice in the matter. In her sessions with intended parents, she asks them,

> 'Why wouldn't you tell other people?' And then there are often issues of shame and embarrassment or cultural issues. In a lot of cultures it [egg donation] is not acceptable. I think the most important thing is everybody's on the same page, but I'm not big on keeping secrets, so I guess if you ask me what I would do, I would encourage people to talk, but at the same time, they might not want to, and you have to respect that. (Mental Health Professional)

By encouraging intended parents to disclose the means of their children's conception to their children, agency decision-makers are trying to prevent damage to children, their parents, and the family as a whole.<sup>555</sup> In their view, greater transparency with regard to these children's conception would necessarily mean less secrecy, and less shame. And less shame among the families that participate in egg donation would mean less shame surrounding the industry as a whole. Even so, agency decision-makers remain sensitive to intended parents' preferences and circumstances, and for the most part, respect their

<sup>&</sup>lt;sup>555</sup> In doing so, agency decision-makers are following the leading mental health literature. See, e.g., Blake et al., "'Daddy Ran Out of Tadpoles;'" Daniels and Thorn, "Sharing Information with Donor Insemination Offspring;" Jadva et al., "Adolescents and Adults Conceived by Sperm Donation;" Mahlstedt, LaBounty, and Kennedy, "The Views of Adult Offspring of Sperm Donation;" Paul and Berger, "Topic Avoidance and Family Functioning;" Scheib, Riordan, and Rubin, "Adolescents with Open-Identity Sperm Donors."

choice about whether to disclose, even pointing out some situations in which disclosure would be more harmful than helpful.

### Contact between Intended Parents and Donors

A secondary way in which a few agency decision-makers attempt to subvert the shame surrounding their field is by encouraging contact between intended parents and donors, typically in the form of a phone call, Skype session, or semi-anonymous meeting (in which the parties meet in person by do not exchange identifying information). Over half of my interviewees encourage their intended parents and donors to meet one another, and ninety percent of the agency decision-makers with whom I spoke believed that such meetings should at least be an option available to people participating in egg donor IVF.

One agency decision-maker felt that such meetings can effectively dispel feelings of shame and embarrassment for the participating parties:

I'm all for people meeting and—you know, whatever their comfort level is, we'll act as the intermediary. I think it is good. I think the more you try and close this off and restrict it and keep it secret, it just sort of has a whiff that something is wrong. Not that I don't believe that everybody has a right to privacy; certainly it's their story to tell, but it shouldn't be—it shouldn't be to the degree that it starts to make it feel like everybody is doing something wrong. I'm a big believer in it [disclosure]. (Director, Midwestern Agency)

Another agency decision-maker thought that because such meetings take place in the context of a positive purpose, they can't help but have a positive influence on intended parent and donor alike:

I think it is because I think ... egg donation, I think it's a wonderful thing. It's a way we help each other and help build families. (Director, Southern California Agency)

Although agency decision-makers more often spoke of contact, as discussed in the previous chapter, as a means of ensuring that intended parents and donors feel good about cycling, and that donor-conceived children can reach their donors in case of medical necessity, a few saw it as a means of dissipating the stigma associated with participating in egg donation. If intended parents and egg donors all feel comfortable

with their participation, purposeful and open, then that attitude may spread within the industry, dispelling any shame associated with it, and thus bolstering the legitimacy of egg donor agencies as a whole.

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Agencies respond to the pressures exerted on them by the media, society, intended parents, and other, unethical agencies in a variety of ways.<sup>556</sup> Agency decision-makers seek to buttress the legitimacy of their business by emphasizing their own agency's transparency and ethical business practices. They strive to share in the legitimacy of the well established profession of medicine, riding its coattails via deferral to clinic norms and professional organization standards, mediating between intended parents and "bad apple" clinics, and developing and maintaining positive working relationships with a variety of clinics. Agency decision-makers also strengthen their claim to legitimacy by using their websites to demonstrate to the public and to prospective intended parents their secure place in the world of ethical egg donation; they post badges of nonprofit egg donor and infertility support organizations and claim affiliation with field professionals such as nurses, mental health professionals, genetic counselors, and attorneys. Finally, agency decision-makers tackle the problem of legitimacy from within, by attempting to subvert the shame that is often associated with egg donation; they encourage intended parents to disclose their children's origins, avoiding secrecy and potential future damage to the child and the family, and making a positive narrative of it, and, less often, they encourage contact between intended parents and donors to dispel any shame between the parties.<sup>557</sup>

All of these business practices are ways in which egg donor agencies, located in an uncertain, unregulated environment, endeavor to secure their place as ethical and legitimate players in the field of egg donation, among their more regulated, professional colleagues. The main way in which egg donor agency decision-makers are attempting to establish their legitimacy, however, is through an effort at self-regulation. They are beginning to professionalize.

<sup>&</sup>lt;sup>556</sup> For institutional isomorphisms, see DiMaggio and Powell, "The Iron Cage Revisited." For an account of how hybrid organizations manage conflicting institutional logics, see Pache and Santos, "Inside the Hybrid Organization." For an account of how professions affect organizations, see Scott, "Lords of the Dance." For accounts of how individual agency shapes organizational responses to outside pressures, see Binder, "For Love and Money," and Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*.

<sup>&</sup>lt;sup>557</sup> Per mental health profession suggestions; see note 554.

### The Project of Professionalization

Professionalization is the process by which an occupation transforms itself into a profession, demarcating itself and its skills from amateurs.<sup>558</sup> Typically, this involves the establishment of qualifications to enter the profession, a professional body to govern it, and a code of conduct or group norms for its members.<sup>559</sup> Normative isomorphism can occur in the context of professionalization, as the professional norms are spread and accepted among the organizations they purport to govern.<sup>560</sup> Professionalization is concerned generally with the appearance of the field to outsiders, but more specifically with gaining control of their field before it is regulated by outside sources.

More than a third of my interviewees expressed their desire to avoid legal regulation of egg donor agencies, not out of fear of regulation in and of itself, but rather that regulation created by the "wrong" people, legislators or others who either don't understand or are unsympathetic to the field, would have unintended negative consequences.

To be honest, I don't have a specific fear like, 'oh, they're going to come in a require agencies or clinics or anything like that. I just have a fear that they will require—somebody who doesn't know the industry will create laws that are not applicable or will make it impossible for us to function. (Director, Southern California Agency)

I am not afraid of regulation, because I think a little regulation you need rules. As the masses, we just need rules or it's chaos. So I am not afraid of rules. I'm just afraid of rules being created by the wrong individuals, like [Jennifer Lahl, creator of the documentary *Eggsploitation*]. (Director, Southern California Agency)

Even when created with the best intentions in mind, such regulations could have negative consequences, according to this agency decision-maker:

Bad regulations are harmful, and every good intention could end up as a bad regulation, if you know what I mean. (Director, Southern California Agency)

<sup>&</sup>lt;sup>558</sup> Larson, *The Rise of Professionalism*, 49-52.

<sup>&</sup>lt;sup>559</sup> Ibid.; Scott, "Lords of the Dance."

<sup>&</sup>lt;sup>560</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-75; Larson, The Rise of Professionalism, 49-52.

Only a couple of interviewees thought that some sort of regulation was completely unnecessary:

I'd like to see any regulation avoided. I feel like things are going pretty well right now. (Director, Northern California Agency)

I think that the industry runs smoothly in most circumstances. And when I say most, I'm talking ninety-five percent of the circumstances.... I think overall, the industry really does the best they can do. I think they put into place things like the mental health evaluation, the legal contract, in order to have multidisciplinary professional evaluate donors ... over the course of time.... So the whole onus doesn't fall on the doctor, for example. (Director, Midwestern Agency)

Several of my interviewees expressed their specific desire that they would have egg donor agencies regulate themselves, in order to ensure ethical practices within the field, and in order to forestall legislative action by the wrong people.

We don't want regulation to happen in our industry. Well, mandates made by people who don't know the industry. So, in theory, that [regulation] sounds good, but in practicality it doesn't work. So we don't—so we're trying to self regulate before that happens. (Director, Southern California Agency)

I would love to make sure that we're not regulated outside of the agencies or outside of the company, I guess if you will, like for the FDA to come in and say, 'OK, you now have to do this or this or that,' without really understanding the business. So we obviously would love to be self-regulated and not have to worry about that in the future. (Director, Southern California Agency)

As a family formation attorney stated:

We're aware of the need [for regulation], and I think we'd be better to make the suggestion and be self regulated than to have some disaster or horror story show up and then have somebody creating emergency legislation, or special legislation that isn't well thought out. (Family Formation Attorney) The Assisted Reproductive Technologies Committee in the American Bar Association's Section of Family Law has suggested just such legislation: The ABA Model Act Governing Assisted Reproductive Technology Agencies, which is still in draft form (yet to be approved by the Family Law Section or the larger ABA) as of summer 2014.<sup>561</sup> And in fact, several agencies have collaborated to make a start at self regulation in the guise of an organization called SEEDS, the Society for Ethics in Egg Donation and Surrogacy:<sup>562</sup>

> We formed ... the organization [SEEDS]. And it was in response to some of the lawsuits and things like that that were happening just in the industry with Theresa Erickson and other stuff like that, and kind of just wanting to make sure that we were not—that if there was regulation coming down the line, that we could help kind of guide and direct it so that it wouldn't be as limiting, and also just kind of to demonstrate the fact that we are doing it ourselves, so please don't mess with us type of thing. (Director, Southern California Agency)

This attempt at self-regulation is currently in process, though it is early stages still. Nonetheless, it encompasses the standard elements of professionalization: 1) entry qualifications, 2) professional body, and 3) code of conduct.<sup>563</sup>

# Entry Qualifications

In a settled profession, the members have established criteria with which one (or, in this case, one's agency) must comply in order to be admitted to the profession.<sup>564</sup> Since the attempt to professionalize egg donor agencies is still nascent, agency decision-makers criticized the complete lack of qualifications for egg donor agencies or people starting them. Half of my interviewees felt that some type of agency licensing should be instituted as a measure to protect the industry and its participants against the unethical, criminal, or simply ignorant behavior of the few. The draft ABA Model Act Governing ART Agencies contains detailed provisions for agency licensing, starting with this

<sup>&</sup>lt;sup>561</sup> See the full text of the ABA Model Act Governing ART Agencies (*DRAFT*) in Appendix IV.

<sup>&</sup>lt;sup>562</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>563</sup> Larson, The Rise of Professionalism, 49-52.

<sup>&</sup>lt;sup>564</sup> Ibid.

requirement: "ART Agencies must be licensed under this Act to operate in this state,"<sup>565</sup> and covering everything from applying for a license to disciplinary action.<sup>566</sup>

Several agency decision-makers criticized the lack of required qualifications for entry into the field as an egg donor agency. They mentioned their own business or medical qualifications and lamented that such qualifications were not requirements, and that instead, many people seemed to think that having been an egg donor or an intended parent qualified one to run an agency:

> At this point, you don't even have to have a business license to become an agency. You could just stand outside and say, 'I'm an agency, and I've created a website, and this is my agency.' So that to me is problematic. You don't have the experience to know what to do or how to do things, and then you make mistakes. (Director, Southern California Agency)

> I think it's better for me to be situated as a business person than a previous egg donor, who decides—there are people doing this out of their garage, OK? So there's no staff, with no knowledge, with no college. (Director, Southern California Agency)

I do trust that if somebody had a medical background, they would certainly approach it [running an egg donor agency] with a different set of eyes, and I would hope, I would hope. (Director, Southern Agency)

One Midwestern agency director deals with the problem of qualifications by employing a number of professionals from related fields:

I make sure that this agency is stocked with people with a lot of skill and talent that can handle the process. (Director, Midwestern Agency)

Another agency decision-maker was appalled at the number of agencies in existence, and of those, the number that were created by previous donors or infertility patients:

You know that every five minutes there's someone new telling you that they've started an agency because they went through it

<sup>&</sup>lt;sup>565</sup> ABA Model Act Governing ART Agencies (DRAFT) § 301.1.

<sup>&</sup>lt;sup>566</sup> Ibid., §§ 201-202.

themselves. How many agencies are out there? (Director, Southern Agency)

It's not as if people who open agencies after participating in the industry as donors or intended parents do so with malice, according to a Midwestern agency director, but that such agency owners often don't know enough to provide quality, secure service to their clients:

Someone who's like, 'I built my family, too, through egg donation, and I can run an agency better than you.' There is a lot of that out there, and again, it's not as if they're not well intentioned. I believe that they are, but ... there is really nothing for the intended parents out there as a safeguard. (Director, Midwestern Agency)

The draft ABA Model Act Governing ART Agencies contains a provision for continuing education of agency owners, to consist of such "topics as ethics, communicable diseases, FDA screening, financial responsibility, psycho-social aspects of assisted reproduction, reproductive medicine/biology and reproductive law or other relevant topics." <sup>567</sup> While this provision does not address qualifications to become an egg donor agency owner, it does address the problem of educating people who are already running agencies, giving them a resource for dealing with tough ethical issues, among other concerns, and facilitating communication—and the transfer of group norms—among agencies.<sup>568</sup>

Half of my interviewees felt that agency licensing would be an appropriate way to regulate entry into the industry. Licensing would, in theory at least, ensure some minimum level of competence, prevent entry by unethical players, and provide a touchpoint for agencies to reference to assert their legitimacy.

Absolutely, I think that you should be required to have a license.... In order to become a[n] ... agency, I think you should have to have proven what your background is, what your qualifications are, how many cases you've done, all that sort of thing. I think ... there should be some sort of central registrar, where if there's been any complaints ... I wish there were, because I think it would get rid of a lot of the crap in the industry. (Director, Northeastern Agency)

<sup>&</sup>lt;sup>567</sup> Ibid., § 306.2.

<sup>&</sup>lt;sup>568</sup> An example of normative isomorphism. DiMaggio and Powell, "The Iron Cage Revisited," 69-75; see also Larson, *The Rise of Professionalism*, 49-52; and Scott, "Lords of the Dance."

If you don't have an enforcing body, people tend to push the line. And sometimes greed takes over, and ethical issues kind of take a back seat. So I'd want to see some sort of agency enforcing body, where you have to apply or get a license or something to that effect. (Director, Southern California Agency)

Some agency decision-makers were more general in their support of agency licensing:

I wish there was a way to license agencies on some level. (Director, Southern California Agency)

Or not quite as enthusiastic, but still supportive of the idea:

I don't know that it would be horrible if they [agencies] were licensed. (Director, Southern Agency)

One agency decision-maker thought that licensing should target all agency employees:

I would like to see, for instance, some sort of licensure for the professionals that run the agencies or work within the agencies. (Director, Midwestern Agency)

And another desired agency licensing chiefly as a means of protecting intended parents from those who would exploit them:

I would want agencies to have some—even though it would be more work for us—to have some regulatory body that we'd have to be licensed from, or something that would allow agencies to ... protect intended parents. (Director, Southern California Agency)

A couple of agency decision-makers explicitly stated professionalization goals when discussing licensing; one desired greater standardization of group norms:

I don't even know if this is possible, I don't know enough about the law—but [for] it to be more standard in the field across each state, rather than each individual [agency owner] making their own decisions. (Director, Southern Agency)

And another mentioned limiting access to the industry:

I guess it's good to have licensing, because it's going to stop people from doing some [bad] things, or you can maybe keep people out of the business. (Director, Southern California Agency)

Only one interviewee stated an express preference against licensing, but only because she felt it would be insufficient to address the needs of the industry:

I have a hard time with licensing.... I think about them [the state] giving drivers licenses to old people without requiring road tests after the age of seventy or seventy-five, or even letting my eighty-[something] father drive. So that's why I think licensing is not the answer. You have to think through it like you're doing. So it's not necessarily creating the license, it's just trying to create the reasonable aura of something. (Director, Southern California Agency)

Other agency decision-makers were leery of licensing, but their concerns stemmed from the idea that such licensing would necessarily derive from the state, as opposed to a self-regulating professional body:

Should agencies be licensed? Absolutely. Absolutely. I mean, this is not a do-it-out-of-your-garage business. I kind of take personal offense to that. Should they be licensed? They should be licensed. Should there be minimum standards? There should be minimum standards. On the other hand, as you and I know, creating government bureaucracies doesn't necessarily mitigate issues or problems. If anything, it makes them worse. (Director, Southern California Agency)

That agency decision-maker was not the only one who mistrusted the state:

If everybody practiced like me, that would be great! I would welcome some type of licensure or regulation. However, I'm skeptical of a lot of governmental interference into things. Every time they meddle, they don't seem to do a good job, and the policy makers and those wonks don't really understand my industry, so why should they be involved in the legislature? However, because what we're doing is very emotionally taxing and financially taxing on behalf of the intended parents, I think that there are no protections for them when they go out into the marketplace, because anybody could hang a shingle and open an agency. (Director, Midwestern Agency)

Several of my interviewees criticized the lack of qualification criteria for entry into the industry as an egg donor agency, and half of the agency decision-makers with whom I spoke supported some sort of agency licensing. The establishment of qualification criteria is one step in the process of professionalization, and licensing would function as a means of demarcating "professional" egg donor agencies from amateur ones, thus establishing their legitimacy.<sup>569</sup> Of course, in order to have licensing requirements, a professional body is necessary to establish and administer those requirements.

#### **Professional Body**

The second element of the professionalization process is the establishment of a professional body.<sup>570</sup> In 2012, a collaboration of four egg donor and surrogacy agencies in California created the beginnings of just such a body, which they named SEEDS, or the Society for Ethics in Egg Donation and Surrogacy.<sup>571</sup> SEEDS does not describe its purpose as the creation of a professional body, but rather the creation of standards for egg donor and surrogacy agencies—which is, of course, an element of professionalization.<sup>572</sup> They do not, however, propose to establish criteria for entry into the industry. SEEDS is trying to preempt regulation that might be imposed on them by legislators and organizations who don't understand what agencies do, and they are also trying to involve other agencies throughout California and beyond in an attempt to achieve a consensus on standards for agency practices.

The ART Committee of the Section of Family Law of the ABA is engaged in a similar project, that of creating standards for egg donor and surrogacy agencies, in the form of model legislation (the draft ABA Model Act Governing Assisted Reproductive Technology Agencies).<sup>573</sup> The draft Model Act has been approved by the ART Committee and will now begin making its way up through the ABA hierarchy. It might be adopted by the ABA within the next one or two years, at which point it can serve as model legislation for states interested in regulating agencies. There is communication

<sup>&</sup>lt;sup>569</sup> Larson, The Rise of Professionalism, 49-52.

<sup>570</sup> Ibid.

<sup>&</sup>lt;sup>571</sup> See Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>572</sup> See Larson, *The Rise of Professionalism*, 49-52.

<sup>&</sup>lt;sup>573</sup> See Appendix IV for the full text of the ABA Model Act Governing ART Agencies (DRAFT).

between agency decision-makers and family formation attorneys who serve on the ART Committee, as evidenced by the legal advisors of SEEDS, and their participation in the first SEEDS conference in April 2014.<sup>574</sup> While the ABA Model Act is simply that: proposed legislation, to be adopted in whole or in part—or not—by each state's preference, it, like the SEEDS standards, is also an attempt to preempt legislation by the "wrong people" by giving them pre-made legislation with which to work. The SEEDS standards are meant to be synergistic with the draft ABA Model Act.

SEEDS's purpose, as stated on their blog:

SEEDS was created by owners of egg donation and surrogacy agencies to define and classify a set of standards that are intended to apply to all such agencies in the United States. SEEDS will not have legislative authority, only advisory status. It is, however, the intention of SEEDS's founding members to expand the organization in size and outreach to the point that SEEDS's recommendations will have a major influence and impact on future egg donation and surrogacy legislation.

SEEDS's goal is to raise the standards by which agencies carry out their work in order to transcend any negative impressions that may have developed from the poor practices of a small number of agencies. Our intention is to reassure potential donors, their families, intended parents and the general public that egg donation and surrogacy can be safe, ethical options for all parties involved to overcome the problem of infertility.<sup>575</sup>

One of the two primary bases for the creation of SEEDS is the preemption of perhaps well intentioned, but ultimately harmful regulation that the SEEDS founders fear will be created in response to the scandals within the industry.

We feel like there's a big need in the industry to regulate before the FDA comes in and tries to regulate. We want to kind of self regulate to keep that from happening. (Director, Southern California Agency)

<sup>&</sup>lt;sup>574</sup> Attorney speakers at the 2014 SEEDS conference included Amy Demma, Greg Masler, Steven Lazarus, and Deborah Forman.

<sup>&</sup>lt;sup>575</sup> "Welcome to the Official Blog for the Surrogacy and Egg Donation Ethical Society (SEEDS)," (blog) posted April 17, 2012, eggdonationethics.wordpress.com/page/2/; Internet; Accessed 29 July 2014.

Even agencies that try to do the right thing can sometimes be stymied:

The legitimate practices that have been around for several years, there's always questionable business practices. Would we do that or would we not do that and how an agency is run, but we try to have the highest ethical standards. (Director, Southern California Agency)

But the founders of SEEDS believed that creating a set of standards, for which there is consensus among agencies, would relieve both the threat of regulation and some of the ethical dilemmas in which agencies find themselves:

So that we can, to a certain degree, self regulate and say, 'this is why I'm not agreeing with this particular decision,' and so on and so forth. (Director, Southern California Agency)

SEEDS was also founded in order to create standards of practice for egg donor and surrogacy agencies. The ASRM provides that service for the medical side of egg donation (and reproductive technology in general), and while some of their guidelines are non-medical in nature, such as the cap on donor compensation, the ASRM guidelines fail to address many issues encountered only by agencies.<sup>576</sup> Additionally, agencies have little say in the creation of ASRM guidelines.<sup>577</sup>

The thing is that there's not really an organization that does it [creates guidelines] for agencies specifically. I mean, ASRM kind of does it as a 'oh, and by the way, we understand there's agencies and here's a general list [of guidelines].' But it's not done on the same level. (Director, Northern California Agency)

The purpose of the standards themselves is to ensure that agencies behave ethically, and have a resource to turn to in order to determine what, exactly, ethical behavior is:

[SEEDS] actually deals with all the ethical kind of issues behind egg donation and surrogacy, just to make sure, as an industry, that we're moving in the right direction and doing the right thing. (Director, Northern California Agency)

<sup>&</sup>lt;sup>576</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

<sup>&</sup>lt;sup>577</sup> ASRM guidelines are developed through a committee process. The most relevant committees for egg donation are the Practice Committee and the Ethics Committee. ASRM website, www.asrm.org.

As one Southern California agency director notes, the SEEDS standards are meant to be best practices guidelines, on which agencies may safely model their business practices, but which also serve as a reference point for intended parents and donors, both to rein in some of their own more outrageous behaviors, but also to ensure that they get the best, most ethical service possible:

> But the intention in our ethics organization is not to change or even modify ASRM, it's actually to suggest standards or principles or a basis for the highest care that you can possibly give to donors and intended parents in this industry, that are really more applicable to agencies as a whole, but not something that the ASRM really wants to get involved in.... If an agency wants to operate at the highest possible standard of care, then they can go to these suggested principles and work with them.... And if we're all integrated and we all agree on this, then we're not telling people they're laws, it's just, this is the highest standard of care. Intended parents are now going to be educated on the SEEDS principles and they're going to expect that high standard of care. So it benefits agencies as well, so you don't have the intended parent saying, 'Well, my doctor said my donor only needed the MMPI and that's \$175 and if she meets with a therapist in person, then it's \$400. And why are you charging me this extra \$400?' And if it becomes the highest standard of care, then the intended parents even stop asking, because they don't feel like it's just another thing that you're trying to get money from. (Director, Southern California Agency)

In order to spread the word of their mission, SEEDS is currently in the process of trying to get agencies across the nation on board with their proposed standards, and to that end they held their first conference in Costa Mesa in April 2014.<sup>578</sup> The purpose of the conference, according to my interviewees, was to spread the word about SEEDS, to try to get other agencies to cooperate with the project of self-regulation, and to incorporate the viewpoints of other agencies in the process. Ultimately, SEEDS would like to build a consensus about the standards to which egg donor agencies should aspire.<sup>579</sup> During the time that I was conducting interviews, in January through March 2014, SEEDS began advertising widely among egg donor and surrogacy agencies, letting people know

<sup>&</sup>lt;sup>578</sup> SEEDS conference website, www.seedsethics.org/events.html.

<sup>&</sup>lt;sup>579</sup> "Our goal is to reach a wide audience of agencies and hear their opinion about industry standards. Ideally, we'll come to a group-wide agreement on the standards we create." SEEDS, "About," www.seedsethics.org/about.html; Internet; Accessed 29 July 2014.

about the organization's existence and its mission, and inviting them to participate in the conference. A number of people whom I had previously interviewed contacted me after they received their SEEDS conference invitations to let me know about the organization, since it seemed to them to be so relevant to my research. The conference was almost canceled due to low registration numbers, but ultimately went forward and enjoyed good attendance.<sup>580</sup>

The SEEDS conference came into being in collaboration with an ethics conference, put on annually by the Mental Health Professional Group of the ASRM.<sup>581</sup> This is appropriate, since many of the issues faced by agencies—the problems for which the founders of SEEDS feel agencies need standards—are ethical ones.

Every year, there's an ethics conference [put on by mental health professionals], and we've [SEEDS has] combined forces with them. We just did that. Yeah, so it's a two-day conference. And it deals a lot with ethics, because we have a lot of mental health professional perspective on, like, egg banking and whether—how about HIV and sperm washing, that kind of stuff. Like it's just a lot of ethical questions that we're dealing with. Some we don't have answers to, and some of them are 'let's get a consensus of what we think is right or wrong and let's start holding ourselves accountable,' those types of conversations. (Director, Southern California Agency)

The conference served as the first gathering of agencies beyond those involved in SEEDS's founding, a place for as many agency owners as were willing to converse and begin the process of building a consensus on agency practices.

So that's why we're reaching out and trying to get other perspectives. To make sure that we are capturing the general consensus of the whole industry, rather than just four agencies. And, of course, we do speak with other agencies, and we talk to them about it, but I think in April [at the SEEDS conference], that's when we're going to make it more official because there'll be more agencies participating in the discussion of 'what do you feel is important in our industry.' (Director, Southern California Agency)

<sup>&</sup>lt;sup>580</sup> Per a conference attendee.

<sup>&</sup>lt;sup>581</sup> In previous years, the Mental Health Professional Group of the ASRM has hosted an ethics conference on its own. Mental Health Professional Group (MHPG), www.asrm.org/MHPG/.

The process of consensus-building continues on the SEEDS website, where the organization accepts feedback on their proposed standards.<sup>582</sup>

To prevent the impression that the founding members of SEEDS are attempting to railroad every other agency, the founders emphasize that they want the input of as many agencies as possible, and that the standards, if they are able to gain traction, will prove to be of benefit to agencies, intended parents, and donors alike:

> SEEDS is in the process of—we've created our own guidelines so far, but our conference is going to be in April [2014] and we're opening up to all the agencies in order to make sure that they feel that this is—we don't want to say, 'this is what agencies should do and who ordered us to be the gatekeepers of ethics?' That's not what we're trying to go for. What we want to do is open it up to our industry and get everyone's general consensus on what is good practice, so that way we can come up with a standards or a—well, we call them standards, but a gold standard for agencies to reach. Some people come into this industry based on personal experience and they say, 'Oh, I needed a donor, so I'm going to start an egg donor agency.' And they make a lot of mistakes. And so we want to make sure for those individuals that do that, they understand what is the minimum standard of care.... If you don't know, then at least there's a place where you can go and get guidelines of what's to be expected. (Director, Southern California Agency)

The Society for Ethics in Egg Donation and Surrogacy is a first, partial attempt at the establishment of a professional body for egg donor and surrogacy agencies. While their stated intent is not to professionalize the industry, their purpose is to create a code of conduct for industry members. All that is lacking, to create a profession, is entry criteria. At this time, however, SEEDS is an effort at the creation of a professional body and code of conduct, not a fait accompli. SEEDS's effort to build a consensus about standards for egg donor agencies is still in its early stages, and when interviewed, the majority of the agencies I spoke with have only informal ethical policies, often involving discussion among the employees of the agency.

<sup>&</sup>lt;sup>582</sup> See eggdonationethics.wordpress.com/; Internet; Accessed 16 July 2014.

### Code of Conduct

The final element in the process of professionalization is the development of a professional code of conduct, or set of group norms.<sup>583</sup> This code delineates appropriate and required behavior and business standards for professional members, and sets the profession apart from amateurs, who may or may not follow the standards in the code of conduct. In the context of SEEDS, or of the draft ABA Model Act Governing Reproductive Technology Agencies, agency decision-makers and others who work in the field are positioning themselves for regulation; they are attempting to define their practices in anticipation of the legislation they expect to result from the fallout of a future scandal involving an egg donor agency.<sup>584</sup> The development of industry standards by the industry may preempt regulation, but the draft Model Act would provide a template for such regulation if it were to transpire. There was general agreement among my interviewees that some kind of standards for the industry are necessary, even if they would prefer that those standards do not originate from government bodies:

Perhaps more than a licensing process, you need to have a standard of practice that's extremely strong and that everybody adheres to. (Director, Southern Agency)

I think that the agencies—I think because there are no rules and guidelines, everyone is kind of just making their own up as they go along. So maybe we just need more consistency. (Director, Southern California Agency)

<sup>&</sup>lt;sup>583</sup> Larson, *The Rise of Professionalism*, 49-52. See Scott, "Lords of the Dance," for a description of how professions devise prescriptive norms for organizational behavior.

<sup>&</sup>lt;sup>584</sup> See Appendices IV and III for the full text of the ABA Model Act Governing ART Agencies (*DRAFT*) and of SEEDS proposed standards.

# SEEDS Standards and DRAFT ABA Model Act Governing Reproductive Technology Agencies

While SEEDS does not define itself as a professional body, its mission is the creation of standards, very much like the code of conduct described by the professionalization process.<sup>585</sup> SEEDS's proposed standards include the following topics: <sup>586</sup>

1. Agency competition: how to handle donors who have registered with multiple agencies, not creating "bidding wars" between agencies for donors, and not "stealing" donors from other agencies;

2. The agency's responsibility to gauge the "emotional maturity and commitment of egg donors;"

3. Checklists for a standard agency agreements with donors and with intended parents;

4. Definitions of terms for known vs. anonymous egg donation arrangements;

5. What information agencies should be obligated to share with donors or intended parents that might affect the parties' decisions to move forward with a cycle;

6. Standards for recruitment advertising for egg donors;

7. Guidelines for psychological and genetic evaluation of donors; and

8. Standards about what medical information agencies should provide to donors about the risks of donation.

All of the above standards address the business practices and necessary decisions of agency owners, guiding them in what the SEEDS founders feel is an ethical direction, and seeking consistency among agencies. The SEEDS website states that the organization is in the process of developing further standards to augment the spread of ethical behavior, as well as building consensus over what the standards should be (as discussed in the previous section).<sup>587</sup> All of these goals are in keeping with the goals of a professional code of conduct.

<sup>&</sup>lt;sup>585</sup> Larson, The Rise of Professionalism, 49-52.

<sup>&</sup>lt;sup>586</sup> SEEDS Standards.

<sup>&</sup>lt;sup>587</sup> As noted previously: "Our goal is to reach a wide audience of agencies and hear their opinion about industry standards. Ideally, we'll come to a group-wide agreement on the standards we create." SEEDS, "About," www.seedsethics.org/about.html; Internet; Accessed 29 July 2014.

The ART industry is a small community, and, as evidenced by the presence of several attorney speakers at the April 2014 SEEDS conference, agencies are in communication with at least some attorneys on the ABA ART Committee.<sup>588</sup> Thus agencies have some input into the draft Model Act, which is supposed to work synergistically with the SEEDS standards. According to one attorney on the ABA ART Committee:

This document is specifically related to regulating agencies. And the agencies that are doing a good job are already complying with everything that we've suggested in this Model Act. So those who are doing a good job and following best practices won't find it onerous at all. But those agencies that are skipping steps and cutting corners and looking the other way, they're going to have—it could be something that will hopefully slow them down and keep them from doing those kinds of things. (Family Formation Attorney)

In addition to the licensing provisions discussed above in "Entry Requirements" (which in fact comprises the bulk of the document), the draft Model Act addressees such issues as the proper content and form of service agreements,<sup>589</sup> prerequisites for commencement of a cycle (including appropriate contracts, insurance, counseling, and payment provisions),<sup>590</sup> recordkeeping,<sup>591</sup> continuing education,<sup>592</sup> and requirements of escrow use, bonding, and professional liability insurance.<sup>593</sup> The draft Model Act also contains an article, customizable to a particular state's criminal code, to allow for enforcement of its provisions.<sup>594</sup> Additionally, the draft Model Act names five affirmative duties and obligations of agencies:

1. Provide Service to its Participants in a non-discriminatory manner....

- <sup>592</sup> Ibid., § 306.
- <sup>593</sup> Ibid., §§ 307-308.
- <sup>594</sup> Ibid., Art. 4.

<sup>&</sup>lt;sup>588</sup> Attorneys involved with SEEDS include Amy Demma, Greg Masler, Steven Lazarus, and Deborah Forman.

<sup>&</sup>lt;sup>589</sup> ABA Model Act Governing ART Agencies (DRAFT) § 303.

<sup>&</sup>lt;sup>590</sup> Ibid., § 304.

<sup>&</sup>lt;sup>591</sup> Ibid., § 305.

2. Respect the autonomy of Participants by not engaging in coercion, fraud, misrepresentation, or unethical behavior.

3. An ART Agency shall not provide legal, medical, psychological or other advice that it is not licensed or otherwise qualified to give.

4. Medical Errors committed by or known to an ART Agency or Operator shall be immediately reported to the affected Participant(s) in the assisted reproduction arrangement to enable them to decide on a course of action.

5. An ART Agency shall not present a Surrogate or Donor for matching to Intended Parent(s), that they reasonably know or should know is not qualified or unavailable.<sup>595</sup>

The provisions in the draft Model Act overlap with the SEEDS standards, but are not at all identical. Both sets of standards address the unlawful practice of medicine by agencies and the proper content of agency service agreements, and they both have guidelines about psychological consultation.<sup>596</sup> Reasonably, however, the draft Model Act has a legal bent and simply requires that intended parents and donors be advised to seek advice from a psychologist (as well as other third party professionals), where the SEEDS standard has a social-ethical perspective and includes details of what a psychological consultation should consist, and how long a donor's psychological evaluation remains valid.<sup>597</sup> This is generally true of the two sets of standards: the draft Model Act concerns itself primarily with legal issues such as documentation, logistics, and legal processes that can function to protect all the parties, but the SEEDS standards

<sup>&</sup>lt;sup>595</sup> Ibid., § 302.

<sup>&</sup>lt;sup>596</sup> Ibid., §§ 302.3, 303, & 304.1(f); and "Psych and Genetic Guidelines," SEEDS Standards.

<sup>&</sup>lt;sup>597</sup> "The Participants are informed to seek advice from medical, psychological, legal, and any other relevant third party professionals to discuss the potential risks and outcomes of the process." ABA Model Act Governing ART Agencies (*DRAFT*) § 304.1(f). Compare: "Psychological evaluations and donor education should include both a written test (such as the Minnesota Multiphasic Personality Inventory (MMPI), or Personality Assessment Inventory (PAI), along with a scheduled appointment with a licensed therapist. Ideally, psych evaluations should be completed in person. Written evaluations are considered outdated one year from date of test, while in-person evaluations are considered outdated after two years. Both written and in-person psych evaluations, however, should be redone after any life-altering events. These events include (but are not limited to) things like: marriage, birth of a child, death in the family, divorce, or loss of a job or home." "Psych and Genetic Guidelines," SEEDS Standards.

speak more to social issues, like the treatment of donors and intended parents, as well as proper inter-agency behavior.<sup>598</sup>

While the draft Model Act prohibits unethical behavior in its affirmative duties section, ethical behavior is the foundation of the SEEDS standards.<sup>599</sup> For example, the SEEDS standard "Agency's Responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors," names several "Emotional or Lifestyle Disqualifiers" for egg donor applicants:<sup>600</sup>

1. Donor's significant other and/or family member is not supportive of her choice to donate.

2. Donor has an inflexible work and/or school schedule that would cause her to fail a class or lose her job if she took time off.

3. Donor has a phobia of needles.

4. Donor does not feel comfortable having a genetic child in the world.

5. Donor would regret donation if she does not have her own children.

6. Donor does not feel she could emotionally handle hormonal changes.

These are social and emotional issues, appropriately addressed by an organization dedicated to guiding the ethical behavior of egg donor agencies—the organizations responsible for screening donors—but unlikely to appear in legislation further than a statement to the effect of "agencies should ensure that the donor is emotionally and situationally prepared to assume the responsibility of donating her eggs." The SEEDS standard goes into great detail, naming specific situations, such a phobias and social support networks, that are intensely private, but also critically important to the donor's

<sup>&</sup>lt;sup>598</sup> See Appendices IV and III for the full texts of the ABA Model Act Governing ART Agencies (*DRAFT*) and the SEEDS Standards.

<sup>&</sup>lt;sup>599</sup> The purpose of SEEDS is "to define and promote ethical behavior by all parties involved in third party reproduction." SEEDS, "About," www.seedsethics.org/about.html; Internet; Accessed 29 July 2014.

<sup>&</sup>lt;sup>600</sup> "Agency's Responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors," SEEDS Standards.

ability to follow through with a donor egg IVF cycle in a healthy manner.<sup>601</sup> The SEEDS standards are intended to represent best practices, a guide through the often complex ethical territory of egg donation. They are also a nascent attempt at standardization within the industry, and as such, possibly part of a new professionalization process.<sup>602</sup>

#### National Donor Registry

Outside of SEEDS and the draft ABA Model Act, there was one standard requested by my interviewees that was repeated over and over: the creation of a national egg donor registry.<sup>603</sup> While a national donor registry—and agency entries of their donors into it—it not in and of itself a directive for agency decision-maker behavior, it is an indirect code of conduct. The fact that most of the agency decision-makers with whom I spoke desire such an agency is an indication that agency decision-makers would like standards.<sup>604</sup> Participation in the registry is a means by which to comply with those standards, whether by simply entering one's donors into the registry, or using it to aid compliance with other standards, such as the ASRM limit on the number of cycles in which a donor can participate.

Seventy percent of my interviewees supported the concept of a national donor registry, although it would be a huge undertaking riddled with obstacles. Such a registry would function as a centralized source of information about donors: profiles, past cycle medical records, current contact information. While many of my interviewees thought that there are (likely insurmountable) obstacles to creating this type of registry (including intrusion into donor privacy, placing inappropriate ongoing obligations onto donors, possible HIPAA violations, and unwillingness of some physicians to share their proprietary medication protocols), they also thought that such a registry would be helpful to their work and the work of reproductive endocrinologists.<sup>605</sup>

<sup>601</sup> Ibid.

<sup>&</sup>lt;sup>602</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-75; Larson, The Rise of Professionalism, 49-52.

<sup>&</sup>lt;sup>603</sup> Such a registry does not exist currently, though provisions for a national registry are made in the ABA Model Act Governing ART § 1003(b)-(c).

<sup>&</sup>lt;sup>604</sup> And a mutual desire for common standards is one element of professionalization. DiMaggio and Powell, "The Iron Cage Revisited," 70-75. See also Larson, *The Rise of Professionalism*.

<sup>&</sup>lt;sup>605</sup> HIPAA is the national Health Insurance Portability and Accountability Act, Public Law 104-191, and agency decision-makers believe that its privacy provisions would prove problematic for a national egg donor registry.

Everybody would be so happy to be able to do that. And then that would also kind of track not having a donor donate again if she's had really bad cycles. Like how do we know about it sometimes? (Director, Southern California Agency)

So maybe it would be great if there could be—I don't know how it would work, but something where we can say, well, this donor has donated five times, or this donor we had to release because she had nicotine pop up in her system every single time, or she's not taking her medications correctly, or just something so we could all work together. (Director, Southern California Agency)

As a whole, the only thing I would love to see that I see is extremely broken in the system is there is no national database. (Director, Southern Agency)

I've always wondered if you could do it from an agency standpoint, if agencies—but then, of course, you've got clinics and that sort of thing involved in it, too. Some type of national pool that everybody can input their data, because I think it would make a big difference. I think it would help intended parents and I think it would regulate it a little bit more just to make sure that things are done a little bit better than they are right now. (Director, Southern Agency)

Several agency decision-makers, while supporting the concept of a national donor registry, couldn't see how it could be done:

I definitely think there should be some sort of registry out there. Tackling creating and managing that registry is certainly not a job I want.... It's an overwhelming task. The problem with it, too, is that it is so hard to maintain it over the course of ten, twenty years.... It's a lovely concept and it's definitely something that should be top of mind. I just think nobody can figure out how to maintain it and create it. (Director, Midwestern Agency)

This agency decision-maker couldn't stop naming the difficulties with a national donor registry:

So, essentially, the problem is HIPAA would make that almost impossible. Upkeep, assuming that the donors are giving all of the

appropriate information, and how the donor would be known on that registry ... for privacy reasons. So what that means is the donor having to be willing to sign up with that and then be willing in good faith to keep up her medical information and continue to sign her yearly HIPAA waivers.... And the fact of the matter is, even if you had a really good team on the back end that is able to follow up with the sheer number of donors that is going to be on there, and then a fraction of those are actually going to follow through with continuing giving the information.... People talk about what would have to happen in order to make it viable—not viable, feasible. How much man hours would have to be put into it, who would pay for it? Is this something that all the agencies would willingly come together and put in? Many of them would and many of them wouldn't, but everyone would want access. (Director, Southern California Agency)

Another agency decision-makers named some of the same concerns, and she also noted that donors could still avoid accountability the same way they do now:

You have so many people who would maybe fill out the information. Who is filling out the information? Who is the administrator? Are they getting the correct information? And if you want to be a serial donor, then you could sign up as different numbers, you know, because we're not all in a central database, so every agency has a different categorization of numbering donors.... I think it would be logistically a nightmare if it could be done. It would be great, because it would make things a lot easier, but ... from a legal standpoint and a liability standpoint, [there are too many obstacles]. (Director, Southern California Agency)

This agency decision-maker agreed:

I don't know, though, that if the donor really wants to donate twelve times, that she couldn't beat the system. She just doesn't produce the record. She doesn't give you her HIPAA release to get the record. And she says, 'I've only donated twice. Here's my last two donations.' Or, 'Here's my first two donations.' And who's going to call her out on it? Like there's no police force here who's following her 24/7. (Director, Midwestern Agency) The ABA Model Act Governing Assisted Reproductive Technology contains a section with guidelines for elements of a donor registry; they include provisions for disclosing non-identifying or identifying information, maintaining donor anonymity, updating information in the registry, and recordkeeping.<sup>606</sup> This last provision, that the registry should "Retain all records involving third party reproduction until the resulting child has reached the age of 40,"<sup>607</sup> speaks to the truly colossal nature of such a registry. Managing the records of donors until each of the children born from their donations has been alive for forty years would be a mind boggling task.

Some agency decision-makers liked the concept of a national donor registry, accessible only to those within the industry, with the thought that it would be highly functional and useful, but simultaneously felt it was a bad idea because it would require government regulation, and that, in turn, would significantly reduce the available pool of potential donors.

> The only way it would work if it became government mandate and regulation, which is the last thing that we want, because I think the intended parents get hurt more than anything else with increased regulation, because you simply lose your donor pool. Period. The more regulation. And once that starts, it kind of continues and goes and goes and goes. (Director, Southern California Agency)

Another agency decision-maker expressed a similar concern:

I'm not sure I want a mandate. I'm not sure I want a mandate. I think that could lose a lot of donors. (Director, Southern Agency)

But another agency decision-maker didn't expect that to be a problem:

The idea of having a registry for donors? I think they should have one. And I think that most donors would be fine with that. They've done it in other countries and they haven't had a drop in the number of women who choose to be donors. So I think it's a little silly. (Director, Northern California Agency)

Aside from the donor registry, there was no consensus on necessary standards for the industry among agency decision-makers. The primary sources of codes of conduct for

<sup>&</sup>lt;sup>606</sup> ABA Model Act Governing ART. Note distinction from the ABA Model Act Governing ART *Agencies* (*DRAFT*), discussed in the previous section.

<sup>&</sup>lt;sup>607</sup> ABA Model Act Governing ART § 1002.

egg donor agencies at the moment are the proposed SEEDS standards, the draft Model Act Governing ART Agencies, and, to a lesser extent, ongoing discussions about the institution of a national egg donor registry.<sup>608</sup> All of these potential standards, if they became standard practice, or the requirements of a new profession, would serve as guidelines for agency decision-makers in conducting their businesses in an ethical fashion. Whether in the context of professionalization or not, if such standards were to enjoy a consensus, and a majority following, they would also serve as a source of legitimacy for agencies working in an otherwise unregulated environment.<sup>609</sup>

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The most assertive grasp at legitimacy by organizations in an unregulated field organizations which wish to remain unregulated by state or federal governments—is through professionalization. Egg donor agencies are in the nascent stages of such a process; agency decision-makers support agency licensing (as qualification criterion), and a few agency decision-makers have established a quasi-professional body, SEEDS, the mission of which is to formulate best practices standards for the industry. While SEEDS's efforts are not explicitly aimed at professionalizing egg donor agencies, the creation both of the organization and the standards themselves can be categorized as the latter two elements of the process. While professionalization, and its consequent self regulation and demarcation of professional egg donor agencies from their amateur counterparts, would be the clearest form of legitimacy available, the simple establishment of a both a body with an ethics mission and of standards to which agencies might aspire, is a major step toward capturing legitimacy on egg donor agencies' own terms, rather than on the tails of other professions' coats.

#### Legitimacy in an Unregulated Environment

The agency decision-makers I spoke with were making attempts to legitimize and professionalize their organizations, and to distance themselves from those organizations that have taken advantage of the lack of regulation in the field. Agency decision-makers responded collectively to pressures exerted on their field by the media, by society, by intended parents, by the market, and by unethical and criminal agencies by claiming legitimacy in a number of ways. They spoke in favor of transparency in business practices and their own agencies' ethical policies. They associated themselves with

<sup>&</sup>lt;sup>608</sup> See Appendices III and IV for the full texts of these two sets of proposed standards.

<sup>&</sup>lt;sup>609</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-75; Larson, The Rise of Professionalism, 49-52.

infertility clinics, and clinics' well established medical professional legitimacy. They affiliated themselves with reputable infertility support organizations. They attempted to subvert the shame associated with egg donation by encouraging openness among its participants: disclosure to children and contact between intended parents and donors. And they made a fledgling attempt at professionalization, through the creation of a nonprofit organization whose purpose is to build a consensus on best practices standards for all agencies.

Agency decision-makers also expressed a desire for health care insurers to be required to cover infertility treatment, including egg donation. If egg donation was included in a standard certificate of insurance, it would, among other things, serve as a sign to those outside the field that the practice is legitimate; in essence, it would serve as a proxy for legitimacy, much like agencies' associations with medical professionals:

I wish they would impose legislation, like Massachusetts I believe, and I think Illinois, that insurance companies should pay ... for the medical costs and the pharmaceutical costs of egg donation and surrogacy. (Director, Northern California Agency)

I'd love to see it. I think that it should be there. The thing is that if you were able to have children, then they would cover your pregnancy. Just the fact that they can't get pregnant shouldn't be a cost savings to the insurance company.... I mean, it would make it more accessible. We would have more clients. (Director, Northern California Agency)

Do you think that will happen? No.... I mean sure, absolutely, it would be great. (Director, Southern California Agency)

I think it should be covered. Nobody chooses to be infertile. (Director, Midwestern Agency)

One decision-maker did have reservations about insurance coverage, because she feared that if coverage of egg donation was treated the same way that mental health coverage is often currently treated by insurers, that it would diminish the legitimacy and autonomy of the field—that it would transfer decision-making authority from field professionals, intended parents, and donors into the hands of the insurance industry:<sup>610</sup>

<sup>&</sup>lt;sup>610</sup> Treatment for mental health problems is often covered by insurance on a piecemeal basis, in which the patient is allowed so many visits to a therapist per year and a smaller percentage of those visits is covered than for visits to physicians' offices.

While I would like to see insurance companies cover IVF, I also get fearful that it will be treated in much the same way as mental health services, where you have the insurance companies dictating what can and cannot be done, because it's a delicate subject, because you don't want IVF clinics to be taking advantage of people, but at the same time—and you do sort of want a gatekeeper like an insurance company—but at the same time, you don't want the gatekeeper to be shutting the doors like they tend to do for certain ailments or treatments. (Case Manager, Northern California Agency)

Whether or not egg donation is ever covered by health insurance providers, and whether it aids or hinders the field's claims to legitimacy, agency decision-makers are currently in the process of grasping legitimacy for their field, by proxy through riding the coattails of medicine and support organizations, and directly by making efforts to subvert the shame surrounding egg donation and through efforts to establish professional best practices for the field as a whole.<sup>611</sup> In such ways, agencies look collectively to their public relations with the world, responding to pressures from the media, the market, and society by shaping their image as a legitimate and professional part of the infertility industry.

<sup>&</sup>lt;sup>611</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-75; Larson, *The Rise of Professionalism*, 49-52; Scott, "Lords of the Dance;" Binder, "For Love and Money."

#### CHAPTER FIVE

### Eggs as Widgets: Embedding the Experience of Commodification

"The money aspect of all of this is complex, isn't it?" (Director, Southern California Agency)

Egg donor agencies' struggle for legitimacy and fledgling attempts at professionalization, at least to the extent that those goals require strict ethical standards, are often at odds with the business side of egg donation. Egg donation through agencies is a process of commodification, whereby women receive remuneration for their eggs—or, alternatively, for the effort they go to to have their eggs retrieved, depending on one's perspective. And that compensation, while sometimes limited by forces such as ASRM guidelines or agencies' unwillingness to go beyond a certain number, is driven by a strong market demand for donor eggs.<sup>612</sup> That market demand, and its resultant economic transaction of money for eggs (or a donor's services), in turn, essentially transforms eggs into a commercial product, in some ways no different from the hypothetical widget discussed in every law school contracts class. Feminist legal theory offers two primary perspectives on this process: damage done to women via commodification of their eggs and/or reproductive labor, and empowerment of women through participation in the public market.<sup>613</sup>

Although a minority of agency decision-makers adopted the stance that egg donors are empowered through donating their eggs,<sup>614</sup> the majority of my interviewees betrayed ambivalence about the commodification aspects of their business. Although, clearly, none of my interviewees rejected payment for egg donation outright, most of them felt that "excessive" donor compensation is somehow ethically wrong, whereas "standard" compensation amounts are acceptable, suggesting a general discomfort with commodification in alignment with the feminist theory on damage to women caused by

<sup>&</sup>lt;sup>612</sup> For ASRM cap on egg donor compensation, see ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

<sup>&</sup>lt;sup>613</sup> For a positive take on the potential of egg donation for women, see Shultz, "Questioning Commodification," 1841; and Johnston, "Paying Egg Donors," 28-31. For the opposite view, see Dickenson, *Property in the Body*; Radin, *Contested Commodities*; and Satz, "Markets in Women's Reproductive Labor," 107-131.

<sup>&</sup>lt;sup>614</sup> This position is discussed in detail in the Chapter Six, "Egg Donors as Empowered Agents," and includes the concepts that women should be able to take advantage of the market to the best of their ability, and that it is patronizing to cap egg donor compensation.

commodification of eggs or reproductive labor.<sup>615</sup> This stance aligns with the ASRM Ethics Committee's position that "Financial compensation also could be challenged on grounds that it conflicts with the prevailing belief that gametes should not become products bought and sold on the marketplace.... Payment for oocytes implies that they are property or commodities, and thus devalues human life."<sup>616</sup> However, at half of the agencies where donor compensation was limited based on some ethical standard, the decision-maker adopted a nonjudgmental attitude towards those agencies that allow high donor compensation, or compensation based on genetic traits (the "who am I to judge?" effect). The other half of such agencies found abhorrent the idea of paying women for egg donation based on the market value of their genetic traits.

In this chapter, I explore the ways in which agency decision-makers view the commodification aspect of egg donation. I examine the forms that commodification assumes in the egg donation business, and look for evidence that agency decision-makers feel some ambivalence about their role in commodifying the young women who serve as egg donors. I then try to understand why agency decision-makers feel that ambivalence; what it is about egg donation that they find ethically troublesome, and whether they articulate that discomfort directly or by implication. Finally, I examine how agency decision-makers attempt to mitigate the potentially negative consequences of commodification by embedding the donors' experience in a positive frame.<sup>617</sup>

### A Uniquely Strong Market Demand

Intended parents create a market demand for donor eggs that is unusually strong, as compared with other material goods or personal services. Once they are contemplating using donor eggs to conceive a child, intended parents have typically already gone to the available extremes of assisted reproductive technology with their own gametes,

<sup>&</sup>lt;sup>615</sup> Dickenson, "Commodification of Human Tissue;" idem, *Property in the Body*; Radin, *Contested Commodities*; idem, "Market-Inalienability," 1849.

<sup>&</sup>lt;sup>616</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 306.

<sup>&</sup>lt;sup>617</sup> The main negative consequence envisioned by feminists concerned about commodification is the dehumanization of those being commodified, by virtue of the characterization of their body parts as objects for sale. Margaret Radin argues that selling body parts threatens our "human flourishing," because our bodies are intricately entwined with our personhood. Radin, "Market-Inalienability," 1851-1852. Similarly, Donna Dickenson argues that "to the extent that persons' body parts can be regulated by property-holding, those body parts are objects, or things. If we are embodied persons, then to some extent we become objects too. The question is to what extent." Dickenson, *Property in the Body*, 4-5.

often incurring tens of thousands of dollars in expenses over the course of multiple IVF cycles.<sup>618</sup> The biological imperative to reproduce is uniquely compelling, and when combined with the economic market, results in a singularly powerful demand for donor eggs.<sup>619</sup> As one reproductive endocrinologist put it, the negative psychological impact on people who are unable to become parents is intense;<sup>620</sup> intended parents will

do anything. You say stand on your head in the middle of 101 [freeway and] they'll say, 'well can I put a pillow [down] or do you want my head right on the concrete?' (Reproductive Endocrinologist)

One result of that strong market demand for donor eggs is the proliferation of egg donor agencies, sprung up to assist IVF clinics in supplying that demand (as discussed in Chapter Two, "A Brief History"). These agencies exist in an unregulated space, and in a space of conflict between the demands of the market, the demands of the infertility industry, and the demands of society at large.

The economic market, in the form of intended parents, calls for easy availability of a wide variety of egg donors; cost seems not to be as much of an issue as might be expected. Although many intended parents are priced out of the market, which is a separate social justice issue, those with financial resources will spend their money without regard to the relative value of what they receive in return; after all, when one spends \$20,000-\$40,000 on a fairly basic car that will completely lose its value within a decade, paying the same amount for a chance at a desperately wanted child seems like a bargain.<sup>621</sup> Nationally, the chances that intended parents will bring home a baby for any

<sup>&</sup>lt;sup>618</sup> Even IVF cycles without donor eggs are prohibitively expensive, ranging in the United States from about \$8000 to \$16,000 or more.

<sup>&</sup>lt;sup>619</sup> As Debora Spar describes the desire to have children: "To those who suffer from it … infertility is a wretched curse—a disease that isn't really a disease, with an outcome that seems to defy nature…. Many infertile couples become consumed with the desire to conceive, willing to do whatever it takes to create a child of their own. For most of these would-be parents, the economic value of their desire—the price of a child, in other words—is literally inestimable." Spar, *The Baby Business*, 2.

<sup>&</sup>lt;sup>620</sup> Again: "Infertility wreaks inestimable havoc on those who suffer from it.... it tends to produce an emotional reaction akin to major illness." Ibid. See also Domar, Zuttermeister, and Friedman, "The Psychological Impact of Infertility," 45-52.

<sup>&</sup>lt;sup>621</sup> For a discussion on some of the social justice issues, such as race, class, and poverty, that are implicated by reproductive technologies, see Radhika Rao, "Equal Liberty: Assisted Reproductive Technology and Reproductive Equality," *George Washington Law Review* 76, no. 6 (Sept. 2008): 1457-1489; and Dorothy E. Roberts, "The Genetic Tie," *The University of Chicago Law Review* 62, no. 1 (Winter 1995): 209-273.

given fresh donor egg cycle are approximately 57%.<sup>622</sup> Egg donors can sometimes command the same fad-like popularity as commercially available material goods, which can drive prices up:

It's crazy ... if you have one donor that's super popular it's amazing how people get so obsessed with getting that donor. (Director, Southern California Agency)

The infertility industry is itself a complex beast, comprised of professionals who desire to serve this particular population of patients, but many of whom also have their own professional or financial motivations. As noted, agencies are to some extent subject to the norms developed by the other professions in the industry, in particular IVF clinics/ reproductive endocrinologists, mental health professionals, genetic counselors, and attorneys (as discussed in Chapter Four, "Deferral to Medical Professional Guidelines and Clinic Standards"). Infertility clinics are governed more strongly (although to varying degrees, depending on the clinic) by their own professional guidelines—in particular, the ASRM recommended cap on compensation of \$10,000.<sup>623</sup> At heart, these professional norms are at odds with the economic forces of the market, in which many intended parents are willing to pay whatever it takes. Additionally, the actors in the infertility industry often have conflicts of interest between the needs of their primary patients, the intended parents, and the needs of egg donors. Agencies must serve their paying customers, the intended parents, while simultaneously recruiting and advocating for egg donors, whose needs can certainly conflict with those of intended parents. Agency decision-makers must balance those conflicting needs with their own need to turn a profit through their mediation of the intended parent-egg donor relationship within the context of the potentially conflicting demands of other players in the infertility industry.

Finally, society at large is highly critical of the infertility industry in general, and of egg donation in particular. Commodification is one of the most obvious ethical issues inherent in egg donation, and is commonly addressed in the media. Media coverage of infertility treatment and egg donation is typically negative, addressing only the most

<sup>&</sup>lt;sup>622</sup> SART, Clinic Summary Reports 2003-2012.

<sup>&</sup>lt;sup>623</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

"newsworthy," e.g., sensational, cases.<sup>624</sup> Although it typically portrays extreme examples, media coverage reflects a general discomfort with commodification that is shared by most agency decision-makers. Yet those decision-makers also feel strongly that their business is justified, both in terms of its treatment of egg donors and, ultimately, on grounds of its end result:

> I feel wonderful! I go to bed every night knowing that I have really made a positive difference in people's lives. As a mother I know that my child is the greatest joy in my life and I feel so content knowing that I have made that possible for others. I feel so very fortunate to have a job that is so satisfying." (Director, Northern California Agency)

Or, more succinctly:

I do this because I believe in it. (Director, Northeastern Agency)

<sup>&</sup>lt;sup>624</sup> See discussion in the Chapter Four, "The Few: Very Bad 'Bad Guys," on criminal behavior among agencies. See also media coverage of the famous Nadya Suleman, so-called "Octomom," and the criticism of her actions as a patient and the physician for treating her. For a very small sample of the media coverage on Suleman and her octuplets, see Jessica Garrison, Kimi Yoshino, and Catherine Ho, "Octuplets' Birth Spawns Outrage from Public," Los Angeles Times, 7 February 2009, available from articles.latimes.com/2009/feb/07/local/me-octuplets7; Internet; Accessed 9 September 2014; Richard Pendlebury, "How the Heartwarming Tale of the U.S. Octuplets Became a Seedy Story of Self-Indulgence," U.K. Daily Mail Online, 2 February 2009, available from www.dailymail.co.uk/news/ article-1133686/How-heartwarming-tale-U-S-octuplets-seedy-story-self-indulgence.html; Internet; Accessed 8 September 2014; Steve Gorman, "Threats Send California Octuplets Mom into Hiding," *Reuters*, 11 February 2009, available from www.reuters.com/article/2009/02/11/us-octupletsidUSTRE51A7R020090211; Internet; Accessed 9 September 2014; Alison Statement, "The Octuplets Mom Speaks, and the Questions Grow," Time, 7 February 2009, available from content.time.com/time/nation/ article/0,8599,1877962,00.html; Internet; Accessed 9 September 2014; Ann Oldenburg, "Octomom Defends Topless Photo Shoot," USA Today, 28 March 2012, available from content.usatoday.com/communities/ entertainment/post/2012/03/octomom-defends-topless-photo-shoot/1#.VA84bEgkPTx; Internet; Accessed 9 September 2014. The case of Suleman is a real exception to the rule of people using IVF to become pregnant; her physician, Dr. Michael Kamrava, violated many professional guidelines in his treatment of Suleman, and subsequently lost his license to practice medicine in 2011, for gross negligence. Alan Duke, "Nadya Suleman's Doctor Loses California Medical License," CNN U.S., 2 June 2011, available from www.cnn.com/2011/US/06/01/california.octuplets.doctor.revoked/; Internet; Accessed 9 September 2014. Suleman herself has recently turned up in the news again, this time for welfare fraud. Alan Duke, "Octomom' Suleman gets Probation, Pays Restitution for Welfare Fraud," CNN Entertainment, 14 July 2014, available from www.cnn.com/2014/07/14/showbiz/octuplets-mom-welfarefraud/; Internet; Accessed 9 September 2014. Whatever one thinks of Suleman's desire to have so many children or her seeking out of publicity after the fact, it is clear from the few facts above that both Suleman and her physician are not your standard IVF participants. Nonetheless, "Octomom" is often the first thing that comes to mind when people think about ART.

That kind of belief in the work that they do may be necessary for agency decisionmakers to continue with their work in the face of societal pressures to change or eliminate egg donation.

The result of these unregulated organizations' location at the node of a number of complex forces is that their attitudes toward and actions regarding commodification are also complex and multi-layered. The strong market demand for donor eggs has created egg donor agencies, and egg donor agencies navigate the issue of commodification, in part a confluence of the conflicting demands of the economic market, professional norms, and society at large, in a number of unexpected ways.

### Forms of Commodification in Egg Donation

Commodification can take several different forms in egg donation. The first, and most obvious, is the actual compensation egg donors receive for participating in the process. The other primary means commodification takes place is through the (sometimes poor) treatment of egg donors, by agencies, clinics, or intended parents, as something other than human beings—as "commodities," existing solely for the purpose of providing a much-in-demand good to clinics and intended parents. In this way, both the donors themselves and their eggs are objectified, offered up to the industry and intended parents as a service for hire or goods for purchase.

### Commodification through Compensation

Compensation for egg donors varies by agency and by region, though the typical range is \$5000-\$10,000 per IVF cycle (\$10,000 is the ASRM recommended maximum compensation).<sup>625</sup> Each agency has its own rules about compensation; the majority of the agency decision-makers I spoke with claim to adhere to the ASRM \$10,000 maximum.<sup>626</sup> Within the agency, compensation can be based on the donor's experience —a donor is paid a little more for each subsequent cycle, or is paid one amount for her first cycle and a slightly higher but consistent amount for any additional cycles—or on

<sup>&</sup>lt;sup>625</sup> Evidence of donor compensation compiled from an extensive internet search for egg donor agencies. For ASRM cap on donor compensation: ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

<sup>&</sup>lt;sup>626</sup> "Total payments to donors in excess of \$5,000 require justification and sums above \$10,000 are not appropriate." Ibid.

her genetic traits, or at least traits that might be considered genetic, but are, at a minimum, variable between women and desirable to intended parents. These traits include ethnicity (some ethnic groups, such as Chinese, Indian, and Jewish women, are much less likely to donate, and can therefore command higher compensation by virtue of their "rarity"), height, weight, hair and eye color, and academic achievement, among others. Universally, compensation is based on the donor's completion of the cycle through egg retrieval, rather than on the quantity or quality of eggs retrieved, thus supporting the agencies' (and industry's) claim that compensation is in return for the donor's services, as opposed to specific payment for eggs.

The agency decision-makers I spoke with, for the most part, offered their egg donors amounts near the upper ASRM limit of \$10,000, especially for repeat donors. The majority of the agencies I spoke with claim to abide by the ASRM maximum, though a few cited the age of these guidelines or their irrelevance to particular markets as reasons for paying their donors more than \$10,000. The agency websites are in accord with the decision-makers' reported compensation practices, with most websites reporting a maximum compensation of \$10,000, and a minimum compensation of \$5000-\$8000.

My interviewees were split evenly on whether they allowed their donors to negotiate their own fee. Some agencies have set fees based on the number of times a donor has cycled. Sometimes, those fees are the same regardless of the donor's location, or the location of the clinic:

It's just set. I made a decision early on that I wasn't going to have any negotiation on that. (Director, Northern California Agency)

Other times, the clinic takes the variables of local markets into consideration, but each donor is paid on the same scale, depending on the number of times she's donated and her geographic region:

Interviewee: For their first time donations we've as a company set that amount and that's based on where they're physically located at, where their home address is.

Interviewer: Is that a market rate kind of thing?

Interviewee: Yeah. Exactly. Depending on what the competition is doing. What's fair to them, what's fair for the intended parents. (Director, Southern California Agency)

Others allow donors to negotiate their own fees, though sometimes decision-makers require these negotiations to take place within the confines of the ASRM recommendations. Agency decision-makers want to keep within the ASRM recommended guideline on compensation for a variety of reasons. They may want to allow the donor some leeway in her fee without compromising the agency's status with the ASRM:

If a donor feels strongly about going higher, I have to kind of keep within the guidelines.... Because I can't risk my ASRM status. (Director, Northern California Agency)

We do allow them to request a fee as long as it's below the \$10,000 by ASRM guidelines. (Director, Southern California Agency)

While some agency decision-makers have reservations about the ASRM recommended cap on compensation (discussed further in Chapter Six, "Patronizing Egg Donors through Caps on Compensation"), others find the ASRM recommendation to be justifiable:

I'm brought up if there's a guideline I'm going to follow it.... Yeah, I mean, it's not an invasive procedure.<sup>627</sup> So I would say [\$10,000 is] reasonable. (Director, Southern California Agency)

I think it's [\$10,000 is] adequate. I think it makes the point and it makes the recognition. (Director, Southern California Agency)

Other agencies allow egg donors to negotiate their fees without regard to the ASRM guidelines, based solely on what the market can bear:

We let the donor kind of pick how they want, what they want to get paid, they choose, and then the parents can decide if they want the

<sup>&</sup>lt;sup>627</sup> This agency director feels that egg donation is not an invasive procedure, presumably because she is comparing it to other, more serious medical procedures. Egg donation—and its requisite hormone injections and egg retrieval under anesthesia via needle aspiration—is not a major surgery; there are no incisions in the skin, and the anesthesia is generally light. Most people familiar with the process, however, would call it invasive: the donor's skin is repeatedly punctured in order to administer hormone injections, and the vaginal walls and ovaries are pierced repeatedly with a needle during the retrieval process. Most young women recover quickly after the retrieval, though there are, of course, exceptions. While it might be considered minimally invasive as compared to, say, a cesarean section, it is clearly quite invasive as compared to the process of sperm donation.

donor, if that's what they're willing to pay. (Director, Southern California Agency)

These agency decision-makers will often allow donors to set their fees high enough that the decision-maker thinks it is unlikely that the donor will be chosen by intended parents:

We actually let the donors decide what they want to be paid per cycle.... We have some first-time donors who come in asking for \$10,000 or \$8,500. If they feel strongly about it, we just let them know that it's less likely that they'll get matched. (Director, Northern California Agency)

Sometimes the donors ask for even more:

What I tell donors when they ask for certain amounts of money is yes we can, but the chances of you getting chosen are slim. So if you use a first time donor that shoots out the gate saying I want \$10,000, \$15,000 I can say ... you need to know that most people for a first time donor are going to kind of laugh about that and just move on. (Director, Southern California Agency)

Such decision-makers tend to subscribe to the philosophy that women are empowered by participating in egg donation, and that they should have the power to set their own fees, "reasonable" or not. Some agency decision-makers who allow fee negotiation outside the bounds of the ASRM guidelines do so based on their sense that certain donors should be compensated more than others:

There's some donors who if they take three or four months off the job that they can't do while they're a donor and they would [otherwise] make X amount of money that's over \$10,000 then I have no issues. (Director, Southern California Agency)

Whether agency decision-makers determine their egg donor compensation rates within the ASRM guidelines or not, compensating donors for their participation in egg donation cycles is incontrovertibly commodification, of the donors' services in providing the eggs, or of the eggs themselves.

## Commodification through Treatment of Egg Donors

Commodification also takes place via the ways in which egg donors are treated during the process of donation, by the agencies, clinics, and intended parents with whom they come into contact. This treatment can consist of direct treatment at the agency or clinic, or indirect treatment in the way egg donors' information is gathered, managed, and shared.

One aspect of the egg donation process with agencies that might encourage intended parents to think of donors (or their eggs) as commodities in the first place is the donor database, which is usually a password-protected online database of donor profiles. The profiles contain a fair amount of information about the donors, typically including (in California) multiple photos of the donor as a child and as an adult. Information transfer is largely one-way; most egg donation cycles are anonymous (no contact or identifying information is shared between the parties), and donors receive very little information about the intended parents. Additionally, agencies are very concerned about maintaining intended parent privacy, as intended parents are the paying customers. The lack of balance in information sharing may lead some intended parents to treat choosing an egg donor like a shopping for a new refrigerator.

Although a comparison may be drawn between dating websites and egg donor databases, in that they are both intended to provide enough information about their respective candidates to enable prospective customers to make an informed choice, dating websites compete with each other in part by furnishing proprietary search algorithms that, in theory, assist the customer in his or her choice of a partner. To date, egg donor databases do not use search algorithms; all searches are done by hand, whether by the intended parents or by an egg donor search service hired by the intended parents to search multiple databases.

Egg donor databases contribute to the commodification of donors by essentially breaking them down into their parts, using objective measures of success, such as college attendance, as proxies for traits that are difficult to measure, such as intelligence. Databases can further commodify egg donors via their means of organizing the donors —by race, by weight, by height—and what agency priorities (e.g., is race given a dominant position in the online search form?) are communicated to intended parents based on what search options are available.<sup>628</sup>

<sup>&</sup>lt;sup>628</sup> Rene Almeling reports that "race/ethnicity is genetically reified to the degree that it serves as the basis for program filing systems." Almeling, *Sex Cells*, 57.

More directly, commodification of egg donors can arise when egg donors are treated with a lack of respect by agencies, infertility clinics, or intended parents. Such lack of respect includes seeing donors only in terms of their genetic or other characteristics, compromising a donor's dignity by disregarding her questions or violating her privacy, or, for physicians, failing to accord egg donors the same duty of care afforded to intended parents. Discussed in further detail below, poor treatment of egg donors, in particular by infertility clinics, is one area in which agency decision-makers' ambivalence about the commodification aspect of egg donation is apparent.

#### **Evidence of Ambivalence about Commodification among Agency Decision-Makers**

Commodification is perhaps the single most obvious ethical issue in egg donation to the layperson, and the target of many media attacks.<sup>629</sup> Agency decision-makers typically take one of two stances on commodification: a minority see the commodification aspect of egg donation as a nonissue, and view the opportunity for young women to participate in the market as a means of empowerment for women, traditionally relegated to the "private sphere."<sup>630</sup> A majority of the agency decision-makers with whom I spoke felt some amount of ambivalence about the commodification of young women's eggs and/or services in egg donor IVF cycles. Some expressed this ambivalence directly, others did so implicitly through their opinions on related topics. A major theme was agency decision-maker's judgments of their clients' attitudes towards potential donors; decision-makers were offended on their donors' behalf when reporting instances of intended parents speaking of donors as commodities. Decisionmakers' ambivalence was revealed also in their stances on compensation, on the practice of frozen egg banking, in their criticism of what they felt was commodifying treatment of egg donors by other agencies and clinics, and in their emphasis on the importance of altruism as a motivation for egg donors' participation.

Several agency decision-makers were explicit about their ambivalence about the commodification aspect of egg donation. Although engaging and facilitating that very commodification, they were uncomfortable with its extremes, and sometimes, with the basic premise of it. For one Northern California agency director, the existence of donor search services concretizes the commodification aspect of egg donation to an unpleasant degree:

<sup>&</sup>lt;sup>629</sup> See examples of negative media treatment of commodification in egg donation listed in note 494.

<sup>&</sup>lt;sup>630</sup> See Chapter Six, "Egg Donors as Empowered Agents," for detailed discussion of this point.

To me, the idea of a personal shopper for the DNA of your child is a little repugnant. But on the other hand, I'm glad that [the donor search service] is willing to do it, because people want *me* to do that and I'm not going to do it for them. So it's good that there's somebody else that will. (Director, Northern California Agency)

This interviewee did not explain why she found it offensive for intended parents to seek expert help when selecting an egg donor—certainly a process for which intended parents are unlikely to hold expertise and might well benefit from the assistance of a person who has seen hundreds of egg donor profiles. Presumably intended parents do something similar to the search service when selecting a donor for themselves. Perhaps it is simply the addition of another commercial layer to the process that makes this decision-maker uncomfortable; the agency serves as an intermediary between the donor and the intended parents during the cycle, and a donor search service then adds an entirely new organization to the process of selecting the donor in the first place. The charging and payment of agency fees, donor fees, and search service fees are all commercial transactions.

# Judgment of Intended Parent Attitudes toward Egg Donors

Almost all of the agency decision-makers I spoke with had some opinions about the ways they have heard intended parents speak about their potential or matched egg donors. Most of them thought that most of their intended parent clients were simply grateful that some young women were willing to participate in egg donation, thus enabling them to have the chance of a child. For example, they found their clients to be:

Very very appreciative and they just want a healthy donor. (Director, Northern California Agency)

So appreciative of what they've [egg donors have] done. (Director, Southern California Agency)

Really thankful for what they're getting. (Director, Southern California Agency)

Extremely grateful, beyond over the moon in general—in general, 99% of the time. (Director, Southern California Agency)

Some agency decision-makers noted a difference in the attitudes of domestic intended parents and those from foreign countries.

I think because of the cultural difference then in those cases [foreign intended parents] it does come across a little bit more as like purchasing something and taking the humanity out of it. But again I don't think that that's necessarily the case and I do believe that there's a deep caring that goes there. But because of the cultural difference it can certainly be misconstrued and come across as that. (Director, Southern California Agency)

Yet even when agency decision-makers were pleased with their clients' attitudes toward donors, they expressed surprise when those positive attitudes reflected an apparent lack of commodification of the donor's specific traits by the intended parents:

I had this couple who, I said we have a form online, tell us what you want in terms of a donor. Height, weight, hair color, academic, artistic ... And they're like, we don't care. Healthy. And I'm like yeah, but ... blonde, brown hair ... and they're like, we don't care if she's black, if she's Chinese, if she's Indian, if she's white, if she's ... we don't care. And I'm like, you don't care at all? These are two white guys, I'm like, I could give you an African American donor. And they're like, we don't care, as long as she's healthy. I'm like, OK. Aren't you worried about academics? We don't care, we just want healthy. I'm like, OK. (Director, Northeastern Agency)

These intended parents wanted a healthy baby, presumably like all intended parents, but the singularity of their attitude in having no preferences for their donor other than health was notable to the agency director, in contrast to the majority of her clients' attitudes toward potential egg donors. These intended parents' lack of preferences in a donor is remarkable among the agency decision-makers I spoke with as well; all other interviewees spoke specifically to the many and varied traits desired by intended parents in their potential egg donors. Perhaps the fact that these particular clients were homosexual had something to do with their (lack of) preferences for their donor. These intended parents knew from the start that they would need an egg donor and a surrogate (or would need to adopt) in order to have children; consequently, they came to the process of choosing a donor without the weight of emotional grief caused by infertility that is experienced by many heterosexual intended parents. Whether or not these clients' sexuality had anything to do with their single requirement for their egg

donor, however, the fact that they had only a single request was unique among intended parents, according to the agency decision-maker.

The vast majority of intended parents, and almost by default, as a matter of customer service, agency decision-makers as well, engage in commodification of egg donors by evaluating them based largely on their genetic characteristics. Yet the fact, and, it could be argued, the necessity, of that commodification in the business of egg donation did not excuse intended parents from having attitudes toward their donors that resulted in a negative type of commodification in the decision-maker's eye.

Even if the majority of agency decision-makers' clients were grateful to their donors, it was the clients who treated donors poorly that decision-makers found worthy of mention. Decision-makers were troubled by these intended parents, by their treatment of egg donors as material goods rather than as human beings. They had general criticisms of intended parents treating the egg donation process like a standard commercial transaction:

Because some people really approach this process like they're buying a car. (Director, Northern California Agency)

Decision-makers complained about working with these clients, and occasionally refused to work with clients with this type of attitude:

Those are the people that I really don't enjoy working with, because they don't see this donor as a person, or a woman that's trying to help them and can also benefit. It's like a piece of DNA. (Director, Northern California Agency)

Sometimes intended parents spoke overtly to agency decision-makers about their view of their donor as something less than a person, to the decision-maker's shock and displeasure:

And he [intended parent] was like, 'Well, you can't expect me to still pay for her. She's just the egg provider. Who really cares?' (Director, Northern California Agency)

Some intended parents commodified egg donors by parsing them into their obvious physical traits, which agency decision-makers universally found ridiculous:

I'm not even exaggerating when I tell you that she would say things to me like, no, the shape of those eyebrows aren't like the people in the family. (Director, Southern Agency)

In another instance, an agency decision-maker was incredulous at the commodifying request of one of her clients:

'I really like this woman, but maybe if her eyes were just a couple of millimeters closer to her nose, and maybe if her cheekbone was slightly higher she [would be] perfect.' And I was like, are you turning this woman down because her eyes are not a millimeter closer to her nose? (Director, Northeastern Agency)

In perhaps the most egregious example of this kind of intended parent behavior, the director of a Northern California agency described a scenario in which her client had become pregnant and felt that ultrasound images showed that her unborn baby's nose was "too big or too angular." The intended parent wanted the agency to contact the donor to get copies of the donor's ultrasound photos (from when the donor was in utero herself) to compare noses. The agency decision-maker was appalled:

But can you imagine contacting a donor and being like, hey, I need you to... (Director, Northern California Agency)

The decision-maker was distressed at the idea of diminishing the donor's dignity and her experience of egg donation by making her aware that the recipient of her eggs cared only for the size of her nose. Additionally, the donor's experience would be compromised by the fact that the intended parent so distrusted the donor—about a thing that most people would likely consider silly, the shape of a fetus's nose—that she was willing to pursue the "truth," even at at time that was clearly too late: the baby was already in existence.

Similarly, the director of a Southern California agency was disappointed in intended parents who viewed donors by their parts rather than as whole persons:

Recipient couples often are focused on strategic and very detailed things about donors rather than their heart. They're looking too much maybe at SAT scores and they reject somebody because they're—literally I've seen this—because they're half an inch too short. Or ... really I had someone say 'the left eyebrow has me worried.' (Director, Southern California Agency) Although articulated in terms of concern for her clients, this decision-maker's criticism reflects the same disquiet with viewing egg donors solely as their parts rather than as a whole person implicit in the anecdotes told by most of my interviewees.

While some intended parents pick apart the available donors in a database, others come to an agency with specific criteria in mind for their potential egg donor. Agency decision-makers can accommodate what they feel to be reasonable requests, but are bothered by intended parents who have "absolutely ridiculous criteria." For example, one client

> wanted a donor who was a member of Mensa, and was a mathematic and chemistry genius, and looked like Cindy Crawford.... I mean, it was almost laughable. (Director, Northeastern Agency)

That decision-maker refused to work with the unreasonable client. Another decisionmaker describes the intended parents who come to her agency requesting

someone who's got a master's or a Ph.D. (Director, Northeastern Agency)

Both of these agency decision-makers feel that intended parents with requests like these are failing to appreciate that outward accomplishments are not all that matters in an egg donor. In one sense, such accomplishments as advanced educational degrees are simply impractical, as by the time a woman has earned such a degree, she is likely either too old or close to too old to be an egg donor. But on an ethical level, agency decision-makers are concerned about reducing egg donors to their parts—their intelligence, their appearance—rather than taking them as a whole; therein lies the real risk of commodification.<sup>631</sup>

While most intended parents, according to agency decision-makers, are looking for egg donors who "match" them in some way, decision-makers were uncomfortable with intended parents seeking egg donors who were clearly different from them, in particular when the egg donors had traits valued by society that the intended parents lacked. In one case, a single man sought the assistance of an agency to create a baby with an egg donor, a sperm donor, and a surrogate. The agency decision-maker described the man as "clearly Middle Eastern of some sort," and the two gamete donors had blonde hair and blue eyes. She was uneasy with the arrangement, and ultimately refused to work with him:

<sup>&</sup>lt;sup>631</sup> See note 617 for Margaret Radin's and Donna Dickenson's arguments on commodification.

It just felt like designing children, that match, and it was kind of like if you can't get at least one woman in your life to sign onto this, to participate in some way, then I shouldn't be that person either. (Director, Northern California Agency)

With a typical intended parent, this decision-maker implies, they are simply trying to replace something that has been lost (or never existed): the ability to reproduce. Such intended parents aim to come as close as possible to what would have been, had they not been infertile or homosexual. In such a way an egg donor is commodified (necessarily, when being paid for her eggs and/or services), but that commodification may be mitigated by the potential to see the donor as a person like the woman whose eggs she is replacing. In the above example, however, the decision-maker felt that the intended parent was aiming for a child who, by visible traits alone, would be a member of an elite class in the United States. Perhaps this was a response to persecution as a Middle Eastern man; we don't know the intended parent's perspective, but the agency decision-maker was disturbed by the plan in part because it makes so much plainer the purely commodifying aspects of egg donation, embodied in the phrase "designing children."

Although egg donors, once they have been matched with intended parents, have been through a process of the agency collecting a great amount of information about them for their screening and donor profiles, agency decision-makers were also uncomfortable with the implications of commodification when an intended parent requested further information about a donor, or confirmation of the information the donor had provided about herself.

I've had a few but very very few—I'd say like two or three out of [hundreds of] couples—who want to *see* her SAT scores, or to *see* her grades, which I'm a little embarrassed when I have to ask the donor, but the donors always comply. (Director, Northern California Agency)

Here, the agency decision-maker might be embarrassed at the implication by the intended parents that they lack trust in the donor, or that the donor's value is comprised, at least in part, by her test scores; this embarrassment is exacerbated by the decision-maker's responsibility to communicate the request to the donor, thus making the donor directly aware of this aspect of her commodification.

These comments reveal agency decision-makers' deep-seated discomfort with the potential for commodification of the young women who serve as egg donors in a way that demeans them and fails to recognize them as human beings first, and potential

sources for the creation of a child second. Most intended parents treat their donors with respect, but even though those who don't are few, the perceived problem is disturbing enough to agency decision-makers that almost all of my interviewees discussed it. Such treatment by intended parents can take the form of approaching the process like a commercial transaction, parsing donors into their individual traits (and nitpicking those traits), having unrealistic or disturbing expectations for their "ideal" donor, or failing to trust their donor to provide accurate information about herself. Agency decision-makers worry that the ways intended parents think and speak about their egg donors will communicate to the egg donors a sense that the donors are not worthwhile as people in themselves, but only as their parts, as a means to an end.

## Criticism of the Commodification Effect of Frozen Donor Egg IVF Cycles

Half of my agency decision-maker interviewees articulated concern about the depersonalization of donors and the commodification of their eggs in the context of the new technology of frozen egg banking. The general concern is that in the process of egg donation via frozen egg banking (in which eggs are donated to an egg bank, frozen, and then later sold by the egg bank), the link between egg donor and intended parent is effectively severed; instead of being "matched" (i.e., the intended parent choosing a donor and the donor going through the IVF cycle to donate specifically to that intended parent), an egg donor has sold her eggs to the egg bank in advance of the intended parent selecting her as a donor. Thus the donor is not donating for a specific couple, and the buffer between commercialism and gift is frayed. It is more difficult to maintain a narrative of gift when the clinic, rather than an intended parent, is the egg recipient, and when the eggs may or may not be selected and bought by intended parents to be given a chance to become a child—or when they might be sold to multiple, separate intended parents.

Agency decision-makers' unease with the implications for greater commodification of the egg donation process with frozen egg banking named two related issues: commodification of the egg donors, and commodification of their eggs. Some pointed out similarities between frozen egg banking and commercial transactions for material goods, and how such commercialization leaves very little room for the donor herself.

You know, really assembly line: you donors give your eggs to multiple couples... (Director, Northern California Agency)

Similarly, another decision-maker worried about the potential effect of commercialization as egg freezing technology improves over time:

It's years away but once it's really efficient it [a frozen egg IVF cycle] goes a lot faster [than a traditional fresh donor egg cycle] and you know you just come in and you just, I just hope it doesn't depersonalize the donor as well. It's like a shelf of goods. (Director, Southern California Agency)

One mental health professional also had concerns that frozen egg banking would encourage the parsing of donors into their separate traits, a process that agency decision-makers strong disapprove of (as noted in the previous section).

> It encourages choosing donors basically by phenotype as opposed to real live people with real live thoughts and feelings and personalities and natures and values. (Mental Health Professional)

Like their treatment solely as part of a commercial process, the parsing of donors into their traits makes it difficult to see them as people, wholes in and of themselves, and thus results in strong commodification. This mental health professional worries about the impact that this commodification of donors will have on the children born from the process:

> There's something about it that absolutely depersonalizes the fact that what we are trying to communicate to our kids is that there was a real live person and her name was Nikki and she had two sisters ... and she walks and talks and breathes and eats and plays basketball.... I just think it's a huge, huge problem. (Mental Health Professional)

Some agency decision-makers called attention to the differences between a traditional egg donor cycle and a frozen egg cycle in terms of the donor's experience.

I would say [a frozen egg cycle is] probably not as healthy ... for the donor [because (from the intended parents' perspective) the narrative of the process changes from] 'We found this girl, here's her profile, she went through testing and she injected herself specifically for us,' [to] 'oh, this girl was going to make ... \$4000, she went through the process, she was retrieved.' (Director, Southern Agency)

In other words, in a traditional fresh cycle, the donor is a kind person who does a great good to a specific intended parent, but in a frozen egg cycle, she's just in it for the money. Similarly, a Southern California agency director says,

I think that the first and foremost thing for the donors is it's not going to be as personal.... If you find really good recipients because the love and the glory that someone feels knowing that even though it was anonymous that they helped a lovely couple who wrote them a nice note and gave them a gift. It's kind of warm versus 'my eggs are banked and I don't even know what's happening.' (Director, Southern California Agency)

Both of these agency decision-makers reference the experience of the egg donor through the process of donation, assuming that if the donor feels some sort of link or connection to the intended parents, that her experience will be more positive, any negative consequences of commodification lessened.

Similarly, some agency decision-makers focused on the loss of connection between egg donor and intended parent as contributing to the greater commodification of the process of egg donation in frozen egg IVF cycles.

The reason I don't love it is because it takes the people out of it. It turns it all into—there's nothing personal about picking eggs out of an egg bank. There's no emotional connection between the donor and that family. (Director, Southern Agency)

A Northern California agency director similarly speaks of the importance of a connection between donor and intended parent, giving the opinion that frozen egg banks will never entirely supersede traditional fresh donor egg cycles:

I think it will still be a need out there for women who are willing to do it in person and have a little bit more connection.... it's an intriguing market to get into frozen eggs, [but] it does take a step back from the human process that's going on here. I don't know, I kind of shy away a little bit from the dehumanization of it because you're still talking about—in the end, you're talking about children, and people, and curiosities, and normal processes. (Director, Northern California Agency)

The loss of the connection between egg donor and intended parent in frozen egg cycles is problematic, according to these agency decision-makers, because of its effect of accentuating the commodification aspect of egg donation.

A Southern California agency director feels that the lack of direct connection between egg donor and intended parent in frozen egg cycles leads to greater parsing of donors into their traits:

Yeah, I think it's less connection for the recipients, too, more like now we really want the stats, right? I've had people do spreadsheets on donors and I could certainly see that with frozen eggs.... When your donor is going through a cycle you're thinking about her all the time hoping she's OK and you feel connected. And just getting an egg is less connecting. (Director, Southern California Agency)

Thus, the greater effect of commodification in frozen egg cycles is caused by the severing of the link between parties, which in turn enables intended parents to treat donors as less than whole persons.

A related criticism of frozen egg banking is its nearly inevitable treatment of human eggs as material goods. This is problematic commodification in the most obvious way: placing commercial value on human reproductive tissue, separate from the source of that tissue. Agency decision-makers don't like to see eggs treated this way, either by intended parents or by the egg banks themselves. Speaking of the head of a large frozen egg bank, a Northern California agency director says,

He is the king of seeing eggs as widgets. (Director, Northern California Agency)

She doesn't like the position into which egg banks place intended parents:

Be happy. Go pick somebody. (Director, Northern California Agency)

Presumably, she finds the "picking" that happens within a traditional fresh donor egg cycle to be less objectionable because it takes place within the context of a current IVF cycle and a direct agreement between the intended parents and their chosen donor.

Similarly, agency decision-makers complain about intended parents and agencies who look directly to the eggs and leave the donor out of their vision altogether.

People all the time say 'I want to buy some eggs,' they're writing me all the time ... You wouldn't want to do that, say 'yeah, OK, just

give me \$12,000 and I'll send some eggs' or something. (Director, Southern California Agency)

Although she doesn't give a reason for her objection, this agency decision-maker clearly finds the notion of paying money in direct exchange for eggs—as opposed to in exchange for the services of an egg donor—ethically suspect. Similarly a Northern California agency director complains of agencies and in-house programs on the East Coast:

I feel like quite often, they see the egg as a widget, rather than 'this is going to be part of a future family.' So that I find kind of frustrating. Not everyone, of course, but many. So that's why they see these frozen egg banks as being the be all and end all, because oh then we take the human factor out, because boy, isn't that a nuisance? It slows down everything! (Director, Northern California Agency)

One Northern California agency director believes that the potential for greater commodification inherent in frozen egg donation simply won't be a problem because most egg donors won't allow themselves to be treated that way:

I think that it takes a certain type of donor to agree to do a frozen [cycle] because most people don't want to just get paid \$5,000 to have their eggs distributed to three different families, knowing that the clinic is going to be making money hand over fist on their eggs. So I am not terribly concerned. (Director, Northern California Agency)

Her lack of concern for the commodifying effects of frozen egg banking is not due to the belief that there is no such problem inherent in the practice, but rather that most egg donors will not agree to participate in that level of commodification.

Half of the agency decision-makers I spoke with expressed concern about the greater commodification of donors and their eggs involved in frozen egg banking. They cited the lack of connection between donor and intended parent, increased parsing of donors into their separate traits, and the treatment of eggs as commercial goods to be sold on the market as contributing to the ethically problematic commodification of frozen egg banking, over and above that present in traditional fresh donor egg IVF cycles. By making a distinction between between the two levels of commodification in fresh versus frozen donor egg cycles, agency decision-makers give evidence of their ambivalence about the overall commodification aspect of egg donation.

# Ambivalence Revealed: Justifications for, Discomfort with, and Criticism of Egg Donor Compensation

The ambivalence of agency decision-makers about the commodification aspect of egg donation is especially apparent in their comments about egg donor compensation. All but one of my interviewees articulated concerns about egg donor compensation and its role in the commodification of donors and their eggs. Compensation is, of course, the foundation of commodification in egg donation; without compensation, there would be no transaction with the effect of turning a person or her eggs into a commercial good.<sup>632</sup>

Several agency decision-makers detailed their reasoning for why egg donors should be compensated; such compensation is necessary, it is the heart of their business.<sup>633</sup> One agency decision-maker viewed donor fees as compensation for lost wages, and for the donor's time,

what we think is fair and reasonable compensation for approximately thirty days of going through this ... plus we pay expenses. (Director, Northeastern Agency)

The director of a Southern California agency sees egg donor fees as compensation for pain and suffering, a legal concept, in addition to compensation for lost wages and the donor's time:

I think some of it at least is, you know, there's pain and suffering and there's costs of doing it. (Director, Southern California Agency)

Other agency decision-makers see donor fees as compensation for the risks, both known and unknown, that donors undertake with each IVF cycle.

<sup>&</sup>lt;sup>632</sup> Commodification is the transformation of goods or services into a commodity, something offered for sale on the commercial market.

<sup>&</sup>lt;sup>633</sup> See Richard M. Titmuss, *The Gift Relationship: From Human Blood to Social Policy*, eds. Ann Oakley and John Ashton (The New Press, 1997), for a discussion of blood donation in the United States and Britain, and his conclusion that a non market system based on altruism is more effective than a market system based on compensation. The same likely cannot be said for egg donation: compensation for egg donation was outlawed in the United Kingdom, but a severe shortage of donors (and the emigration of U.K. infertility patients to foreign countries to seek treatment) led the British government to allow some compensation. Human Fertilisation and Embryology Act. Sociologist Kieran Healy argues that the success of a gifting system rests on the fairness of the exchange, rather than the altruistic or financial motives of the donor. Kieran Healy, *Last Best Gifts: Altruism and the Market for Human Blood and Organs* (Chicago and London: University of Chicago Press, 2006).

The assumption of risk ... goes up with each subsequent time you put more hormones in your body and go through a retrieval and all the sort of potential dangers that could happen ... in the future. It's still relatively new. (Director, Southern California Agency)

Whether as compensation for lost wages, a donor's time, pain and suffering, or the donor's assumption of risk, half of my interviewees expressed discomfort with egg donor compensation taken to extremes. One Northern California agency director simultaneously (and tentatively) condemned the idea of very high egg donor compensation (\$15,000-\$30,000 in this example) and disclaimed judgment of those who do pay high fees:

Yeah, I mean, I don't want to do it, but I don't feel angry that there are people who are. You know, if there are people who want to do that with their money, I mean, I kind of ... who am I to say they can't? I wouldn't want to be involved in that transaction in any way, but if there are people who feel comfortable with that, then I don't feel like it's my place to say that it's wrong for them to do it. To me, it's just too awkward, I wouldn't want to be involved in it. *It feels too much like, I don't know, selling your body parts, which I guess all egg donors are doing*, but I don't know, well, you get it. (emphasis mine) (Director, Northern California Agency)

This agency decision-maker acknowledged that her business engages in commodification, but is not entirely comfortable with it, especially when it seems to her that the commodification is taken to an extreme—when the egg donation is framed in a way that emphasizes the monetary side of the transaction via high donor compensation. Thus her ambivalence; she disapproves of high donor fees in exchange for egg donation, but her business is a version of that practice, with lower fees, and the boundary between the practice in which she "wouldn't want to be involved" (high donor fees) and her own, actual practice (ASRM-compliant fees) is fragile. A mental health professional shared this agency decision-maker's ambivalence about high donor compensation:

> It's so controversial. Yes. They [egg donors] should be compensated. Do I think there should be a cap? I don't know if there should be a cap. It's all arbitrary. It's all arbitrary whether someone deserves \$5,000 or someone deserves \$100,000. (Mental Health Professional)

Many agency decision-makers were more certain in their condemnation of very high donor compensation.

There are people [agencies] who just flagrantly do whatever the bleep they want and the donors are not shy about asking for it. (Director, Southern California Agency)

Some feel that the risks undertaken by egg donors simply do not justify very high compensation:

At a certain point, you take advantage [of intended parents].... [Egg donors know] what the risks are after the first one [cycle]. It still [isn't] fifty grand worth. (Director, Southern California Agency)

Some agency decision-makers worry about what a high requested donor compensation will communicate to the intended parents about the donor:

We certainly try to talk her out of [asking for more money] because we have shared with her that we think that makes her look like she's not doing it for the right reasons. (Director, Southern Agency)

One non-California agency decision-maker finds that donor compensation is so high in California that she simply doesn't want to compete:

We don't work with anybody in California anymore because it's a pretty tough road out there. And a lot of that comes from the donor recruiting. I mean it's a little bit insane. In my opinion it is—you have to be the highest bidder as an agency. (Director, Southern Agency)

This agency decision-maker feels that high donor compensation is inappropriate on its face. Similarly, one mental health professional is concerned that high donor compensation compromises the purpose of egg donation:

I think [there should be] some kind of a limit on compensation. I don't know if that results in trying to keep this process what it's really intended to be, which was to help people become parents, to whatever. I don't know. It's a really complicated issue. (Mental Health Professional) This mental health professional feels that limiting egg donor compensation might also limit the commodifying effect of egg donation, presumably by putting a ceiling on the effect of the pure market on the egg donor market.

A related issue is the payment of extreme compensation for donors with particular traits. The most often cited example of this kind of extreme is very high fees paid to women who attend or attended Harvard, Yale, Princeton, or Stanford. These types of transactions have received a lot of media coverage over the years, and thus exposed those who facilitate egg donation to negative press, which perhaps helps to explain the prevalence of complaints among my interviewees.<sup>634</sup> Some complain about the practice of extreme compensation for Ivy League students, but still allow such donors to charge high fees in their agency.

When you have an egg donor from Princeton, or Yale, or Harvard, there is this underlying, unspoken rule that they can ask for whatever they want, and there are intended parents out there that will pay them \$45,000 for their eggs. (Case Manager, Northern California Agency)

Although this case manager feels uncomfortable with such extreme donor compensation, the agency that employs her allows the economic market and the willingness of intended parents to pay those fees to guide their policy. Although not enthusiastic about very high donor compensation, the director of a Southern California agency justifies it as a means of empowerment for donors on the one hand, and for intended parents the possibility of finding the "right" donor, on the other:

> Ultimately, we don't say no, we can't work with you. We just say, at the end of the day this is their body and we respect that and understand that they're offering themselves and it's a great opportunity for somebody who needs a donor to find someone like themselves so we leave it at that. (Director, Southern California Agency)

Other agency decision-makers are so uncomfortable with very high donor compensation for Ivy League students that they do not allow it at their agencies.

<sup>&</sup>lt;sup>634</sup> See, e.g., Kolata, "\$50,000 Offered to Tall, Smart Egg Donor," *The New York Times;* Lowrey, "The Egg Donor Market Wants You, Harvard Women, and It'll Pay," *The Harvard Crimson Magazine;* Su, "Not By the Dozen," *The Yale Herald*.

I think what is absolutely ridiculous is when you find a Harvard donor who demands \$30,000. Are we really here to create a designer baby ... or are we here to procreate a live healthy birth because isn't that the end goal? (Director, Midwestern Agency)

This agency decision-maker feels that high donor compensation, and the level of commodification it implies, compromises the moral value of the process of egg donation. The director of a Southern agency says similarly,

We don't let the Ivy League, blonde hair, blue eye[d] girl come to us and say, 'we want \$20,000.' That girl is by default—she has a sense of entitlement. She feels like she deserves that, which is fine and for some people that's good. (Director, Southern Agency)

Although this agency decision-maker finds very high compensation for Ivy League students ethically troublesome—which is why she doesn't allow it at her agency—she is also reluctant to condemn those who do allow it, on grounds that it might potentially be a means of empowerment for some young women.

One Southern California agency director has no qualms about denouncing high compensation for high educational status.

I had this woman, a Supreme Court clerk, call me and tell me what she wanted for her eggs, and I just like laughed.... They want to receive \$50,000 for their eggs they can go somewhere else. They'll find somebody to work with them, it's just not going to be me. (Director, Southern California Agency)

Two mental health professionals similarly condemned high compensation for Ivy League students.

The things you read about in the popular press that give egg donation a bad name, which is the ads in Stanford's newsletter and people that are looking for Ivy League donors and \$100,000 for the athlete and the whatever.... You're not getting a clone of anybody, and when you throw all the genes up in the air you do not know who you're going to get or what you're going to get. (Mental Health Professional)

This mental health professional sees high compensation for Ivy League donors as a mistake both for public relations and for practical reasons, as choosing an Ivy League

donor simply does not guarantee a child who could attend an Ivy League school. Similarly, another mental health professional points out the error of logic in paying so much for an overachieving donor:

> Someone that pays \$100,000 for a Harvard graduate or \$100,000 for an Olympic gold medalist, maybe they have athletic potential, but does it mean your child is going to have it? Who knows? Is that egg worth \$100,000 versus another woman who had all these other qualities that you liked and that you paid \$5,000 for and if you put them in training and did all these other things? (Mental Health Professional)

A major element of this type of extreme compensation is the implication that some women (or their eggs, or their genes) inherently have more value than others.<sup>635</sup> This implication makes many agency decision-makers decidedly uneasy, and they criticize those agencies that make such distinctions in their egg donor databases.

But, you know, I'm sure, that there are some agencies that put a different fee on each donor, which I find really repugnant. What about the gal who's at the low end? I mean, what do they say to her: 'You're just regular. You're not as special.' (Director, Northern California Agency)

The director of an agency in the South was similarly horrified at the idea of such blatant commodification of egg donors via their monetary valuation on the economic market:

Another thing that I want to say is that we have no sliding scale for donors. I am just nauseated beyond words by the concept that any one woman is worth more money than another. (Director, Southern Agency)

The director of another agency in the South denounces agencies that determine egg donor fees based on the donor's traits, whether those be academic achievement, physical beauty, or reproductive success:

That to have a Ph.D. or be a model or have gone to an Ivy League school or have had twenty eggs instead of ten eggs or whatever

<sup>&</sup>lt;sup>635</sup> The idea that the genetic traits of some women have more value than others has strong echoes of the early twentieth century eugenics movement in the United States. See Kevles, *In the Name of Eugenics;* Lombardo, *Three Generations, No Imbeciles*.

guideline people [agencies] come up with to make this—people [agencies] even label them. They have like queen donors and gold standard. I don't even know, whatever. (Director, Southern Agency)

The labeling of egg donors and determination of their fees by those labels is something that struck many agency decision-makers as ethically suspect.<sup>636</sup> The director of a Southern California agency was particularly offended by agencies who made such distinctions among their donors, though her complaint centered on the unfairness of different agencies creating different values for the same women, simply on the basis of the labels the agencies created for them:

Calling yourself suddenly having something like super donors or elite donors or ... when they're really the same donors everyone else has, but because you're calling them super or elite, suddenly the standard fees start at \$10,000 and go up to \$25,000 or \$30,000. Yet, we might have a lot of the same donors on our site. (Director, Southern California Agency)

The vast majority of my interviewees had something to say about egg donor compensation that indicated some level of unease with the ethical implication of exchanging money for egg donation.<sup>637</sup> They expressed this ambivalence about donor compensation by justifying it, by condemning very high donor compensation, and by criticizing the valuation of egg donors based on their apparent intelligence, physical beauty, or other traits. This ambivalence about egg donor compensation reveals that many agency decision-makers have misgivings about the impact of commodification of

<sup>&</sup>lt;sup>636</sup> This may be because labeling and valuing egg donors based on traits that are genetic (or appear to be genetic), with the intent that the "best" donors can be chosen by picky intended parents, feels too much like "positive eugenics," which, in the early twentieth century, was a program "aimed to foster more prolific breeding among the socially meritorious." Kevles, *In the Name of Eugenics*, 85. As bioethicist Leon Kass framed it: "We stand in much greater danger from the well-wishers of mankind, for folly is much harder to detect than wickedness. The most serious danger from the widespread use of these [collaborative reproduction] techniques will stem not from desires to breed a super-race, but rather from the growing campaign to prevent the birth of all defective children, and in the name of population control, quality of life, and the 'right of every child to be born with a sound physical and mental constitution, based on a sound genotype.'" Leon R. Kass, M.D., *Toward a More Natural Science* (New York: The Free Press, 1985), 62, quoting Bentley Glass, "Science: Endless Horizons or Golden Age?" *Science* 171 (1971): 28.

<sup>&</sup>lt;sup>637</sup> The opposite position, that commodification is not a problem, and that compensation for egg donors should not be limited except by the economic market, which in turn empowers young egg donors, is discussed in detail in Chapter Six, "Egg Donors as Empowered Agents."

egg donors and/or their eggs, on the donors themselves, and on others who participate in the practice of egg donation.

## Criticism of Infertility Clinics' Commodifying Treatment of Egg Donors

Another area in which agency decision-makers' ambivalence about the commodification aspect of egg donation is apparent is in their criticism of the ways in which donors are treated by infertility clinics. Agency decision-makers complain about clinics treating donors "like a commodity," and seek feedback from donors about their experiences with clinics, sometimes keeping lists of clinics they will not work with because of a history of poor treatment of donors. These agency decision-makers are offended on behalf of their donors, when they perceive the clinics have not accorded the donors respect.

Sometimes these complaints center around a specific problem in clinics' treatment of donors:

There are offices that clearly don't have a clue, where donors are begging to get the medication on time for her to take her shots, or they treat donors like a commodity. (Director, Southern California Agency)

One agency decision-maker said that such treatment is especially prevalent in big infertility clinics:

I will have donors that will say, wow, they felt like they were cattle, just straight through.... I've heard that in California, New York, and Boston ... the big huge clinics ... [that] do just massive amounts [of cycles]. (Director, Southern Agency)

Some clinics' treatment of donors is not only disrespectful, but outrageous on its face. At one Southern California agency, an experienced donor told the agency director about a clinic she had just worked with for the first time:

> 'I don't think you should send new donors there.' She said, 'when I was done with the donation they made me get up off the gurney and I was really sore and they said get some Tylenol and handle it. And then also when I had to give them a urine specimen they watched me.' (Director, Southern California Agency)

This agency decision-maker reported the incident to me in tones of great indignation, incensed that one of her donors should have had such a negative experience in a donation arranged by her agency.

Some agency decision-makers create a blacklist of clinics to which they will no longer send donors, after previous donors have had poor experiences with them. When asked what sorts of behavior would merit inclusion on such a list, the director of a Southern California agency replied,

Treating the donors as a commodity. You know, not treating her as a human being, or if they have a history of mistreating the donors by hyperstimulating them, or we've had miscommunication problems, or just negligence, or things of that nature. (Director, Southern California Agency)

In addition to the general "treatment of donors as a commodity," this list includes clinic behavior that threatens the donor's health, as well as behavior that causes logistical problems with the cycle—all of which have the potential to severely impact the donor's experience of the egg donation.

Another agency decision maker who refuses to work with clinics that mistreat donors names the following criteria for inclusion on her list:

There are some clinics who say, 'well, she's [the donor is] not really our patient'—they don't say it but they think 'the intended parent is our patient, the donor is not our patient,' and that's where the lack of respect usually comes into play. (Director, Southern Agency)

She refers to the inherent conflict of interest for physicians managing egg donation cycles between their primary patient—the intended parent—and the woman who comes to them for the benefit of the intended parent—the donor—who also becomes a patient, but whose interests may become directly in conflict with those of the intended parent.<sup>638</sup> This agency decision-maker feels that clinics must treat egg donors with

<sup>&</sup>lt;sup>638</sup> Conflict of interest is a concern for physicians managing egg donation IVF cycles because 1) the physician is the intended parents' physician first; the donor only comes to be his or her patient because of the primary patient's need, and 2) what the intended parents need (lots of good eggs) is potentially in direct conflict with what is best for the egg donor (not stimulating her ovaries so much that she develops OHSS). However, as one of my reproductive endocrinologist interviewees pointed out, it's not quite so simple, because if an egg donor had her own physician looking out for her interests, his or her advice would undoubtedly be to not do the cycle—an unnecessary (for the donor) medical procedure—in the first place.

respect, as patients in their own right, and she refuses to send donors to clinics that fail to meet that standard. She is, however, cautious about adding clinics to the blacklist:

I have chosen not to work with clinics, but I also know [that] ... sometimes the donors' expectations are a little bit higher. (Director, Southern Agency)

She attempts to gain a clear picture of the clinic's behavior, from everyone's perspective, and does not rely on the experience of a single donor to build her blacklist:

I totally understand that a donor can have a bad experience and it can be just an isolated event because of something. We send evaluations to each of our donors, intended parents, and our clinics at the end of cycles and that usually helps us to piece any puzzles together that we would want to. (Director, Southern Agency)

Mental health professionals are similarly concerned that the treatment egg donors are subjected to at clinics can exacerbate the sense of commodification experienced by the donor:

The feeling of the commodity [of being commodified] isn't so much based on the money that they're receiving, but more how they're treated by [clinic] staff. (Mental Health Professional)

I think that often they [egg donors] feel as if they're just a number in a factory. (Mental Health Professional)

When asked to elaborate on how clinics make egg donors feel commodified, one mental health professional said,

I think from the feedback that I get from donors ... it is probably the medical staff at the doctor's office, usually. The nurses.... [Also] some doctors can be relatively condescending or some [infertility medical] practices are very large so people are coming and going and egg donors leave feeling like they just were a commodity. (Mental Health Professional)

Mental health professionals echo the concerns of agency decision-makers that the ways in which egg donors are treated by infertility clinics—entirely aside from the fact that they are being compensated for donating their eggs—serve to exaggerate donors' sense of commodification, of being valued only for their parts, and not for themselves as human beings.

#### An Emphasis on Altruism in Egg Donors

Almost all of my interviewees mentioned donor altruism as an important factor when selecting donors.<sup>639</sup> Agency decision-makers acknowledged that most donors started the process for the money, but that they had at least a streak of altruism that typically grew through the course of a cycle. When pressed, some agency decision-makers claimed that altruism as a motivation didn't matter to them in a philosophical sense, but that it was a marker of whether or not the donor was likely to be reliable and complete the cycle. Others felt that an altruistic motivation on the part of the donor resulted in a better experience for both the donor and the intended parents. In other words, if the donor was at least partially motivated by the desire to help the intended parents, her experience of the commodification of her body would be more likely to be a positive one.

The nature of egg donation is such that it can result in a paradoxical coexistence of financial and altruistic motivations in an egg donor. Agency decision-makers acknowledged this paradox, citing the difference between initial, financial motivations, and later, greater, altruism. Many of my interviewees made clear that donor compensation is what first attracts potential donors.

I think that they're always drawn to it initially for the money. Maybe not always, but quite often the initial motivation is the money. (Director, Northern California Agency)

I think when they initial[ly] call, it's because they see advertisements with large numbers for them and it's at least worth a phone call. (Director, Southern California Agency)

I think every donor comes to us with the motivation of money. I think that's what makes them first think of it. They hear and see the ads. I think that's the very first motivation to get them in the door, if you will. (Director, Southern California Agency)

<sup>&</sup>lt;sup>639</sup> For the purposes of this dissertation, "altruism" in egg donors is the desire to donate/sell one's eggs for, at least in part, the benefit of giving an infertile person or couple the chance to have a much-wanted child.

One agency decision-maker justifies this commodifying aspect of egg donation by its end result: the recruitment of donors who will help intended parents.

I think it is OK if a donor says 'I'm doing this to make extra money' because that's usually how most people find it or that's usually how they're attracted to it. (Director, Southern Agency)

Agency decision-makers recognize that even with donors whose initial motivation is entirely financial, that motivation can be altered during the course of the cycle, as the donor learns more about the process and the people who require her assistance in order to have a child.

> So the part that says, 'You know what? I want to help someone and I'm OK with that' has to kick in at some point for most people. (Director, Southern California Agency)

Another agency decision-maker believes that whether a donor's motivation changes depends in part on whether she is treated with respect by the infertility clinic:

I think the motivation can change along the way. And it depends upon the clinic that she works with. If she's made to feel that she's very special, and she's making a big contribution, it makes her feel good about this. (Director, Northern California Agency)

A mental health professional, experienced with screening egg donors prior to their cycles, similarly reports that repeat egg donors often say,

'The first time I was probably more motivated by money, but by the time I was done with it, I didn't even care about the money anymore. I just wanted to help the family. It was such a great experience that I want to do it again. I would do this even if I wasn't getting paid.' ("Maybe, maybe," commented the cynical mental health professional.)

Whether or not a donor's motivations change during the course of an IVF cycle, agency decision-makers acknowledge that financial motivation and altruism can and often do coexist.

I would say [for] most of them it is very altruistic that they want to help. I'd say probably seventy/thirty. Thirty [percent] altruistic, seventy percent I'm in school, I'm desperate, I've got student debt out the wazoo and this is going to help me. (Director, Northeastern Agency)

A mental health professional believed that the coexistence of the two motivations was simple necessity:

Ultimately they're [egg donors are] all altruistic and they're all wonderful, but I feel probably if they were not being compensated, they probably wouldn't be doing it. (Mental Health Professional)

Despite their rather practical views on the importance of compensation for attracting donors to their agencies, many agency decision-makers also held the strong belief that their donors were largely motivated by altruism:

I do not believe for a minute that donors are doing it just for the money. (Director, Northern California Agency)

There's a human aspect of this all. Once you relate to somebody [intended parents] and they become real, even if it's just an idea of who they are, it becomes personal. (Director, Southern California Agency)

Some agency decision-makers felt that altruism was clearly a component of donor motivation, because the financial compensation was otherwise insufficient:

Because it is quite invasive, I think that they have to have—or most of the time, they have to have another reason for wanting to do this. Because they can help other people. (Director, Northern California Agency)

One agency director thought that her donors' altruism extended beyond egg donation:

Most of them do have some element of altruism in them.... And honestly, I can tell you that probably ninety-plus percent of them are active community service people. (Director, Southern California Agency)

Agency decision-makers' insistence on the inherent altruism of egg donors, in combination with their recognition of the primary importance of compensation in convincing potential egg donors to participate, reflects further ambivalence about the commodification aspect of egg donation.

That ambivalence is most obviously revealed in agency decision-makers' opinions that a donor's altruism is important for her ultimate experience of egg donation; in other words, if the donor is altruistic, she is more likely to have a positive experience and the commodification of her body is less likely to have a negative effect on the donor. One agency decision-maker rejects egg donor applicants who fail to show altruistic motivation. When asked why she thought altruism was so important, she replied,

It's going to make them feel good about themselves and they do. Women come back to me and say 'I don't know if you remember when I did this eight years ago and I was only twenty-one, it's the best thing I've ever done in my life.' (Director, Southern California Agency)

Another Southern California agency director says similarly,

I think your motivation, I think it will affect how you experience what your experience is like throughout that journey because I think if you really understand why you're doing it, then I think that the reward at the end is not just the financial, it's 'wow, I helped someone. I made a difference. I did something that was important.' I think that the experience will be more rewarding. (Director, Southern California Agency)

Some agency decision-makers express the same idea in reverse:

It would just really kill me to think that any of our donors had ever done it and then lived to regret it. (Director, Southern Agency)

Professionals who work with egg donors agreed with the agency decision-makers that altruism has a big impact on the experience of the egg donor. One attorney said,

I don't think that a donor ... should do this just for the money. It's not enough. It's a much bigger deal than just the money. There are huge ramifications, permanent consequences to what's happening here. So they have to be in the right mental place, understanding the broader picture. (Family Formation Attorney)

A mental health professional believed that it was important for an egg donor to feel a personal connection with the intended parents because:

it's giving them informed consent. It helps them understand why they are doing it and the long-term implications of what they're doing. It's going to give them a more rewarding satisfaction at the end, I think. (Mental Health Professional)

While agency decision-makers' ambivalence about the commodification aspect of egg donation is clearly revealed in the importance they placed on altruistic motivations for donors, it is also, if more subtly, visible in their insistence that altruism is important for donors to be able to complete an IVF cycle. Many of my interviewees felt that egg donor compensation was insufficient to motivate the donor for everything involved in a cycle, from time and inconvenience, to pain and suffering, to present and future medical risks, and the chance of a cycle getting thrown off track (often through nobody's fault) and therefore requiring even more resources from the donor. Three different Southern California agency directors—a geographic location known for its high donor compensation—assert the importance of altruism in addition to compensation:

I really do believe that there has to be a little bit of this altruistic 'I'm going to help somebody else out' feelings involved. (Director, Southern California Agency)

Your altruism has to kick in. Because ... you have to be willing to help somebody, to take daily injections, to give up your genetics, and so on and so forth. (Director, Southern California Agency)

They're not getting paid so much that it's worth what they're going to go through. (Director, Southern California Agency)

The director of a Midwestern agency made this point in more detail. Altruism is:

important because it can be a lengthy process and it can be a difficult process sometimes for the donor. If she doesn't have some compassion or empathy for the intended parents, even though it might be an unknown [anonymous] situation, she could probably easily get discouraged and withdraw from the program and that's devastating for my clients. Having that element of empathy and altruism or compassion or whatever it is that stirs within her to do this for somebody else is really a necessary component to kind of keep her on track. (Director, Midwestern Agency)

Similarly, the director of a Southern agency felt that the compensation donors received did not cover all their contributions:

There has to be some motivation to just be doing this because they want to help somebody and they want to make a difference because —definitely for a first time donor [\$5000]<sup>640</sup> doesn't always compensate really if you factor in everything. If you factor in their time ... that [they'll] be away from work or kids or school and then just the potential risks and complications. (Director, Southern Agency)

Agency decision-makers' emphasis on the importance of altruism to ensure that a donor has the motivation to complete a potentially difficult IVF cycle is another way of saying that altruism is important for the donors' experience of the cycle, and thus of the commodification of her eggs and herself. A donor's motivation and experience are entangled to the extent that a multilayered motivation may improve her experience of a cycle to the point that she would choose to stick it out upon encountering difficulties that might otherwise prompt her to back out of the cycle, if financial compensation was her only motivation. Thus an altruistic motivation can serve both as a source of emotional fortitude during a difficult cycle, and of emotional reward for the completion of a cycle and a chance given to a deserving intended parent. Without that altruistic motivation, a donor encountering difficulties during a cycle may more easily decide that the cycle is not worth the compensation she is getting, and if she backs out of the cycle, she will also forgo any potential emotional reward. Consequently, a donor's altruistic motivation is important, in agency decision-makers' eyes, both for the completion of a cycle and for the positive experience of that cycle—and a positive experience of the cycle can lessen the negative impact of commodification on the donor (as discussed in the next section).

Some agency decision-makers mentioned that donor altruism is important, but to intended parents, rather than to donors themselves. This is another piece of decisionmakers' ambivalence about commodification: if donor altruism is important to intended parents, it is because intended parents want the egg donation to be something more than an exchange of money for goods or services, something more than a commercial transaction. While agency decision-makers may care about intended parent desires solely as a matter of customer service, they may also be anxious to lessen the impact of commodification on both sides of the interaction. One Northern California agency director says simply,

I think couples probably care [about donor altruism]. (Director, Northern California Agency)

<sup>&</sup>lt;sup>640</sup> Amount adjusted to preserve confidentiality.

And another Northern California agency director:

Sometimes the intended parents care.... For them, it seems important just to get an idea of the reasoning. (Director, Northern California Agency)

A Midwestern agency director gives a little more context:

I think [donor altruism] matters—well, it matters to our client base for the most part. Not all of them, but many of them. They want to see that. Because this is an emotional journey for them. (Director, Midwestern Agency)

While the majority of agency decision-makers emphasized the importance of egg donor altruism, whether for the donor's experience of a cycle, for her likelihood of completing a cycle, or for the intended parents, and expressed a strong belief in that altruism (and its coexistence with financial motivations), a few decision-makers thought that a donor's motivations mattered little, as long as she was committed to seeing a cycle through.

For me, to be honest, I don't really care, because I don't think it matters. (Director, Northern California Agency)

We've got donors that come for all sorts of different reasons. Frankly, I don't necessarily care. (Director, Northern California Agency)

To be perfectly honest with you, I really don't care what the donor's motivation is. (Director, Northeastern Agency)

All three of these agency decision-makers "admit" their honesty when stating the opinion that they are unconcerned with donor altruism, implying that they are breeching an unspoken norm. And as noted, most decision-makers not only declared that egg donor altruism was important, but they highlighted its importance when screening donors for their agencies' egg donor databases. One agency director justified her acceptance of egg donor applicants whose sole motivation was financial:

We all wake up in the morning and go to work for a paycheck.... At the end of the day, too, everyone has bills to pay. I think maybe as long as you're educated in the process and you understand the risks and you have proper informed consent. (Director, Southern California Agency)

Ultimately, on the topic of egg donor motivation, agency decision-maker ambivalence about commodification may occasionally be overruled by the exigencies of business:

I don't really think the motivation matters. I think the commitment to the process matters and the commitment to see it through. (Director, Southern California Agency)

## Attempts to Mitigate Ethically Suspect Effects of Commodification via Embedding the Experience of Egg Donors

The majority of the agency decision-makers with whom I spoke feel ambivalence about the commodification aspect of egg donation, but they also believe in their mission of helping infertile people become parents. They worry implicitly about the potentially negative consequences of the commodification that forms the core of their business, and attempt to mitigate those consequences by embedding the donor's experience in a positive social framework. To do so, they engage in a number of different strategies. First, they make a distinction between payment for a donor's services and payment for her eggs, in order to avoid commodifying the eggs themselves. Second, some of them structure their compensation so that donors are compensated for their time, pain and suffering, and/or assumption of risk, rather than for their specific genetic traits. Third, agency decision-makers grant autonomy to their egg donors, respecting their choices about the egg donation cycle. Fourth, decision-makers frame the egg donation as a loving gift. Finally, agency decision-makers attempt to humanize the parties to one another, to evoke sympathy from one side for the other, in order to embed the commercial transaction of the "donation" in an emotional and beneficent framework.

#### Distinction between Payment for Services and Payment for Eggs

Universally, agency decision-makers assert that the fees egg donors receive are for their services, rather than for their eggs. As one Southern California agency director put it, the assumption of risk:

is what a donor's truly paid for, not her eggs. (Director, Southern California Agency)

And when discussing some of the problems with frozen egg banking, another agency decision maker said:

It looks a little bit more like buying the genetic material. You have to be really careful with that. I mean I know they've done that with sperm for years but we actually don't put a price on the eggs. We only do it as a cycle to avoid that. I think it's much better. There's a guarantee of a certain number of mature eggs but people are paying for the cycle. ICSI<sup>641</sup> is included, and the transfer and the ultrasounds and all those things for a cycle which includes frozen eggs. (Director, Southern California Agency)

By technically avoiding paying egg donors "by the egg," agency decision-makers set a limit on the scope of donor compensation meant to minimize any negative impact of commodification, by preventing the assignment monetary value to human gametes.

Similarly, agency contracts, between the agency and the egg donor, the agency and the intended parent, and the egg donor and the intended parent, emphasize that donor compensation is for the donor's services, not for her eggs.

Agency agrees to compensate Donor for each egg retrieval process which Donor undergoes ... regardless of how many eggs are produced by Donor. (Contract between agency and egg donor, Northern California Agency)

Donor shall be paid the Donor's Fee regardless of: (1) the quality or quantity of the Eggs retrieved; (2) whether the Eggs are fertilized in vitro, and result in Embryos; (3) the quality or quantity of the Embryos; or (4) whether Intended Mother ... becomes pregnant after the embryo transfer procedure. (Contract between egg donor and intended parent, Northern California Agency)

Funds provided to Donor shall not in any way constitute payment to Donor for her eggs, and that neither the number or quality of eggs retrieved, whether any embryos are formed, or whether Intended Parents achieve a pregnancy shall affect Donor's right to reimbursement for her time, effort, inconvenience, pain, and

<sup>&</sup>lt;sup>641</sup> ICSI is intracytoplasmic sperm injection; a needle is used to inject a single sperm into an egg in order to facilitate fertilization.

suffering. (Contract between egg donor and agency, Southern California Agency)

The Egg Donor will receive ... the remaining sum of her fee at the time of the Retrieval regardless of the amount or quality of her retrieved oocytes. (Contract between intended parent and agency, Southern Agency)

These contracts seek to minimize the impact of commodification by preventing its most overt possible manifestation: the direct exchange of money for eggs.

Likewise, professional organization documents contain clauses stating that payment to an egg donor is not for her eggs. The ASRM Ethics Committee states that:

Compensation should be structured to acknowledge the time, inconvenience, and discomfort associated with screening, ovarian stimulation, and oocyte retrieval. Compensation should not vary according to the planned use of the oocytes, the number or quality of oocytes retrieved, [or] the number or outcome of prior donation cycles.<sup>642</sup>

Similarly, the draft of the Model Act Governing ART Agencies states:

No ART Agency or Owner shall compensate or permit a Donor to be compensated based on the number or quality of Gametes or Embryos donated. Violation of this section shall be a misdemeanor and punishable accordingly.<sup>643</sup>

And the ABA Model Act Governing Assisted Reproductive Technology also prohibits payment based on the quality of the eggs retrieved:

Compensation may not be conditioned upon the purported quality ... of the gametes or embryos.<sup>644</sup>

Like many agency decision-makers, lawyers practicing in the field of collaborative reproduction arrangements clearly believe that donor compensation is ethically tricky, and have striven to set limits to restrain any negative effects of commodification.

<sup>&</sup>lt;sup>642</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

<sup>&</sup>lt;sup>643</sup> ABA Model Act Governing ART Agencies (DRAFT) § 405.1.

<sup>&</sup>lt;sup>644</sup> ABA Model Act Governing ART § 802.2.

As always, there are exceptions among agency decision-makers that prove the rule. One Northeastern agency director freely admits to giving higher compensation to donors who have produced a large number of eggs in previous cycles (though it should be noted that this stops short of actually compensating a donor based on how many eggs she produces in a particular cycle, and in some ways is a common practice in the field, as "repeat" donors often earn a slightly higher fee, and a donor can only be a "repeat" donor if she has previously had at least a moderately successful cycle; this agency decision-maker simply takes it a step further with her emphasis on the number of eggs produced).

> It's fair and reasonable to pay someone who's a proven donor who's had astounding results.... Average is about, you'll retrieve maybe like fifteen, sixteen, eighteen [eggs]? She's had thirty-six and thirty-seven.... We do expect to pay more for experienced donors with good results.<sup>645</sup> (Director, Northeastern Agency)

Interestingly, this opinion, at odds with the majority of my interviewees, also comes out of the Northeast, where agencies have a number of differences from their counterparts in the rest of the country, as discussed in Chapter Three, "Divergence: Reverse Modeling."

The firm line drawn by agency decision-makers between payment for a donor's services and payment for eggs is at odds with the structure of compensation in sperm donation, where donors are only paid if their samples meet minimum viability criteria.<sup>646</sup> Rene

<sup>&</sup>lt;sup>645</sup> In a traditional fresh donor egg cycle, in which the donor is matched with a specific intended parent or set of intended parents, the more eggs retrieved, the more chances the intended parents have at pregnancy. IVF cycles are plagued with attrition at each stage of the process: not all eggs retrieved will be mature, not all mature eggs will fertilize, not all fertilized eggs will make it to day three (eight cells), not all eight-celled embryos will make it to blastocyst stage on day five, not all blastocysts will implant, and not all embryos that implant will become continuing pregnancies that result in live births. Consequently, more eggs is generally considered to be a good thing, in that it allows the intended parents a better overall chance at bringing home a baby. Additionally, many intended parents desire more than one child, and if they create multiple embryos in a single IVF cycle, they may be able to conceive more than one child over time by freezing any "leftover" embryos and then transferring them later via a frozen embryo transfer, which is a simpler medical procedure that costs only a fraction of the price of a fresh donor egg IVF cycle. Frozen embryos remaining after an intended parent has completed their family are sometimes stored indefinitely (for which the intended parent pays an annual fee), or they are disposed of by donation to another intended parent, donation to research, or a simple thaw and discard procedure.

<sup>&</sup>lt;sup>646</sup> "Women who complete a cycle are paid regardless of how many eggs they produce, yet men are paid only if the sample meets bank standards for sperm count. Otherwise, men receive nothing for that day's donation, a form of piecework compensation in which payment is based on production." Almeling, *Sex Cells*, 68-69.

Almeling argues that one reason for this disparity may be the difference in our cultural conceptions of motherhood and fatherhood. Mothers nurture, but fathers who don't nurture are still fathers. Consequently, although men "draw a short line from sperm to baby," and view themselves as the father of a baby conceived with their sperm, egg donors must "de-emphasiz[e] the importance of the egg in favor of highlighting the gestational or caregiving components and pointing to the recipient as the 'real' mother, the one who nurtures."<sup>647</sup> In this way, egg donors avoid identifying as a mother who fails to nurture—a "bad mother"—because the intended parent is the "real" mother of the resulting baby.

## Structure of Compensation

Whereas asserting a distinction between payment for eggs and payment for a donor's services was a universal strategy to minimize the negative consequences of commodification, only half of my interviewees structured their compensation to achieve the same effect. In order to avoid the specter of eugenics (as discussed in Chapter One, "Introduction," and this chapter, "Implication of Eugenics"), half of the agency decision-makers I spoke with used "flat" compensation structures, in which donor compensation was based on a donor's geographic location or the number of cycles a donor had completed, as opposed to the donor's genotype or phenotype. By paying donors in similar circumstances the same amount, rather than allowing the market to dictate their value based on their personal inherent traits, some agency decision-makers sought to avoid the implication that different women have different worth, depending on their genetics.

Of the agency decision-makers who structured their donor's compensation based on the particular donor's market value, slightly over half of them made a concession to the potential for negative effects of commodification by setting a limit on their donors' compensation, following the ASRM guideline of no more than \$10,000.<sup>648</sup> Between those agency decision-makers who maintain a flat compensation structure, and those who place caps on the compensation they offer to their donors, most of my interviewees make attempts to ameliorate the possible negative consequences of commodification by limiting compensation; they share the idea that very high donor compensation enters into iffy ethical waters, whereas more "standard" compensation is acceptable. This view reflects the ASRM Ethics Committee's opinion that "As payments to women providing

<sup>&</sup>lt;sup>647</sup> Ibid., 162.

<sup>&</sup>lt;sup>648</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

oocytes increase in amount, the ethical concerns increase as well.... High payments, particularly for women with specific characteristics, also convey the idea that oocytes are commercial property."<sup>649</sup> Yet at the same time, most interviewees express nonjudgment of those who deal in higher fees (though some do condemn all higher fees). Fewer than one quarter of the agency decision-makers with whom I spoke allowed their donors to be compensated at market rate, imposing no limitations at all.

Professional organization guidelines also recognize the potentially problematic nature of payment based on the donor's characteristics. The ASRM Ethics Committee suggests that "Compensation should not vary according to … the donor's ethnic or other personal characteristics."<sup>650</sup> Likewise, The ABA Model Act Governing Assisted Reproductive Technology states: "Compensation may not be conditioned upon the purported … genome-related traits of the gametes or embryos. [And] Compensation may not be conditioned on actual genotypic or phenotypic characteristics of the donor…" <sup>651</sup> Interestingly, the draft Model Act Governing ART Agencies prohibits payment to donors based on the number or quality of gametes donated, but contains no clause prohibiting payment based on the genotype or phenotype of the donor.<sup>652</sup>

## Respect for Egg Donor Choices

Another way in which agency decision-makers lessen the negative consequences of commodification on egg donors is by giving donors choices during the process, and respecting those choices. Some donors have very strong feelings about the characteristics of the intended parents to whom they're willing to donate, or about what the intended parents may do with leftover embryos. Agency decision-makers strive to ensure that those choices are executed to the greatest of their ability, or embodied in the legal documents the donors sign.

There are many reasons a donor might refuse to work with intended parents. Often, a donor's preferences have to do with the wellbeing of the child; for example, whether she feels that the intended parents will be able to parent the child as long as the child needs:

<sup>649</sup> Ibid., 306.

<sup>&</sup>lt;sup>650</sup> Ibid., 305.

 $<sup>^{651}</sup>$  ABA Model Act Governing ART §§ 802.2 & 802.3.

<sup>&</sup>lt;sup>652</sup> See Appendix IV for the full text of the ABA Model Act Governing ART Agencies (DRAFT).

Donors would not want to work with somebody that old, either [in her fifties]. I've had donors reject an older recipient. (Director, Northern California Agency)

Other donors are concerned with whether the child would be wholeheartedly welcome:

I had a donor ... and recipient family who wrote to one another and just based on that email that she got from the family, she opted to not donate to them and it was devastating to the family.... What she felt in the email was ambivalence when she said, 'I can't donate to a family who's ambivalent.' (Director, Southern Agency)

Other donors have personal preferences based on religion, marital status, or sexual orientation; agency decision-makers claim to abide by these preferences:

If a donor is very adamant about, let's say, working with a specific type of family, or not working with a specific type of family, then we should never match them with that type of family, even if it's anonymous and that the donor would never even know. (Director, Southern California Agency)

SEEDS has also created a thorough standard addressing the enforcement of egg donor choice, stating explicitly what information the egg donor is entitled to in order to make an informed decision about her donation:<sup>653</sup>

Emotional Disclosure of information to egg donors regarding the intended parents during the matching process of the cycle should include non-identifying information that allows the egg donor to make an informed decision about the family she is donating to. For example, an egg donor should know if they are working with a single parent, a gay family, a heterosexual couple and/or the marital status [of the intended parent]. She should be informed of the following:

They are capable of supporting a family.

Intent for future contact.

<sup>&</sup>lt;sup>653</sup> This standard is also addressed in Chapter Three, "Concern for Egg Donors."

That the agency, clinic, and/or licensed psychologist feel they are emotionally prepared to move forward with this process.

They have not shown signs of verbal abuse to the agency and / or their staff.

There is no known criminal record of drug abuse or physical abuse.

There are no signs of instability or obvious mental illness present.<sup>654</sup>

As discussed in Chapter Three, "Concern for Egg Donors," the agencies involved in the creation of SEEDS would like to see a standard like this followed by all egg donor agencies, thus creating respect for egg donor choice across the board.

One of the major issues that donors must address in their agreements with intended parents is the disposition of any "leftover" embryos from the donor egg IVF cycle. According to a Northern California agency director,

almost every single one [donor] signs something saying that they do not want their embryos donated to other couples or any other purpose. So, yeah, they're pretty clear that this is a donation they're doing to one [intended parent]. (Director, Northern California Agency)

While the disposition of leftover embryos is not something that's under the control of agency decision-makers, it is something that can be addressed in legal paperwork, and agency decision-makers can educate donors to that effect. The ABA Model Act on Assisted Reproductive Technology has a provision that enables egg donors to "condition donation on other reasonable use or disposition restrictions as set forth in a record prior to donation."<sup>655</sup>

Another choice that some agencies allow egg donors to make, which increases their autonomy and thus minimizes the effects of commodification, is which physicians the donor is willing to work with:

There [are] some donors that we have that say, 'I only want to work with Dr. [X],' and we go, 'OK, great,' and then people [intended parents] will ask for that donor and we'll say, 'no, the donor wants

<sup>&</sup>lt;sup>654</sup> "Agency's Responsibility Regarding Emotional Disclosure: Donors," SEEDS Standards.

<sup>&</sup>lt;sup>655</sup> ABA Model Act Governing ART § 204.3.

to work at this office. If you'd like to change to this doctor I'll set you up with a free consult, but this is what she's requested.' And sometimes people are really angry about that, but I think the donor has a right. It's her body, right? (Director, Southern California Agency)

Allowing egg donors autonomy and the ability to make informed choices about their egg donation cycles is one way agency decision-makers minimize the negative effects of the commodification of the donor and/or her eggs.

## Framing Egg Donation as a Gift

Using the rhetoric of gift is another way that agency decision-makers minimize the negative consequences of commodification, by embedding the donor's experience in a positive social framework. Rene Almeling has discussed this phenomenon at length in her book *Sex Cells*, and my findings support her claim that agency decision-makers deliberately speak of egg donation as a "gift" in order to encourage donors and intended parents to avoid thinking about it as a commercial transaction, and instead to see it as a particularly generous act, such as might take place between great friends.<sup>656</sup> This framing takes place at a very high level: even the term "egg donation," used almost universally among agencies and the infertility industry in general (and technically inaccurate, as the "donations" that take place via egg donor agencies are without exception the exchange of eggs or services for money) steers the donor and intended parent to think in terms of gift from their very first contact with the process.

Yet when agency decision-makers speak using the rhetoric of gift, it is heartfelt, and certainly appears to be genuine:

We treat them very well because we know what they're doing well, you know as a mom. It's the greatest gift anybody can ever give to someone. (Director, Southern California Agency)

Perhaps the framework of gift is so ingrained in agency decision-makers that it serves to embed their experience of commodification as well:

<sup>&</sup>lt;sup>656</sup> "In many cases, egg recipients also give the donor flowers, jewelry, or an additional financial gift, thereby upholding the constructed vision of egg donation as reciprocal gift giving, in which donors help recipients and recipients help donors." Almeling, *Sex Cells*, 77.

I give every opportunity I can to teach them [interviewee's children] what it means to be kind to others. And how is being an egg donor any different than that? 'Look at this wonderful gift that this lady I don't even know gave to me, and that is you.' I think it's a beautiful story. I don't think it's shameful. I think it talks about selflessness, generosity, caring compassion. What is there to hide in all of those things? (Director, Midwestern Agency)

Some agency decision-makers compare the benefits of thinking of egg donation as a gift versus as a commercial transaction:

I feel like when you, as a donor, contract with a couple for a cycle, that arrangement should be honored. It should be 'this is for you; it's a gift. It's a gift of my eggs, and it's been a thoughtful gift.' Not 'I just donated a bunch of eggs to the thing [frozen egg bank] and whoever wants to buy them can buy them off the shelf.' (Director, Northern California Agency)

Many agency decision-makers see that these two views can coexist:

I think that what they do is a very selfless gift which is also maybe financially motivated. Not a problem for me. I think it's a beautiful thing to be able to do. (Director, Midwestern Agency)

Even while acknowledging the commodification side of egg donation, agency decisionmakers try to embed a donor's experience in positive social frame, as a beautiful gift, one that is well informed and freely given:

> What they're [donors are] doing is helping build families and I think we need to change the mindset for some people because the donors aren't commodities. They're not being exploited. These women know what they're getting themselves—what they're doing, and obviously there is a financial compensation which helps them, too. So it's women helping women, and I think it's a wonderful thing. (Director, Southern California Agency)

By framing egg donation as a gift, agency decision-makers dismiss the commercial aspects of the transaction from serious consideration, thereby minimizing the importance of the financial transaction in the experience of the donor. A focus on the compassionate side of egg donation, that it is "women helping women," enables donors to see their participation in terms of their own autonomy and generosity, thus

minimizing the potentially negative effects of the commodification of their person and / or eggs.

## Attempts to Humanize the Parties

Half of my interviewees actively encourage egg donors and intended parents to view each other with compassion and respect, an attempt to embed the experience of commodification in a positive social framework. Although agency decision-makers often verbalized a nonjudgmental attitude about donors and intended parents who treated the egg donation process purely as a business transaction, they were also concerned that such a lack of empathy for the other party in the transaction compromised the ability of the egg donor and the intended parents to characterize the donation as a beautiful thing, the creation of families. Most of my interviewees said that the vast majority of their donors had a great deal of empathy for the intended parents, and that their intended parents were grateful to the donors for the miraculous "gift" they had received. However, agency decision-makers acted from the beginning of the donation process to ensure empathy on both sides, and when that empathy was lacking, agency decision-makers took affirmative steps to encourage its development.

As discussed previously, in "An Emphasis on Altruism in Egg Donors," many agency decision-makers felt that donor altruism is a necessarily component of a successful donor egg IVF cycle, because it improves the donor's experience of the cycle (one result of which is to make it more likely that the donor will see the cycle through, even if she encounters difficulties along the way). One agency decision-maker has intended parents write a letter about themselves to their donor, which serves both to humanize the intended parents to the donor, and to encourage gratitude to the donor in the intended parents:

That's one reason why we do the letter, because then they remember that this is for people. This isn't for a dollar amount and it does encourage that commitment level that needs to be there. And like I said, I think most of our donors are genuinely excited to help someone. (Director, Southern Agency)

Other agency decision-makers have made it a standard of practice to tell the donor the story of the intended parents, thus encouraging empathy in the donor. Some agency decision-makers tell donors generally about intended parents at the donor's first interview:

When we meet with them [the donor] we talk a little bit about the intended parents as a whole, how come they've come to us, the journey that they've been on. So we can kind of explain the mindset of the intended parents coming at them. (Director, Southern California Agency)

Another agency decision-maker prides her agency on its education of donors, and the resulting donor empathy:

I think there's a lot of just sort of empathy and altruism that happens just by how good of a job the agency does of explaining who they're [the donor is] working with and what it's going to mean to them [the intended parents]. (Director, Southern California Agency)

Sometimes agency decision-makers give specific examples of their intended parentclient's stories to elicit donor empathy:

> There's so often when just in the interview we're telling them specific stories about intended parents and maybe a story that stood out. So we say, 'you know, these are the types of people you are helping,' ... And so many times, you see the donor kind of tear up because they can put themselves in that position. (Director, Southern California Agency)

Many agency decision-makers tell donors about the specific couple or intended parent who has chosen them.

A lot of the donors come here because they need money to pay their tuition, and they really don't have a sense of any empathy—feel much empathy towards infertile couples. So I—that's why it's good for me to meet with them and tell them why the couple is infertile. (Director, Northern California Agency)

A Southern California agency director maintains a similar practice:

We want them to know about the couple. They typically don't meet that often, but it's really important that they feel comfortable with who they're doing it for so they can be at peace. (Director, Southern California Agency) Agency decision-makers attempt to humanize the intended parents to the egg donors, in an effort to encourage empathy from the donor toward the intended parents, and thus embed the donor's experience in a socially positive framework as well as ensuring that she will complete the cycle.

While most agency-decision makers will facilitate meetings between intended parents and donors when both parties request it, a few agency decision-makers take the practice of telling donors about their intended parents a step farther by affirmatively advocating that the parties meet in person.

> I encourage the couples to meet with the donor. I facilitate the meeting and it's confidential because you want to make an impression upon the donor that this is the most important thing going on for the couple right now, where it's just one thing for the donor, in her life. (Director, Northern California Agency)

Similarly, the director of another Northern California agency sees benefits in meeting for all parties:

I think that for both the donor and the intended parents, having the opportunity to have, say, that semi-anonymous meeting, can make a world of difference. Because the donor gets to see that, 'oh, this is a really nice couple.' Otherwise, sometimes donors sort of have this perspective of 'the intended parents are rich people, and oh my gosh, why am I doing this?' But when they meet, they say 'wow, they're so nice, I really hope this works.' And they're pulling for the intended parents and really hoping ... for a positive outcome, because they want that for them. For the intended parents, they can see that she's such a nice girl. 'I really like her. I feel really good about my choice.' So I think that's a good thing. (Director, Northern California Agency)

For these agency-decision makers, direct contact between donors and intended parents is most likely to result in empathy on both sides.

Sometimes agency decision-makers will attempt to humanize the parties to one another as a specific response to their perception that the donor or the intended parent lacks compassion for the other side: So I might ... really push hard at trying to tug on their empathy strings and see if I can get a little bit of that in there. (Director, Southern California Agency)

Most often, agency decision-makers were responding to their perception that a donor was too motivated by the money. As one director of a Southern California agency director reported, when a donor agreed to a cycle, and then asked for more money for the same cycle, threatening to go elsewhere if she was refused, her agency replied candidly:

> We just say, 'Look, what you're doing right now, this is who it's going to affect [intended parents] and this is the domino effect that's going to happen if you make this choice [to back out of the cycle], but it's yours to make. (Director, Southern California Agency)

While most of the agency decision-makers' attempts to humanize the parties involve encouraging empathy in donors for intended parents, sometimes agency decisionmakers felt they needed to do the opposite. When, on occasion, intended parents spoke about egg donors as if they were commodities, or as more obligated to the intended parents "because it was their job" than the agency employees felt was appropriate, agency decision-makers said that they tried to give the intended parents some context about the donors to humanize them and encourage empathy.

> You get some intended parents who are just 'this is a commodity and they should be treated as such,' so we try and humanize them, the donors to the intended parents. (Director, Southern California Agency)

The director of a Southern agency tries to induce guilt among intended parents so they will feel empathy for their donor:

I like to call people on their behavior sometimes just by—if I get an email from a family and I'm interacting with them post-retrieval and they have asked me nothing about their donor, I will interject, 'oh your donor is [OK].' Because I'm like, 'come on, I need you to care about what happened to her, she's a person.' (Director, Southern California Agency) And when frustrated by intended parents' particularity about donors' physical characteristics or genetic traits, one agency decision-maker reminds the parents that the donors are people who have made the generous decision to undergo this process:

I also emphasize to my couples, because some people are frustrated that they can't get exactly what they want in a donor, and I remind them that there's a very limited pool of people who are willing to inject themselves with hormones for three weeks and then go under anesthesia for people they don't know. You know, we're lucky that anybody's willing to do that. (Director, Northern California Agency)

#### **Explanations and Ultimate Joy**

Agency decision-makers' comments about egg donor compensation, intended parent attitudes toward donors, frozen egg banking, clinic treatment of donors, and donor altruism reveal that the vast majority of them harbor some ambivalence about the commodification aspect of egg donation, despite the fact that commodification lies at the heart of their business. This ambivalence takes shape in several different strategies intended to minimize any negative consequences of that commodification. What remains unclear is precisely what they find ethically troublesome, given that at baseline, they are all presumably accepting of commodification; if not, why would they engage in running a business in which the fundamental premise is the exchange of eggs/egg donor services for money? Certainly a general sense of distaste for commodification is a theme that runs through my interviews; this view reflects the feminist theory that commodification compromises our basic humanity, and is a view shared by society at large.<sup>657</sup> I propose two main possible sources of ethical disquiet for agency decisionmakers: first, the implication of eugenics inherent in providing a database of egg donors, to be chosen based at least in part on their genetic and physical traits.<sup>658</sup> And second, the threat to traditional concepts of family implicit in egg donation; not how

<sup>&</sup>lt;sup>657</sup> See, e.g., Spar, *The Baby Business*; Mundy, *Everything Conceivable*; and Miriam Zoll, *Cracked Open: Liberty, Fertility, and the Pursuit of High Tech Babies, A Memoir* (Northampton, MA: Interlink Books, 2013).

<sup>&</sup>lt;sup>658</sup> To the extent that donors are categorized by their genetic traits, the practice echoes that of "positive eugenics" from the early twentieth century United States. Kevles, *In the Name of Eugenics*, 85. Kass, *Toward a More Natural Science*.

many parents a family should have, or what their sexual orientation should be, but rather the challenge to our societal definition of motherhood.<sup>659</sup>

### Implication of Eugenics

Although none of my agency decision-maker interviewees mentioned eugenics, two of the field professionals I spoke with did. One mental health professional criticized frozen egg banking, in much the same way as agency decision-makers, but taking it one step further and noting that the purchase of eggs from a frozen bank based on a donor profile, without a direct agreement with the donor,

leans a little more backward toward eugenics, which is where we were probably over twenty years ago. (Mental Health Professional)

She believes that the lack of connection between egg donor and intended parent encourages intended parents to choose their donor by phenotype. A reproductive endocrinologist pointed out that genetics is important to every job, but that egg donation has the potential to take that valuation a step too far:

> Now getting back to paying the donors, another aspect of it that people don't like to deal with has to do with the genetics of it. Because I can imagine in five years you're going to be able to have genetic profiles of donors which actually might make them more or less attractive. And on an official level we don't like to recognize genetic differences even though they're obvious and we reward people for having certain genetic things like beauty, athletic skill.... The bottom line is [that] at some level genetics is underlying almost everything. But I think the idea of valuing things differently on the basis of their genetics is something that is very ethically troublesome.... Even though the marketplace does it for you. (Reproductive Endocrinologist)

<sup>&</sup>lt;sup>659</sup> "It is not just that individual women have fewer eggs than individual men have sperm, or that eggs are more difficult to extract, that produces both high prices and constant gift-talk in egg donation, but the close connection between women's reproductive bodies and cultural norms of caring motherhood." Rene Almeling, *Sex Cells*, 84.

This physician finds egg donation as currently practiced somewhat problematic because of its overt valuation of genetics, and foresees an inflation of that problem with increased availability of egg donors' genetic information.

Similarly, the ASRM Ethics Committee sees eugenics as a problem with payment to egg donors based on their characteristics:

High payments are disturbing because they could be used to promote the birth of persons with traits deemed socially desirable, which is a form of positive eugenics. Such efforts to enhance offspring are morally troubling because they objectify children rather than assign them intrinsic dignity and worth.<sup>660</sup>

The specter of eugenics is probably the issue that agency decision-makers are grappling with when they discuss their concerns about intended parents viewing egg donors as commodities, their issue with the severing of the link between donor and intended parent in frozen egg banking, the limits they set on donor compensation, their criticism of clinic treatment of donors, and their desire for egg donors to have an altruistic motivation. And the possibility of eugenics is likely what they are trying to combat by asserting that a donor's compensation is for her services rather than for her eggs, by respecting egg donor choice, by framing egg donation as a gift, by attempting to humanize the parties to each other, and by limiting the amount of donor compensation and basing its determination on characteristics other than genotype and phenotype. Ultimately, most agency decision-makers are distressed by the thought of reducing a donor to her component parts, as if she was no different than any other material good:

I mean, it's not like an insurance policy, it's not like an insurance claim, it's not ... like letters of credit and finance ... It's really personal. For lack of a better term. (Director, Southern California Agency)

And they certainly don't want egg donors to feel the full impact of commodification:

I definitely encourage [donors meeting with intended parents], but it can't be in a way that makes the donor feel like she's willing to give her eggs ... and now what if the couple doesn't want her. I mean, it's just not a good situation. (Director, Northern California Agency)

<sup>&</sup>lt;sup>660</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 306.

"Eugenics" is not a word that agency decision-makers use. Yet concern about eugenics is, at heart, what drives a number of the concerns about commodification shared by the majority of my interviewees. They are ethically uncomfortable with the parsing of a donor into her genetic components, followed by the evaluation and selection of that donor based largely on her outstanding genetic traits, or at least traits that intended parents believe or assume to be genetic in origin. Treating a donor in those terms both threatens the donor's own humanity and dignity, and that of the members of the society that allows such treatment by devaluing both the source of the genetic "good" and, simultaneously, all of the genetic "not-so-good" (e.g., people with traits deemed socially undesirable) that makes up our diverse population.<sup>661</sup>

#### A Threat to Traditional Concepts of Family

Motherhood has, until the advent of egg donation, been a fairly certain prospect for women. While no woman was guaranteed the experience of motherhood, if she did become pregnant and bear a child, there was no question about who the mother was.<sup>662</sup> This is in stark contrast to fatherhood, which has never been certain. In addition, our society tends to believe in an archetype of mothers as loving, caring, and devoted to their offspring, and of fathers as providers for the family.<sup>663</sup> As Rene Almeling discusses, this leads to a need to separate the concept of motherhood from the donation of an egg.<sup>664</sup> If a woman's egg is the precursor to her child, the beginnings of motherhood, and she abandons it to another woman, then she breaks the motherhood archetype.<sup>665</sup> Thus, selling eggs is problematic because it implies that the donor has failed as a

<sup>&</sup>lt;sup>661</sup> See Kevles, In the Name of Eugenics.

<sup>&</sup>lt;sup>662</sup> For a discussion of how reproductive technology has introduced entirely new definitions of motherhood and family, see Janet Dolgin, *Defining the Family: Law, Technology, and Reproduction in an Uneasy Age* (New York and London: New York University Press, 1997), 188 et seq.

<sup>&</sup>lt;sup>663</sup> And in the case of sperm donation, providers of genetic material. "Men cannot help but see themselves as fathers, because they are providing sperm in a culture that equates male genetics with parenthood." Almeling, *Sex Cells*, 164.

<sup>&</sup>lt;sup>664</sup> "Women [egg donors] can define themselves as not-mothers, because they are providing eggs in a culture in which it is possible to separate female genetics from parenthood. This is more than just a possibility for egg donors, though; it is a necessity given the censure of 'bad mothers.'" Ibid.

<sup>&</sup>lt;sup>665</sup> For a related discussion of the continuing gendered division of labor in the household, see Paula England and George Farkas, *Households, Employment, and Gender: A Social, Economic, and Demographic View* (Aldine Publishing Co., 1986).

mother.<sup>666</sup> If, in contrast, a donor sees herself as the beneficent donor of a chance of parenthood to another woman, and as separate from any potential motherhood (literally separated by the number of biological processes that must take place between her donation and the existence of a baby: fertilization, transfer, implantation, gestation, and birth), then instead of invoking psychological distress about her "failure" at motherhood, egg donation can instead be a source of the great psychological satisfaction of helping someone else to achieve a much-desired goal, the creation of a family.<sup>667</sup> Therefore, commodification of the donor's services, and her "innate" philanthropic nature as a woman and a mother, is more ethically acceptable than commodification of her eggs.<sup>668</sup>

Agency decision-makers bear this theory out, as over half of them were careful to make a distinction between the egg donor and the mother (intended parent).

> The egg donor is not the mom ... when the egg donor comes in, that's how we present it to her as well, and that's how we present it to the parents, because they are the parents. (Director, Southern California Agency)

Agency decision-makers are concerned that intended parents understand the distinction, that they will be the parents of the child:

You really need to think about what's your life going to be like in the future with your children, because they're your children, they're not her [the donor's] children. (Director, Southern Agency)

<sup>&</sup>lt;sup>666</sup> As noted in Chapter Three, note 419, "When a woman calls her donation 'just an egg,' she is removing her herself from any suspicion of being a bad mother, the kind who would sell her baby." Rene Almeling, *Sex Cells*, 167.

<sup>&</sup>lt;sup>667</sup> By calling her donation "just an egg," a donor is "underscoring her contribution to the recipient's motherhood project, a contribution that she defines as a 'huge gift." Ibid.

<sup>&</sup>lt;sup>668</sup> Framing egg donation as a gift shapes the experience of commodification for donors, intended parents, and agency decision-makers. "Commodification is not a generic or uniform process, and it can result in different kinds of outcomes for different kinds of people in different kinds of situations." Ibid., 171. L.D. de Castro makes a similar argument regarding organ donation: "Compensated donation and altruism are not incompatible." Yet de Castro does not advocate for a completely free market in organs, but rather for a compensation-based organ donation scheme "fitted with safety nets to ensure that gains in the number of donated transplantable organs are not cancelled out by injustices in the allocation of organs or violations of the requirement for free and informed donor consent." L.D. de Castro, "Commodification and Exploitation: Arguments in Favour of Compensated Organ Donation," *Journal of Medical Ethics* 29 (2003): 142-146.

One Midwestern agency director actually discourages ongoing contact between donor and intended parents, specifically for fear of blurring the line between donor and mother:

> I think for an intended mother she's trying to ... wrap [her] brain around this way of family building and I think there is this element of concern that are they going to bond, are they going to truly feel like it's 'theirs.' All of us on the other side of the process know, of course, of course, of course. But they've got to figure that out in due time for themselves. If there is this, not interloper, but this presence of this donor in their lives, that's muddying the waters. (Director, Midwestern Agency)

Agency decision-makers were also wary of egg donors whom they felt were failing to make the distinction between donor and mother for themselves:

The other thing I have to impress upon the donor is that she has got to be clear that she sees herself giving this couple a chance to have a child. If she sees herself giving a child to this couple, then I don't want to work with her.... That would be like an adoption. It would be too much of a loss. (Director, Northern California Agency)

Egg donors whom agency decision-makers felt would have a difficult time separating from their eggs—i.e., those who harbor maternal feelings toward their eggs—are routinely rejected from the applicant pool:

If, when I'm interviewing a donor, she says that meeting the couple is a requirement, I won't work with her as a donor. Which sounds really harsh, except I've learned from experience, that's someone who's likely to back out. Because she is too attached to her eggs. (Director, Northern California Agency)

Some such donors actually state a desire to play a motherhood role in the children's lives:

I had a donor who applied once and she very much wanted to be involved with the family and the children and I didn't think that was appropriate. We ended up not accepting her because I thought she had too much of an investment in those children, as if they were her own, but really it's her genetic information. There has to be some kind of healthy split off in that. (Director, Southern Agency)

Of course, a statement distinguishing the donor and the mother appears in every egg donation contract, since that clause is the very purpose of the arrangement: for one women to give her eggs to another, so that the other may become a mother. Similarly, the ABA Model Act Governing Assisted Reproductive Technology contains at least two clauses addressing the issue of motherhood:

SECTION 602. PARENTAL STATUS OF DONOR. A donor is not a parent of a child conceived by means of assisted reproduction.

SECTION 603. PARENTAGE OF CHILD OF ASSISTED REPRODUCTION. An individual who provides gametes for, or consents to, assisted reproduction by a woman as provided in Section 604 with the intent to be a parent of her child is a parent of the resulting child.<sup>669</sup>

And, with similar effect,

Except as provided in this Act [i.e., for surrogacy arrangements], the woman who gives birth to a child is presumed to be the mother of that child for purposes of State law.<sup>670</sup>

This concern with making a distinction between donor and mother, exhibited by more than half of my interviewees, is evidence of another source of ethical disquiet: the challenge that egg donation poses to traditional concepts of motherhood. Consequently, donors are framed as beneficent philanthropists, another female archetype, rather than neglectful mothers.<sup>671</sup>

## Joy in the Face of Ambivalence

The vast majority of agency decision-makers expressed concern about the potentially negative consequences of the commodification that is inherent in their business, but they dealt with such ethical issues as best they could—and quite effectively, given the

<sup>&</sup>lt;sup>669</sup> ABA Model Act Governing ART §§ 603-604.

<sup>&</sup>lt;sup>670</sup> Ibid., § 701 [Alternative B].

<sup>&</sup>lt;sup>671</sup> "Women talk with pride about the 'huge' gift they are giving to recipients." Almeling, Sex Cells, 20.

number of egg donors who report they are satisfied with their experiences, and return to do repeat cycles—and decision-makers ultimately find that the ethical issues raised by commodification are typically trumped by the ends of egg donation: the creation of babies and families.<sup>672</sup>

It just moves me and reiterates why I do what I do. (Director, Southern California Agency)

Agency decision-makers, for the most part, feel that the motivations of others in their position are not malicious:

I think for the most part, most people that are in this industry really are in it for the right reasons. They're really working to help these intended parents become parents. (Director, Southern California Agency)

While most of my interviewees were ambivalent about commodification, they attempted to minimize its negative effects by framing the experience of the donors and intended parents in a affirmative social light. By limiting the extremes of donor compensation, structuring compensation as pay for donor services rather than for eggs or genes, encouraging empathy, and focusing on a rhetoric of "gift" and family, rather than on the business side of the transaction (but again, many with nonjudgment of clients who *are* focused on the business side), my interviewees tried to embed the experience of commodification in a positive, altruistic way. These actions are in accord with Rene Almeling's argument, in her call for a more nuanced interpretation of commodification, that how the commodified person experiences the commodification should influence how we judge that particular incidence of commodification inherent in egg donation placed great emphasis on the personal aspect of donation.

In the end, while participating in what is clearly a process of commodification, agency decision-makers were uncomfortable with the idea of commodification and attempted

<sup>&</sup>lt;sup>672</sup> My interviewees report high satisfaction and repeat cycle rates among their donors. See also: Nancy J. Kenney, Ph.D. and Michelle L. McGowan, Ph.D., "Looking Back: Egg Donors' Retrospective Evaluations of their Motivations, Expectations, and Experiences During their First Donation Cycle," *Fertility and Sterility* 92, no. 2 (Jan. 2010): 455; S.C. Klock, A.M. Braverman, and D.T. Rausch, "Predicting Anonymous Egg Donor Satisfaction: A Preliminary Study," *Journal of Women's Health* 7, no. 2 (Mar. 1998): 229-237.

<sup>&</sup>lt;sup>673</sup> As Rene Almeling observes, the way that egg donors "respond to the organizational framing of paid donation … *does* have consequences for how individuals experience bodily commodification." Almeling, *Sex Cells*, 111.

to contextualize it so that donors and intended parents experience the commodification in a positive light, thereby mitigating any potential ethical concerns that can arise from such transactions. As such, most egg donors and intended parents, according to my interviewees, walk away from the process feeling good about their participation. Likewise, agency decision-makers feel good about their role, despite the commodification aspect of egg donation:

> I really found something that I gravitated towards because, obviously, you're helping people ... seeing families who are incomplete emotionally and they feel like they need to create a family or they need children. And helping them in that small way [is] very fulfilling and emotionally gratifying. (Director, Southern California Agency)

And for those intended parents who experience success in creating the family they long for, there is no greater gift.

### CHAPTER SIX

#### The Deliberate and Incidental Avoidance of Exploitation

*"These are young women. A lot of times, they don't really understand." (Director, Southern California Agency)* 

To exploit others is to take unfair advantage of them.<sup>674</sup> In the context of egg donation, exploitation is the act of using an egg donor as a means of profit or other benefit, to the donor's emotional, financial, or physical detriment.<sup>675</sup> An young woman may be exploited if she is offered very high compensation for donating her eggs, thus inducing her to participate in a donor egg IVF cycle even though it might do her psychological or physical harm. A potential egg donor might also be susceptible to exploitation if she is too immature to make sound choices for her own wellbeing, or if she lacks the proper education to inform those choices. Finally, a donor may be exploited if she engages in egg donation after making a fully informed choice to so, but the respect to which she is inherently entitled is violated by some means; for example, if her privacy is compromised, or if she suffers poor medical treatment or inadequate legal representation during the course of her egg donation.

Next to commodification, exploitation is the most easily recognized ethical issue in egg donation.<sup>676</sup> Exploitation is related to commodification, but the one may exist without the other. While commodification, in the context of egg donation, is the exchange of money for a donor's eggs and/or her services, exploitation is when the donor is unfairly taken advantage of. A donor may be exploited via offers of high compensation —through the act of commodification—but she also may be exploited if she is convinced to donate her eggs for no remuneration, if doing so compromises her

<sup>&</sup>lt;sup>674</sup> Stanford Encyclopedia of Philosophy, available from plato.stanford.edu/entries/exploitation/; Internet; Accessed 1 July 2014.

<sup>&</sup>lt;sup>675</sup> NB: I discuss "exploitation" in this chapter, as defined here. Some of my interviewees refer to "coercion," though I believe they mean exploitation. Coercion is when one party forces another to do something. I am working under the assumption that nobody forces someone to become an egg donor, but that young women's youth, ignorance, and financial distress may be unfairly taken advantage of, and thus they may be exploited.

<sup>&</sup>lt;sup>676</sup> Media coverage of egg donation often focuses simultaneously on commodification and exploitation: Darnovsky and Fogel, "Let's Not Expand the Market in Women's Eggs," *Huffington Post Los Angeles;* Griffin, "The Cost of Life," *Huffington Post Women;* Johnson, "Egg Prices at Top Universities," *The Washington Post;* Rabin, "Demand for Donor Eggs Soars," *The New York Times;* Tuller, "Payment Offers to Egg Donors Prompt Scrutiny," *The New York Times.* 

wellbeing. Thus exploitation can be an element of commodification, but can also exist in separate from financial transactions.

In this chapter, I explore how agency decision-makers deliberately and incidentally attempt to minimize the likelihood of exploitation of their donors. Some of them recognize that there is the potential for exploitation in their business. Many agency decision-makers who have been in the industry since its inception mentioned the advent of the internet as a business-changing moment, in which agencies proliferated. Without any sort of regulation, there were no controls or standards for recruiting, screening, or educating donors. Since the internet provided access to a vast pool of potential egg donors, unscrupulous individuals could suddenly and with ease recruit women as donors, fail to educate them, and pay them vast sums of money (or steal the fees they were supposed to receive), all without ever renting an office space or meeting the donors in person.

Only some of the agency decision-makers I spoke with were explicitly concerned with avoiding exploitation of their donors—commodification was a much more often recognized phenomenon. Most mentioned that they only accepted a small fraction of their donor applicants, who in addition to meeting medical and genetic criteria, are screened for emotional maturity, an understanding of the commitment required by egg donation—during the cycle and beyond if a child is born—and sometimes for financial distress. Some agency decision-makers felt that donors motivated solely for financial reasons were more likely to be in dire financial straits, and were therefore at risk for exploitation. Consequently, a few agencies, citing donors' youth and inexperience, even check a donor's financial background in order to establish that the offered compensation is not sufficient to be considered exploitative for a particular donor.<sup>677</sup> Most, however, deem this step to be invasive of a donor's privacy and prefer to rely on a donor's capacity to make good decisions for herself.

Overall, as with issues of commodification, there is a fair amount of ambivalence among agency decision-makers about how to minimize the potential exploitation of donors. Some agencies defer responsibility onto clinics or onto the donors themselves, adopting the view that the physicians are the proper people to ensure informed consent, and that with complete information, these women are perfectly capable of making a decision appropriate to their situation. Other agencies take on more responsibility for minimizing exploitation, with programs to thoroughly educate donors and checks on their financial situation. Those agency decision-makers who recognize the possibility of

<sup>&</sup>lt;sup>677</sup> There is, of course, no real way to tell whether a particular amount of offered compensation would be exploitative for a particular donor; such things depend very much on the person in question, her situation, her beliefs, her way of being.

exploitation agree that its avoidance is the desired goal, yet they differ on how best to achieve that goal, and whether their actions are explicit or implicit attempts to prevent exploitation.

## Egg Donors as Empowered Agents

A minority of the agency decision-makers with whom I spoke believed that exploitation of eggs donors was not a problem in their business. These decision-makers tended to view egg donors, and women in general, as capable of making decisions about their bodies and their participation in egg donation, without the patronization or interference of regulatory or other bodies, as long as the women were educated and thus enabled to make an informed choice.<sup>678</sup> Compensation, according to this perspective, is something that should generally be left to donor choice and market forces, and does not pose a risk to donors, as they are capable of refusing compensation for an action that will do self-damage. Another part of this stance, that egg donation is simply not exploitative, is the idea that egg donation does not have enough potential negative consequences to merit the amount of attention it is often given in the press and society in general.

# No Risk of Exploitation from Egg Donation

Some agency decision-makers felt that the way the industry functions now does not expose egg donors to possible exploitation:

If there needs to be regulation [of egg donation], it's not so much in the area of protecting donors, because I don't think donors are really being exploited. (Director, Northern California Agency)

One agency director cited the high quality of medical care in Northern California as a reason that she is unconcerned about exploitation of egg donors: according to her, egg donors are

OK already.... We have a higher standard of medical care here than in other places. (Director, Northern California Agency)

<sup>&</sup>lt;sup>678</sup> For a feminist theoretical perspective on this issue, see Shultz, "Questioning Commodification," 1841; Johnston, "Paying Egg Donors," 28-31; Mundy, *Everything Conceivable*.

Other agency decision-makers believe that the process of egg donation is just not that big of a deal:

It's not that invasive of a procedure. We're not talking about giving up your kidney.<sup>679</sup> (Director, Northern California Agency)

This agency decision-maker emphasized the relatively minimal physical commitment involved in donating one's eggs as opposed to donating a kidney: although the donor is committing to the potential that she will have genetic offspring out in the world, her own body will not be changed dramatically by the experience; she will not undergo a major abdominal surgery and live the remainder of her life with the knowledge that she must be cautious with her one remaining kidney. Similarly, another Northern California agency director puts into context the experience of being an egg donor in a typical donor's life:

> Donors generally are kind of like, 'oh, you know, I'm doing this. I don't mind doing it. It's not a huge inconvenience. It's perfectly fine on my body, and I could use the extra cash.' So for them, it's not like a life-altering, changing, crazy experience. (Director, Northern California Agency)

These points of view appear to discount the potentially damaging psychological consequences of egg donation that concern the majority of my interviewees (discussed in the previous chapter and in this chapter), but even agency decision-makers who are unconcerned about exploitation sometimes use the rhetoric of gift to contextualize the donors' experience and explain why exploitation is not happening in egg donation:

They're [egg donors are] compassionate, they're empathetic, but they're goal oriented. The egg donors, they have a lot of self assurance and self confidence. They really do. I mean, I could even go so far as to say in many of them, there is even a thread of narcissism that runs through them. They think that they have great genes, they're sharing them, and they're also doing something for themselves in return. They're getting some compensation and they're using it to make a difference in their [intended parents'] lives. Win-win. (Director, Midwestern Agency)

<sup>&</sup>lt;sup>679</sup> See note 627 for an explanation for why this agency director might view egg donation as "not that invasive."

## Donor Autonomy and Education

Although a minority voice, the agency decision-makers who were unconcerned about exploitation shared a belief that women, young though they may be, are capable of making decisions for themselves, and that to imply that they are incapable of making good decisions is patronizing.<sup>680</sup> One Northern California agency director stated her belief that once women reach the age of majority, they should be allowed to make the decision about whether or not to become an egg donor. A Midwestern agency director was more emphatic about it, referencing the evolutionary power of women:

When I hear this 'we're preying upon women,' I just say, 'get out of town!' We're not preying on women. Women are extraordinarily powerful and ... since the beginning of time women have truly had the advantage from an evolutionary perspective, being able to capitalize on their bodies. They have! Men could never do that. Ever! If you think that's not power and full of ingenuity, then you're wrong. Biologically, we're very expensive, and if we can leverage that, more power to you. ((Director, Northern California Agency)

Two of the field professionals I interviewed echoed this thought, in terms of modern legal tenets:

In my industry, and my training, we believe in autonomy and letting patients make these decisions for themselves, especially regarding reproductive risk. (Genetic Counselor)

And a reproductive endocrinologist explained why it's not exploitative to ask egg donors to undertake risk for remuneration:

Some absolutists might say, 'well then, this is totally unethical because how could you possibly ask somebody to put their life at risk for nothing other than remuneration?' But hell, don't cops and firefighters and people do that? And how about the nineteen-yearolds we enlist in the armed services? (Reproductive Endocrinologist)

<sup>&</sup>lt;sup>680</sup> See Shultz, "Questioning Commodification," 1841; Johnston, "Paying Egg Donors," 28-31; Mundy, *Everything Conceivable*.

Agency decision-makers who hold the belief that egg donation is not potentially exploitative, however, also emphasize the importance of educating donors in order that they are able to make an informed decision in their own best interests.<sup>681</sup>

I look at this as more of an empowered feminist viewpoint. I think if you screen a young woman appropriately, I happen to think that she has the wherewithal to make informed consent. (Director, Midwestern Agency)

Or, as the director of a Southern California agency says,

I'm in the school of thought that everyone is accountable for their own actions, so as an agency, my job is to just give everyone the proper education and the proper information, and then let the adults make their decision. (Director, Southern California Agency)

A genetic counselor agreed, saying also that young women deserve the opportunity to become egg donors if they wish:

I think egg donation can be a win-win situation for everybody. I mean, if the donors are well counseled and understand what they're getting into and want to do it, I think it can be done. I feel like it's not fair to just limit this possibility. I guess I believe that women can make their own decisions about these things. If they want to do it they should be able to do it. (Genetic Counselor)

One Midwestern agency director felt strongly that limiting a young woman's ability to become an egg donor, or attempting to talk her out of it during the education process, was nothing more than patronizing.

It's not this bogey man thing. It's informed consent, it's relatively safe, takes a certain kind of person to be able to do it, a certain mind set about what it is that they're donating and what their feelings are about it. Women are very clear thinking. It just makes me nuts when I hear it. (Director, Midwestern Agency)

<sup>&</sup>lt;sup>681</sup> This is an expanded vision of informed consent, which legal doctrine is confined to questions of medical consent. Egg donation requires consent not just to medical risks, but also to social and emotional risks. For the development of informed consent doctrine in the United States, see Starr, *Social Transformation of American Medicine*, 388-393.

She also criticized the early days of egg donor education:

There used to be sort of this approach that it was almost like, not talking a donor out of it, but, again, trying, 'are you sure? Are you really sure?' Again, I just that speaks to—it's almost patronizing. It really is. (Director, Midwestern Agency)

## Patronizing Egg Donors through Caps on Compensation

One of the most common complaints from the minority of agency decision-makers who believed in empowerment rather than any potential exploitation (or commodification) was that caps or other limits on donor compensation are patronizing of the donors.<sup>682</sup> Even a few agency decision-makers who had some concerns about the commodification aspects of egg donation supported the free market version of donor compensation. These agency decision-makers together felt that allowing egg donors to request the compensation of their choice—to place a high value on themselves—and the free market to set any limits on compensation, was to empower the donors.<sup>683</sup> Access to the economic market via egg donation, in this view, enables donors to realize their market worth, as with any other job, and helps to subvert a long history of mistrust of women's judgment and their relegation to the private sphere. And interestingly, such access to the free market, in some cases, can lead to the increased empowerment of women traditionally subordinated by means of their race or ethnicity, as well as their sex: some egg donors with minority ethnicities can command a higher compensation than white egg donors, because of their rarity.<sup>684</sup>

Of the minority of agency decision-makers who expressed the opinion that there should be no limits to donor compensation, some simply felt that the economic market should be the only "regulation" of donor compensation:

<sup>&</sup>lt;sup>682</sup> In part, this belief stems from the historical exclusion of women from the "public sphere;" women have had much more limited access to the economic market than men, and these interviewees feel that capping donor compensation is a continuation of that history. According to feminists Julie Nelson and Paula England, "women, love, altruism and the family are, as a group, [viewed as] radically separate and opposite from men, self-interested rationality, work and market exchange." Julie A. Nelson and Paula England, "Feminist Philosophies of Love and Work," *Hypatia: A Journal of Feminist Philosophy* 17, no. 2 (Spring 2002): 1-18.

<sup>&</sup>lt;sup>683</sup> This view is the other side of the coin: freeing women's access to the economic market is empowering, exactly the opposite of what they've historically experienced. See especially Johnston, "Paying Egg Donors," 28-31.

<sup>&</sup>lt;sup>684</sup> See Almeling, *Sex Cells*, 173.

Whatever the market will bear. (Director, Northern California Agency)

Several decision-makers compared donor compensation to the compensation of professionals involved in egg donation, pointing out that no other party in egg donation was subject to regulatory (or rather, professional organization) limits:

This is another thing that's not fair. Some of these clinics will put a ceiling on the donor's compensation. For example, [a prominent California infertility clinic]. The maximum a donor can receive there is \$10,000. Well, there's no maximum limit put on what the fertility physician is paid. So I think that's a great disparity. (Director, Northern California Agency)

And another agency decision-maker:

What right do they [the ASRM] have to regulate the compensation of a donor? When the physicians' and nurses' salaries are not regulated? (Director, Northern California Agency)

A reproductive endocrinologist failed to see anything unethical, either in terms of commodification or exploitation, in unlimited donor compensation:

In terms of compensation, why in the world should there be any arbitrary limit placed on the compensation? ... But what are you going to say? Well, it's unseemly if they make more than \$10,000? Are you kidding me? ... A few years ago there were people putting ads in *The New York Times*, 1400 college boards, Ivy League degree, you want my eggs one hundred grand. Well, why the hell shouldn't that be the case? ... A top professional ball player is going to make twenty million bucks a year just for genetics. Why shouldn't a woman sell eggs for genetics? ... I think they were just arguing that well, if you pay them too much then it becomes an incentive. Well, that's like quibbling like gee, would you sleep with me for five dollars? Hell no. Would you sleep with me for five million dollars? Well, I might think about it. And so that old joke about we know what you are, we're just quibbling the cost of doing business. (Reproductive Endocrinologist)

In these agency decision-maker's (and reproductive endocrinologist's) eyes, any limits to egg donor compensation are inherently patronizing of the donor.

By making that statement [that donor compensation should be limited], you're saying that a woman doesn't have the capacity to make her own decisions regarding her body. I take great offense to that and I think that there is no financial coercion if the appropriate measures are taken in the screening process. (Director, Midwestern Agency)

Similarly, an attorney who practices in the field sees it as a matter of legal agency:

I don't think you can artificially set a compensation limit. It sort of presumes that the woman, the donor, has no ability to make an informed decision for herself. (Family Formation Attorney)

Part of these decision-makers' objection to caps on donor compensation is that such caps prevent egg donors from engaging in self valuation. These decision-makers believe that donors should be able to request whatever compensation they feel makes donating worth their time and effort, and leave the rest to the economic market.

This is their body and they determine their own value as far as their time and their pain and suffering. Whatever it's worth. (Director, Southern California Agency)

They point out that allowing donors to request their own fees might make available to intended parents donors with particular characteristics, who would otherwise decline to donate.

Maybe somebody's a professional athlete, for instance, and they might have to take off two to three months of what their job is and ask what the cost loss would be. And then they would be able to charge a higher amount because it's the only way they could feasibly do it. (Director, Southern California Agency)

A Northern California agency director says similarly,

I have one donor who asks for [over \$10,000] and, frankly, she's booked all the time. She is absolutely gorgeous. She had like a perfect SAT, perfect ACT, great 4.0 GPA. She's stunning. She's in super shape. She does great egg retrievals. And she wants [over \$10,000]. And for her, it's like, 'look, this is what my time is worth. This is what I'm giving up'—because she does fitness competitions. It's like 'when I do those, if I'm doing hormone injections, I lose some of my season that I can do.' (Director, Northern California Agency)

Or, stated simply by a Midwestern agency director,

It's 2014, and the criteria in a particular egg donor that is important to an intended parent might be very hard to come by if you do not incentivize her for her time and energy. (Director, Midwestern Agency)

A reproductive endocrinologist sees no problem with allowing egg donors to determine their own value as a donor:

If you're paying somebody to do something risky, theoretically in a free market they should be deciding for themselves whether that's worth it.... At some point they become more of a nature of psychology almost than ethics, because we do allow people to put themselves at risk for compensation, right? I mean, every day. (Reproductive Endocrinologist)

Or, as a Northern California agency director puts it:

We do live in this capitalist society, and they realize their value, and I don't think you can fault them for that. (Director, Northern California Agency)

Although this position was in the minority among my interviewees, some agency decision-makers were unconcerned about the potential exploitation of egg donors, because they failed to see such potential in the industry, because they believed in the agency of women, because they found such caps to be patronizing of women, or all of the above. Often coincident with this lack of concern about exploitation was a lack of concern about commodification. These interviewees saw egg donation as a win-win; as long as donors are well educated, they are empowered to make appropriate decisions for themselves, and if they choose to donate their eggs, they are helping someone to build a much-wanted family. It is, in its essence, a feminist perspective of empowerment.<sup>685</sup> These interviewees also see the donors' ability to command high fees

<sup>&</sup>lt;sup>685</sup> In particular, it is empowerment in its most basic form: recognizing the capacity for women to make decisions, big and small, for themselves, the same way that men already do. See Johnston, "Paying Egg Donors," 28-31.

on the market as a good, empowering thing that also has a positive end result, building a family.

# Complaints about the ASRM Cap on Egg Donor Compensation

Some agency decision-makers who criticized caps on compensation nonetheless abide by the ASRM guideline on compensation, with its maximum of \$10,000 per cycle.<sup>686</sup> Most of these agency decision-makers criticized the ASRM cap for its outdated monetary value, rather than its intent to prevent exploitation, and argued that they felt compelled to follow the ASRM guideline because of its default function as an arbitrary proxy for ethical behavior by agencies.

Agency decision-makers who complained about the ASRM cap per egg donation cycle often cited its age, within the context of the rising costs in the industry:

I don't love the limit of \$10,000 because I think everybody in this industry has made more money since that was ... a long time ago. Never changed, never went up. And every attorney, every reproductive doctor, every agency, everybody has made more or raised their cost since then. (Director, Southern California Agency)

Another agency decision-maker argued that the maximum donor compensation allowed by the ASRM is worth a lot less today than it was when it was set in 2007:

The problem with it is that ASRM guidelines, first of all, are very old and things change with medicine and finances and everything. What was a lot of money back then is not so much anymore. (Director, Southern California Agency)

According to a Northern California agency director, the only ASRM guideline

that I think really is somewhat irrelevant is how much a donor can be paid. Because ... they've had the same stipulation for the last [seven] years. (Director, Northern California Agency)

Finally another Northern California agency director questions not only the ASRM guideline's age, but also its premise:

<sup>&</sup>lt;sup>686</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 305.

My understanding is that the compensation was determined about fifteen years ago [sic] based on what sperm donors were receiving at the time, and it was multiplied by the 'pain and suffering' [of egg donation], which as you know for sperm donors is not really legitimate.... I would like to see it go up. (Director, Northern California Agency)

Even among the group of interviewees who espoused the view that donor compensation is unproblematic with regard to commodification and exploitation, some followed the ASRM guidelines in order to cement their status as ethical agencies within the industry. One Midwestern agency director complained about the ASRM guideline functioning not only to limit young women's agency and access to the economic market, but also as a restrictive proxy for ethical behavior of agencies:

> I think that we're [agencies are] all beholden to look as if we're practicing in an ethical manner to adhere to those compensation guidelines so as not to prey on financially strapped women. (Director, Midwestern Agency)

Note that she doesn't believe that her business *does* prey on financially strapped women, but rather that following the ASRM cap on donor compensation serves as a signal to other agencies and potential egg donors that her agency is not preying on women, that the agency is ethical. Similarly, a Southern California agency director follows the ASRM guideline on donor compensation, in part to maintain her status as an ethical agency, but she is simultaneously uncomfortable with the implications of limiting donor compensation (and, therefore, limiting donor agency and empowerment):

> I think it's such a sticky subject because, again, there's no real regulation. I know the ASRM has some guidelines, and I absolutely try to work within those guidelines. But then I'm just not sure where I can say, no, donor, you cannot make \$5,000. (Director, Southern California Agency)

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A small minority of my interviewees are unconcerned about the potential ill effects of commodification and the possibility of exploitation of egg donors that their counterparts clearly saw in their mutual business; these few agency decision-makers simply do not believe that such risks to donors exist. They also tend to believe that young women are capable thinkers, able to make good decisions for themselves and

their bodies if supplied with sufficient education. Furthermore, they believed that setting artificial limits on egg donor compensation is patronizing to potential donors and unfairly prevents them from engaging in empowering self-valuation and taking advantage of the free economic market. These agency decision-makers complained that the ASRM guideline on donor compensation is dated and, if it continues to exist at all, should be raised to keep pace with the industry and the economy. While some of these decision-makers deliberately do not abide by the ASRM guideline because of their philosophical differences with it, others do abide by it, citing the necessity of doing so as a means of outwardly proving their ethical behavior as an agency.

# Deliberate and Incidental Avoidance of Exploitation

While a minority of my interviewees advocated the position that egg donation is an empowering opportunity for young women, the majority of the agency decision-makers with whom I spoke expressed some concern over the potential for young women to be exploited in the course of participating in an egg donation IVF cycle. They expressed these concerns explicitly with regard to donor compensation, but apprehension about the potential for exploitation was also implicit in agency decision-makers' discussions of perceived donor immaturity, the recruiting process, donor education, donor privacy, donor medical care, and donor legal protection.

# Compensation

According to the ASRM Ethics Committee, "[M]onetary compensation ... create[s] the possibility of undue inducement and exploitation in the oocyte donation process. Women may agree to provide oocytes in response to financial need.... There is a possibility that women will discount the physical and emotional risks of oocyte donation out of eagerness to address their financial situations."<sup>687</sup> The vast majority of my interviewees claimed to comply with the ASRM compensation cap (though this compliance was sometimes "with occasional exceptions"), whether out of agreement with them, as a means of preventing exploitation, or simply as a way of "appearing ethical," as discussed in the previous section.

Some agency decision-makers were concerned about exploitation of egg donors only with very high compensation.

<sup>687</sup> Ibid., 306.

If people [intended parents] pay higher [than the ASRM recommended maximum], then people [donors] might negate the risks involved. (Director, Northeastern Agency)

In answer to a question about exploitative compensation, another agency decisionmaker pointed to advertisements for high sums:<sup>688</sup>

> Ads where they're saying they're going to pay \$20,000 or \$30,000. (Director, Northern California Agency)

These agency decision-makers were concerned about the potential exploitation of egg donors, but only with respect to larger than usual compensation amounts.

Compensation within the ASRM limits garnered different responses. One agency decision-maker was concerned about exploitation, even with the standard ASRM-compliant sums of \$5,000-\$10,000:

Because there is a high number ... financial number being thrown at them, essentially, that can be a little blind siding. (Director, Southern California Agency)

Another position, best expressed by a genetic counselor, held that caps on compensation could function to prevent exploitation, but that the current ASRM caps are perhaps on the low side:

I think that ASRM has tried to keep it to a reasonable level because I believe that there is a level at which it becomes coercion.... I feel like there could be some middle ground because I feel like there's compensation that's just beyond the pale that is, I think, coercive in nature. (Genetic Counselor)

Most of my interviewees, however, felt that compensation within the ASRM guidelines, and sometimes a little beyond, was both justified and non-exploitative. Some agency decision-makers felt that instead of compensation caps, a better way to prevent financial exploitation would be to screen egg donor applicants for financial distress:

The reason why they capped it is to make sure that donors were not being unfairly targeted or coerced. They didn't want coercion. They

<sup>&</sup>lt;sup>688</sup> For examples of media coverage of advertisements for egg donors featuring very high compensation, see the articles cited in note 634.

didn't want the financial benefit to be so much that donors would agree to be a donor even though they don't want to, but just because the fee is so high. But I think there's other ways to deal with that through psychological evaluations. (Director, Northern California Agency)

Several agency decision-makers employ screening for financial distress as a routine part of their evaluation of potential donors, in order to prevent exploitation.

We go through and we look at their ... current situation. You know, if someone says, 'I'm on welfare Section 8,' like all these different things. We're like, 'OK, is she being coerced? Is this something she really wants to do?' (Director, Southern California Agency)

An agency director in the South relies on her interviews with potential donors to suss out any financial exploitation:

> We also will never accept a young woman who is doing it for the wrong reasons.... if I discover in that period of time [during a long interview] that the driving force behind this decision is some desperate need for cash, I won't even accept a donor like that. I take that very, very seriously. (Director, Southern Agency)

Another agency director explained that her agency screens donors for financial distress both in their psychological evaluation:

> Speaking with the psychologist, they [the psychologists] ask about their [the donors'] intent. 'Why do you want to be an egg donor?' 'I just want to do it for the money. My mom's in foreclosure. I have to get the money.' Well, she's not going to pass screening. (Director, Southern California Agency)

And through review of their financial records:

Then also ... we disqualify individuals that are screened that are doing this under duress or financially being blackmailed by their credit card companies or whatever. So we just disqualify them. (Director, Southern California Agency)

Half of my interviewees believed that compensation for egg donors puts them at risk for exploitation. This view is in contrast to the position that egg donors are adults

capable of making sound decisions for themselves, but it reflects a concern stated by the relevant professional organization (via the ASRM Ethics Committee) and the general perception in society that young women are susceptible to financial exploitation.<sup>689</sup> Some of these agency decision-makers take deliberate action to prevent such exploitation by screening out donors who are in dire financial straits. Most do so via interviews or psychological evaluations, but a few also investigate the donor's financial records—which may well prevent financial exploitation, but, it could be argued, compromises the donor's dignity in other ways by invading her privacy and by implying that the donor is incapable of evaluating her situation and making a decision in her own best interests.

### **Donor Maturity**

Given that egg donors are of medical necessity young women, one would assume that their level of maturity would be of primary importance in evaluating their susceptibility to exploitation. Only two agency decision-makers mentioned the maturity of their egg donor candidates, however:

> Legally, at eighteen, you are an adult. But I guess maturity comes into that, too. Are you capable of really understanding the implications of your decision to donate at eighteen versus twentyone? (Director, Midwestern Agency)

Similarly:

They're young girls and there should be somebody that walks them through the thought process. (Director, Southern California Agency)

Far more agency decision-makers spoke directly of women's inherent capacity to act as empowered agents, than of young women's potential incapacity to make informed decisions for themselves.

Other agency decision-makers reference their donors' maturity level indirectly. One Southern California agency director said that she:

<sup>&</sup>lt;sup>689</sup> ASRM Ethics Committee, "Financial Compensation of Oocyte Donors," 306.

prefer[s] donors who are in school or getting an education, because it already shows a sense of responsibility. (Director, Southern California Agency)

Responsibility in an egg donor is a valuable trait for more than one reason; responsible donors are more likely to complete their cycles, in addition to perhaps being better able to make a sound decision about whether to cycle or not in the first place. In the same vein, some agency decision-makers implicitly express concern about their donors' maturity level when they explain that donors must think of their role in the cycle as a job.

They have to look at it as a job, so even if they have another job it's like having two jobs. They can't just miss a day without being in breach of contract, that there's legal obligations to it as well and they can't just call in and say, 'oh, my boss won't let me come.' That doesn't matter; if that happens, they're in breach of contract. (Director, Southern California Agency)

Similarly, another Southern California agency director says that donating eggs

is a time commitment and they [donors] have to realize that this is a job.... It needs a commitment to make the appointments.... I have all these young girls that I have to just kind of remind that they—I don't have to remind them all but they all need a little handholding to some degree. (Director, Southern California Agency)

While this solicitude over donors' ability to meet their cycle commitments is understandable in the context of the agency's role as cycle coordinator and liaison between donor and intended parent, it also reflects a presumption that egg donors lack the maturity to follow through with the commitments of an IVF cycle. And if a person can't be expected to attend appointments on time, how can she be expected to make lifealtering decisions for herself?

Some agency decision-makers attempted to curb the effects of possible donor immaturity by ensuring that she has adequate social support for her decision to sign up as an egg donor. If she wants to keep the donation a secret from her primary social network, alarm bells ring for some agency decision makers.

She said, 'yeah, that's fine [to do another donation],' and then she didn't want—she was now married [since her first donation] and

didn't want her husband to know about it. So there's problem one. You can't do that. (Director, Southern California Agency)

They have to have support through their family. Like if they're married ... their partner has to be completely supportive of the process. (Director, Southern Agency)

Several agency decision-makers relied on psychological evaluations performed by mental health professionals to determine the level of social support enjoyed by a particular donor. One mental health professional asks donors

who they have shared the information [that they are donating their eggs] with because that tells me how they actually feel about what they're doing and whether it's a big secret. (Mental Health Professional)

Another mental health professional joked,

My favorite thing is I'll ask them 'what are the strengths of your family?' 'Oh, we have very open communication. We're very close. We tell each other everything.' And then I'll ask them, 'Have you told your family about being a donor?' 'No, I'm not telling them.' That's always one of my favorites. (Mental Health Professional)

This mental health professional explores further with the donor the possible consequences of keeping her donation a secret from her family:

I get that it's a personal decision. Now, what happens if they [the donor's family] do find out? Or why wouldn't you tell them? Or your family is not supportive, but yet you still want to move forward with this and what are the repercussions of doing this? How will this play out in your family if your family finds out? I don't want them to uproot and destroy their family and have this big crisis in their family over egg donation. (Mental Health Professional)

The agency decision-makers involved in the effort at professionalization, embodied in the organization SEEDS, recognize the potential for exploitation of egg donors, and

have created a standard aimed in part at preventing exploitation by ensuring that donors have adequate social support for the process:<sup>690</sup>

An Egg Donation Agency should ask a series of questions to each egg donor to determine her suitability to move forward with the process. These questions should include the following considerations to access her readiness to move forward: Does the donor have a social support system that includes at least one close friend, family member or significant other that she has confided in about her choice to donate her eggs. If there an unforeseen complication has she considered what she would tell those closest to her?<sup>691</sup>

While only two agency decision-makers directly addressed the concern about donor maturity, others referenced it indirectly by referring to their donors' overall level of responsibility. Some agency decision-makers attempt to counter the possibility of an immature donor being inadvertently exploited by ensuring that the donor has adequate social support, whether via interviews by the agency, or through psychological evaluation.

# Recruiting

Agency decision-makers all recruit egg donors for their programs using very similar means, typically a combination of advertising on Craigslist, social media, and other online sources targeted at college students, along with word of mouth advertising. When asked how they recruited donors, they answered:

All on Craigslist.... which ... if you really know Craigslist, sounds a little scary. But there's also a lot of reputable people on Craigslist. (Director, Northern California Agency)

Yeah, Craigslist, and then word of mouth. A lot of the donors will refer candidates to me. (Director, Northern California Agency)

<sup>&</sup>lt;sup>690</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>691</sup> "Agency's Responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors," SEEDS Standards.

We ... plac[e] ads on various networks. We also run ULoop ads, which is basically the boards for all the various universities. (Director, Northern California Agency)

Social media. We used to run ads in the schools and stuff and now it's all Google, Facebook, social media, really. And friends of recruitment of the donors who send us their friends, because we know they're happy. And we know they're satisfied with their experience and then we also know that we have someone vouching for the donor. (Director, Southern California Agency)

Well, we advertise. And we advertise in different forms. We do advertise on college campuses.... We advertise in school newspapers. We advertise on ULoop sometimes. We advertise on Facebook. So there's all kinds of things like that. (Director, Southern California Agency)

A lot of it comes through referrals. But mostly through sororities, colleges.... We do events on campus. We also do a lot of Facebook marketing, we do a lot of campus advertising, online campus magazines, online Facebook stuff directed at college-age students. (Director, Northeastern Agency)

We do some Craigslist, but there's so many different agencies on Craigslist, we just seem to get lost in it. Then again, it's a lot of word of mouth. (Director, Southern California Agency)

As one agency decision-maker pointed out, agency recruiting tactics are necessarily going to echo one another because they are targeting the same people: college-aged women. Recruiting at colleges serves a twofold purpose. For intended parents, a donor's attendance at or graduation from college can serve as a proxy for intelligence, ambition, or success, traits that are generally desirable and difficult to measure in a donor profile. But for agencies, a donor's status as a college student ensures in their eyes that she is not impoverished and that she is at least reasonably intelligent—intelligent enough to make an informed decision about donating her eggs.

> We do local advertising in all the normal places that you would see it, you know, Barefoot Student, Craigslist, all those kind of things. Plus we target colleges ... and various things like that. And I don't think people deviate from that because we're all looking for really the same market. (Director, Southern California Agency)

This is one area in which there is little digression from the norm, and agency decisionmakers look to one another for marketing ideas.

Some agency decision-makers take recruiting a step beyond Craigslist and university newsletters, by introducing direct recruiting. Two agencies engage in direct recruiting, along with the usual methods of recruiting:

[We recruit in] various ways, and most of it is online, as well as campus advertising. We do a lot of moms' blogs, and we do have someone in different cities actually, like, hitting the streets, handing out literature, that sort of thing. (Director, Southern Agency)

Similarly:

[We recruit] all different ways. We have online campaigns. We have advertisement campaigns. We have face-to-face recruitment. We also have [a] referral program. So there's no, like, set way we do it. (Director, Southern California Agency)

One genetic counselor, a former employee of an agency, expressed concern over the concept of face-to-face recruiting. At the agency at which she was previously employed, she said, they didn't:

go out and just talk to people that aren't showing us an interest in our flyers, in our Craigslist advertisements or something, but I've heard of many agencies that will just approach young women and talk to them about it and ... that does concern me.... I believe there should be some kind of regulation around self-selection—that donors respond to some kind of advertisement or some kind of alert about 'this is a possibility for you' rather than the other way around. (Genetic Counselor)

This egg donation professional is concerned that the social pressure of a face-to-face recruiting attempt on an egg donor would push the recruitment into exploitation territory, if the donor felt that she couldn't refuse the recruiter, whether just to stay and talk, to attend an information event at the agency, or, once she had gone so far, to sign up with the agency as an egg donor.

Some universities have reservations about allowing on-campus recruitment of their young women students as egg donors:

We do some ads in universities. Some universities are really open to it. Some universities do not allow it.... So we do university newspapers. (Director, Southern California Agency)

These universities are likely concerned about potential exploitation of their students or, at a minimum, the appearance of exploitation of their students—and thus forbid such recruiting to take place on their grounds.

Aside from the implications of recruiting solely among a group of young people, which although medically necessary, is potentially problematic in terms of the target population's general level of maturity, one agency decision-maker implies that exploitation might be implicated because she not only recruits from a young population, but a young population in greater financial need than their peers:

> Everyone always says to me, why don't you recruit from [Ivy League school]? Those kids are super smart. And I'm like, recruit from [Ivy League school], are you stupid? If they can afford to go to [Ivy League school], they don't need money. Their parents are probably paying their way, or they're on scholarship. And I'm not going to try to recruit from [Ivy League school] because I'm not going to get anywhere. (Director, Northeastern Agency)

The fact that this agency decision-maker deliberately recruits from college populations that she perceives as having greater need, and expects a greater response to her advertising efforts among that population, implies that exploitation may be at play in egg donation. If young women who "don't need the money" are unwilling to donate, but women who do need the money, to pay student debt, or for whatever other reason, are the ones to respond to recruitment ads, that is perhaps exploitative of those women.

On the other hand, at what point financial compensation becomes exploitation is a hotly debated issue in the media and among theorists; we all work for money, and whether a work arrangement is exploitative can only be established on a case-by-case basis.<sup>692</sup> While exploitation of egg donors is implicated by some recruiting practices, and by the fact that some colleges refuse to allow egg donor recruiting to take place on their

<sup>&</sup>lt;sup>692</sup> See, e.g., Brenda Almond, "Exploitation, Greed and Why Paying a Bounty to Egg Donors is So Wrong," *U.K. Daily Mail Online*, 21 October 2011, available from www.dailymail.co.uk/health/article-2051606/ Exploitation-greed-paying-bounty-egg-donors-wrong.html; Internet; Accessed 8 September 2014; Ian Craft, "Should Egg Donors be Paid?" *British Medical Journal* 314 (May 1997): 1400; Dickenson, *Property in the Body;* Radin, *Contested Commodities;* Satz, "Markets in Women's Reproductive Labor," 107-131; Shultz, "Questioning Commodification," 1841; Williams, *Unbending Gender*.

campuses, most of my interviewees use the same techniques to recruit the same target population, and they don't see any problems with their recruiting practice as it stands.

A few agency decision-makers, who see the potential for exploitation in very high donor compensation, try to prevent it with truth in advertising:

A lot of people will put an ad for an egg donor saying, 'Make up to \$15,000,' so donors are calling thinking they're going to make fifteen grand and then it's bait and switch. It's like, 'Well, we can match you now for five [thousand dollars].' (Director, Southern California Agency)

The agencies that collaborated on the SEEDS professionalization effort created a standard to prevent advertising practices likely to lead to exploitation of egg donors:<sup>693</sup>

To the extent that such ads do state [donor] fees, they must be the fees relevant to the donor opportunities being advertised.... If a range of fees or varying fees are presented in the ad, it must clearly be stated what conditions will govern the actual fee.... Monetary arrangements should be presented in an appropriate professional manner, not dominating the ad nor in presentation format to call undue attention over other elements of the ad. The monetary information should not be presented in comparative manner to any other agencies' fees.... Media selected should be reputable and non exploitative.<sup>694</sup>

This standard addresses both the amount and the presentation of donor fees in ads, suggesting that either element could potentially result in exploitation of donors, and that care should be taken to avoid that result. For the most part, however, agency decision-makers do not see their college-targeted recruiting methods as problematic or likely to result in exploitation of donors. They rely on interviews and psychological evaluations, along with donor education, to ensure donor social support and prevent any incipient exploitation before a donor signs up to be matched with intended parents.

<sup>&</sup>lt;sup>693</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>694</sup> "Ethical Standards for Advertising for Egg Donors," SEEDS Standards.

## Education

The main means of preventing exploitation of egg donors is to ensure that they receive sufficient education about the process that they can make an informed decision for themselves.<sup>695</sup> All of the agency decision-makers with whom I spoke have some sort of education protocol in place for the donors that they recruit, though some such protocols are more detailed than others. Only a few agency decision-makers found inadequate the education that donors are currently receiving in the industry in general. A few more (about one third of my agency interviewees) explicitly discussed education of donors as a responsibility that they assume in order to prevent exploitation.

The few agency decision-makers who criticized donor education at other agencies spoke generally, indicating that they felt donors were inadequately informed when making the decision to donate.

I do get concerned [about] that and wonder about the level of education given to women in this process. (Case Manager, Northern California Agency)

One Midwestern agency director blames the profit motivation for agencies' failure, in her eyes, to educate donors thoroughly:

Most agencies, they do a bad job at that [educating donors], and this is why.... 'Oh, I got a recruited candidate. Great. Add her to the list. Who's the next intended parent in line? ... Match them up. Match them up. Quick, quick, quick.' But nobody has taken time to say to that ... egg donor, 'you're going to be taking these injections. These are the side effects. I suggest you talk to your OB about the side effects before you choose to be an egg donor.' I've never [seen] one agency do that. Now, if my daughter was donating her eggs, you bet I'd say to her, let's go talk to the OB first.... Yes, [an] independent, unbiased professional. (Director, Midwestern Agency)

As the director of a Northern California agency concludes,

<sup>&</sup>lt;sup>695</sup> As noted previously, this is an expanded vision of informed consent, which legal doctrine is confined to questions of medical consent. Egg donation requires consent not just to medical risks, but also to social and emotional risks. For the development of informed consent doctrine in the United States, see Starr, *Social Transformation of American Medicine*, 388-393.

I think that there needs to be—they [donors] need to be more informed, so they understand the risks that they're putting themselves at. (Director, Northern California Agency)

A third of my interviewees discussed their donor educations programs explicitly as a means of preventing exploitation. The director of a Southern California agency works to ensure that donors understand the breadth of consequences for egg donors:

Does she really understand what this is? I mean, obviously we all work and we do it for financial reasons. But I want to make sure that there's more to it, because you're really helping to bring a life into the world. This is a really huge thing. This isn't like giving blood. I mean, that's huge, too. But I want to make sure that they really understand that this is your genetics. (Director, Southern California Agency)

Some agency decision-makers are concerned about educating donors in specific circumstances, such as when they donate to frozen egg banks:

When we educate the donors about the possibility of doing ... a frozen cycle, we do let them know that there is no set amount of intended parents it could go to, and that this is a risk. It could go to one parent. It could possibly go to no parents or it can go to six intended parents. We just don't know. (Director, Southern California Agency)

Or if a donor is contemplating doing more donations than recommended by the ASRM,<sup>696</sup> another Southern California agency director says that the donor:

has to talk to two doctors. Not from the same practice; two separate doctors. And it can be doctors of her choice, or people that I can suggest or I can give her a list and then I'll just call in a favor and they'll be very transparent as to why the ASRM suggested this [limit on number of cycles per donor]. (Director, Southern California Agency)

Sometimes, agency decision-makers look to other field professionals for help in effectively educating donors:

<sup>&</sup>lt;sup>696</sup> ASRM Practice Committee, "Repetitive Oocyte Donation," S194.

I would hope that they would use effectively the mental health professionals that are teaching them. (Director, Midwestern Agency)

Or, as put by one such mental health professional:

Are they educated enough and do they have the support to run things by other people to be able to make an informed consent? (Mental Health Professional)

The majority of my interviewees discussed their donor education protocols, but not with the explicit goal of preventing exploitation of donors. The most common means of educating donors practiced by my interviewees was through face-to-face interviews or conversations between donors and agency employees:

> We start in the very beginning. We Skype with them or we see them face-to-face. They talk to two different people and we go through a long explanation of the medical procedures and we send them information. And of course the doctors do that as well. (Director, Southern California Agency)

Well, we obviously talk to them in detail about the process itself.... They also have two separate interviews that they go through. One has to be an in-person interview so it's either face-to-face or if you're not local, then it's through Skype. (Director, Southern California Agency)

We inform them and we inform them and we inform them. And we might annoy them to death. And I mean, when I go to clear a donor I say, 'let me just review this again with you. This is what the next three months of your life are going to look like. And if this not for you, it's fine. Tell me now. Think about it.' (Director, Southern California Agency)

Once they're accepted they are brought in for an in depth interview and consultation about the process. We cover all facets of the process from the legal to the medical to the psychological. (Director, Midwestern Agency) We go over the process, answer any questions that they have and make sure that they understand the commitment involved in being a donor. (Director, Southern Agency)

If they have questions before they're filling out the application we will Skype with them or call them and answer questions. And then on the final interview I go over all the risks again. We go over everything. So it's done one-on-one. (Director, Southern Agency)

The other primary means of educating donors was via written resources, mostly agency websites.

We have a lot of information on the website, for starters. (Director, Southern California Agency)

The first thing we do before a donor ever even applies is we ask her to please go and read through the entire FAQ section of the donor data—we have a donor site. On our regular website there's a donor FAQ. Basically, we give them a lot of information in there. We answer a lot of their questions. (Director, Southern Agency)

Agency decision-makers also rely on other professionals in the field to thoroughly educate egg donors. Some make sure that each egg donor has separate legal counsel:

We have independent legal representation. (Director, Midwestern Agency)

A Northeastern agency director explains her donors' legal education in more detail:

They also have a consult with an attorney, so the attorney can basically explain. There's two attorneys here in the contract negotiation phase, one advocating on behalf of the parents, one advocating on behalf of the donor, so the donor understands basically what she's giving up in terms of her legal rights. So both parties must be represented by their own independent legal counsel. So it's explained to them it's not like they're just going, 'Oh OK, well, I'm just giving up my eggs and I'm going to the clinic going and getting shots for a month and then I go in and then I'm done.' They have to make sure that they understand they have no parental rights, they have no claim on the child or on the child's family or on the child's estate. (Director, Northeastern Agency) Almost all agencies require their donors to be screened by a mental health professional (which is typically a requirement of the infertility clinic), and they expect some education to take place during that evaluation:

They have to undergo a psychological evaluation, and basically the psych eval is not to see if they're crazy, but it's for that exact purpose [education], to make sure they understand their rights, their responsibilities, what they're getting themselves into. (Director, Northeastern Agency)

The psychological evaluation serves a dual purpose: to screen out inappropriate donors, and to educate potential donors so they may make an informed choice for themselves.

They have the psychological evaluation. But some of that is asking them questions about how would they feel in the future about a variety of issues. (Director, Northern California Agency)

Agencies also take it upon themselves to educate donors about the potential emotional consequences of donating their eggs. At one Southern California agency, the director reported:

We have this ... consent form that covers everything, their feelings before the retrieval, during the retrieval, after the retrieval, all the effects, not just on them but on their family, future family. (Director, Southern California Agency)

Many agency decision-makers encourage donors to think to the future, and what kind of relationship, if any, they expect to have with children born from their donation:

How does she think she'll feel five years from now? Or how does she think she'll feel if the child wants to get ahold of her at some point? (Director, Southern California Agency)

It's [egg donation is] not for everybody, and certainly you have to really help them [donors] examine what their expectations are and what they think about these children and how much ownership they feel toward them. (Director, Southern Agency)

Other agency decision-makers want egg donors to think toward their own future, and the unknown risks they are assuming by donating:

I know one of the questions I would always ask them is how would you feel—you know, when I was interviewing donors, not psychological evaluations ... I would ask them, suppose five to ten years down the road, you find out that you have fertility issues. Will you regret having been a donor? And so I think it's something they need to think about. (Director, Northern California Agency)

In addition to legal and mental health professionals, agency decision-makers expect their donors to be educated about the medical aspects of donation by the physicians and nurses at the infertility clinics.

> They [donors] have the opportunity and option to talk to a doctor as well before saying yes to our program. Even though they'd be required to, obviously, once they were matched, they do have the opportunity to do that before they even sign up. (Director, Southern California Agency)

Though in fact, most agencies do educate the donors about the medical side of the process.

Now, we're not a medical clinic so we can't really give them medical advice, but we say, 'This is kind of what it's going to look like.' (Director, Southern California Agency)

Agencies often go into great medical detail with potential donors during their education process:

Initially our intention is to tell them what all the potential complications are, what they're going to be expected to do, that they're going to have to take daily injections, that they're going to get vaginal ultrasounds, that they're going to get their blood taken on a fairly regular basis. (Director, Southern California Agency)

Or, at another Southern California agency:

Then we explain the process itself: what the medications are, what they do, what their [the donor's] body physically goes through. We show them the needles, explain what it's like to have to take a shot, what the actual medications do to the physical body, what the risks are, just kind of go through the whole process so they leave feeling informed about what they're fixing to put their body through. (Director, Southern California Agency)

Medical topics covered by my interviewees' donor education protocols include injections of hormone medications, vaginal ultrasounds, blood draws, and the risks of donating, including ovarian hyperstimulation syndrome.

Interestingly, many agencies appear to take on the burden of medical informed consent, which is not within their scope of practice since it lies soundly within the physicians' scope.<sup>697</sup> Technically, they must defer the responsibility of informed consent onto the (intended parents') clinic physicians. Informed consent is:

up to the fertility clinics. For the procedures? Yeah. (Director, Northern California Agency)

While informed consent is appropriately located in the medical setting for medical procedures, egg donation gives rise to questions about the physicians' conflict of interest.<sup>698</sup> The physician's primary patient is the intended mother, which could potentially lead the physician to minimize risks when obtaining informed consent from the donor, or to push the donor harder physically to produce a lot of eggs during the cycle. None of my agency decision-maker interviewees mentioned this possible conflict of interest, yet almost all of them engaged in educating donors about the medical aspects of egg donation. That would imply that decision-makers are concerned about it, even if not overtly so.

In fact, the SEEDS professionalization effort encourages agencies to educate donors about the medical side of egg donation.<sup>699</sup> Part of one of their standards is:

Does the donor understand that she will be taking daily injections, making multiple appointments, and have a semi-invasive retrieval/surgery at the end? Does she feel confident she can give herself injections? Does she feel confident that she can give blood

<sup>&</sup>lt;sup>697</sup> See Chapter One, "Exploitation and Empowerment of Women," for further discussion of informed consent, a concept that emerged in the post-Civil Rights era. See Starr, *Social Transformation of American Medicine*, 388-393; Canterbury, 464 F.2d 771; Cobbs, 8 Cal. 3d 229.

<sup>&</sup>lt;sup>698</sup> See note 638 for a brief discussion of physician conflict of interest in egg donation IVF cycles.

<sup>&</sup>lt;sup>699</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

several times? Does she know that she will have several vaginal ultrasounds  $\!\!\!^{700}$ 

SEEDS also devotes an entire standard to the issue of "What Medical Information Should Agencies Provide to Donors about the Risks of Donation?", in which the organization states that agencies "should not give actual medical advice" and should, "if possible, arrange a conversation with a nurse or reproductive endocrinologist."<sup>701</sup> However, when a donor is matched, the standard advises that the agency should remind the donor "about the medical process and expectations" in order to ensure the donor's full education and ability to go forward with a cycle.<sup>702</sup> The agency should also remind the donor about the medical side effects of egg donation, such as "bloating, feeling of fullness, headaches, possible mood swings, bruising around the injection site, etc." and should "encourage them [donors] to come up with a list of questions for the doctor for their first patient appointment, including bigger risk factors such as ovarian hyperstimulation, torsion or rare reactions to the medications."<sup>703</sup>

In addition to educating donors about the emotional and medical aspects of egg donation, agency decision-makers see their agencies as responsible for educating donors about the many logistical details of an egg donor IVF cycle, which can be complicated, and decision-makers recognize that donors must understand how much of their time is going to be required.

> And then also the logistical process of, 'OK, if you're living far away and you have to fly in,' I mean, we kind of really break it down for them. 'So you'll be staying in a hotel, and after your retrieval you need to have someone to drive you.' We really go into the nitty-gritty. (Director, Southern California Agency)

At another Southern California agency, employees give the donors

details about the clinic. 'This is where you'll be going. This is [the] kind of the protocol for that clinic,' and then ... the case manager manages that donor throughout the whole entire cycle. So she's

<sup>&</sup>lt;sup>700</sup> "Agency's Responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors," SEEDS Standards.

<sup>&</sup>lt;sup>701</sup> "What Medical Information Should Agencies Provide to Donors about the Risks of Donation?", SEEDS Standards.

<sup>&</sup>lt;sup>702</sup> Ibid.

<sup>&</sup>lt;sup>703</sup> Ibid.

with them [the same case manager] from selection to the completion of the retrieval.... If she's traveling, that case manager would be the one who makes all the travel arrangements and everything. (Director, Southern California Agency)

Or, as a Southern agency director puts it,

we go over the process, answer any questions that they have and make sure that they understand the commitment involved in being a donor. (Director, Southern Agency)

With a few exceptions, most agency decision-makers felt that the education potential egg donors receive in agencies is generally adequate. About one third of my interviewees consciously design their donor education protocols with the explicit hope of preventing exploitation of young women. Those agencies tend to have extensive donor education programs to ensure that donors understand all aspects, from medical to legal, logistical and emotional, of the egg donation process before they participate. These agency decision-makers express a feeling of responsibility to ensure that the donors they recruit are not exploited, and their education campaigns are a concrete step to minimize the likelihood of exploitation. Even the agency decision-makers who did not express a desire to prevent exploitation had donor education protocols in place, however, which has the perhaps incidental effect of preventing exploitation of young women who are potential egg donors.

#### Privacy

Privacy is a major concern for agency decision-makers, and a potential source of exploitation of donors. Egg donation, whether a person involved in it is acting as a donor or employing a donor to become pregnant, is largely stigmatized, and thus many people do not want their participation to become widely known. The ABA Model Act Governing Assisted Reproductive Technology states that "A donor of gametes or embryos may condition donation on a reasonable assurance of anonymity so long as non-identifying health information is provided in accordance with the requirements set forth elsewhere in this Act."<sup>704</sup> However, the disclosure of only "non-identifying" information is insufficient to protect donor privacy, in many of my interviewees' eyes. Two thirds of my interviewees expressed concern about a variety of threats to donor privacy. Many fewer discussed possible solutions to those threats.

<sup>&</sup>lt;sup>704</sup> ABA Model Act Governing ART § 204.1.

Several agency decision-makers mentioned that the contents of donor profiles information available to intended parents—has increased as time goes on.

> We are getting more and more information; what books they [donors] like to read and all of this other stuff. (Director, Northern California Agency)

Lots of photos. The donor, her family, different developmental stages, if we can get it. We get a transcript. (Director, Northern California Agency)

A Southern agency director complained that intended parents had no control over whether or not they viewed donor photos:

You don't even have a choice about whether you're going to see a photo, because the second you open that thing [donor profile] there are photos flying up at you. (Director, Southern Agency)

One Southern California agency director described how the information agencies gather about their donors goes beyond the basics:

Agencies that are run by clinics on the west coast still have photos and personality questions and things that are trivial things, that you don't think of, like 'what's your favorite color, what are your favorite childhood memories.' Personal questions, I should say. Not trivial, but personality questions to see what type of human being this person is. (Director, Southern California Agency)

Things are a bit more restrained on the East Coast:

We ask for one adult photo and one baby photo. (Director, Northeastern Agency)

Some agency decision-makers feel that this collection of information on donors, available in their database profiles, has gone too far:

Sometimes there's even too much information in the profiles. For example, name of the school that girls are attending. Because everybody's on Facebook now. I've had so many clients who have identified their own donor—I mean, found her on Facebook after they've selected her. (Director, Midwestern Agency) Sometimes, however, the intended parents push for even more information.

You've got these intended parents who, not only do they want to see the medical records of the donor, but they also want to see the medical records of her mother and her father. In those circumstances, 'no, that's not part of the process and you can't ask to see a whole generation of family medical records!' (Case Manager, Northern California Agency)

Agency decision-makers were disapproving of intended parents who demanded too much information about their donor, but even more so about intended parents who crossed the line into overt violation of their donor's privacy:

I had a family once who broke three, four contracts that we had.... I don't know what they were thinking, but they violated all those contracts and then found their donor and started to email her and it was not really ... it was sad for a number of reasons. (Director, Southern Agency)

Agency decision-makers were particularly distressed when intended parents sought to contact their anonymous donors outside of the agency. Such a step is a clear violation of the donor's privacy.

It's very rare. But yeah, absolutely, I've seen it. I've seen intended parents overstep boundaries by reaching out, finding out who they [the donors] are and reaching out to them personally.... I've heard that where it's freaked out the donor.... They [intended parents] call them [donors] at work and say, 'Hi. You know, I saw your profile and I want to know if you want to donate to me. My name is —' you know, 'I would like to get coffee.' I mean, it's so bizarre to have that type of conversation. You're [the donor is] not expecting somebody to call you at work. (Director, Southern California Agency)

While such serious violations of donors' privacy cause great consternation among agency decision-makers, they are fortunately the exception, rather than the rule, among intended parents.

A more commonly expressed concern among agency decision-makers is the fact that donor anonymity and privacy is becoming more and more difficult to maintain as donors provide more information to agencies and as technology, such as facial recognition software, continues to improve.<sup>705</sup> Several agency decision-makers felt that they could no longer guarantee the protection of their donors' anonymity.

How much are anonymous donors really anonymous? I mean, with all the information that they [intended parents] have, even if they don't have their [donors'] last names and their address and their phone number, couples can figure out who their donor is if they really want to. (Director, Northern California Agency)

Or, as a Southern agency director puts it with brevity:

What is very clear is that the way the world is operating today has made it almost an impossibility to ensure that you're going to have privacy and anonymity. (Director, Southern Agency)

In fact, some agency decision-makers try to prevent exploitation of their donors by putting provisions in their contracts to the effect that the agency will do its best, but cannot guarantee anonymity, with the idea that as long as the donor understands the risk to her privacy, she is not being exploited.

I [donor] acknowledge that it is the intent of [agency] *to attempt* to maintain [donor's] anonymity to the best of their ability via the contractual agreements with the Recipient(s), but that it cannot be guaranteed. I [donor] understand that with the advances in technology, facial recognition software, the ever expanding use of social media, etc., there is an increased risk that my anonymity may be compromised. (emphasis in original) (Contract between Egg Donor and Agency, Southern Agency)

<sup>&</sup>lt;sup>705</sup> Between the wide availability of personal information online through sites such as Facebook and MySpace (especially for younger people, who tend to be accustomed to public sharing and less cautious with their privacy), and the ability of the layperson to make use of advanced technology to search and identify information online, anonymity becomes a virtual impossibility. See Darrell Etherington, "Apple Patents Face Recognition Tech for Enhanced iPhone Privacy and Automated Controls," *TechCrunch*, 3 December 2013, available from techcrunch.com/2013/12/03/apple-patents-face-recognition/; Internet; Accessed 9 September 2014; Lance Whitney, "How to Use Facial Recognition on your iPhone," *CNet*, 20 December 2013, available from www.cnet.com/news/how-to-use-facial-recognition-on-your-iphone/; Internet; Accessed 9 September 2014.

#### And similarly:

Donor acknowledges that [agency] cannot provide an absolute guarantee that her identity will not be disclosed accidentally to a third party either by [agency] or by other service providers involved in the egg donation arrangement. (Contract between Egg Donor and Agency, Southern California Agency)

A less obvious threat to donor privacy was not mentioned by any of my agency decision-maker interviewees, but bears examination. Agency decision-makers referred to facial recognition software and social media as ways that laypeople might track one another down, but a genetic counselor pointed out that genetic descendants of a donor might well track the donor down via commercial genetic testing through websites such as Ancestry.com:<sup>706</sup>

I never anticipated a social component to genealogy like that Ancestry.com, but with that I think donors could definitely be relationships can be inferred and people can—identities can be disclosed beyond what the risks that have already been present from pictures, identifying information and some potentially identifying information, like the school they [donor] went to, their major, all that stuff. I feel like this is way beyond what we've faced in the past and I feel like it's not appropriate for us to pretend that they can be anonymous and pretend we have the security in place to really make that happen. They need to be advised that it's [discovery through genetic testing is] very possible in the future. We don't know how it's going to work out but it's very possible that donor offspring or relatives of donor offspring or somebody could figure out a relationship and you may not, this may not be something you just close the book on and walk away from and never think about again. (Genetic Counselor)

The question of private genetic testing is in some senses the ultimate threat to donor privacy, as the risk it poses, while perhaps not as immediate as an intended parent directly contacting an unwilling donor, stretches well beyond the immediate interaction between the donor and the intended parents.<sup>707</sup> Donor registries pose a similarly broad

<sup>&</sup>lt;sup>706</sup> Per the Ancestry.com website: "Millions of stories. Find yours. Join us on a journey through the story of how you became, well, you."

<sup>&</sup>lt;sup>707</sup> Theoretically, an egg donor could be identified not only by the offspring from the IVF cycles in which she participated, but also by their offspring and anyone else down the line who shares the donor's DNA.

risk, since they (could) contain a wealth of information about egg donors, subject to the risk of being hacked and the security of the registry data compromised.<sup>708</sup> The main such registry in existence is the Donor Sibling Registry, founded by Wendy Kramer, the mission of which is "to assist individuals conceived as a result of sperm, egg or embryo donation that are seeking to make mutually desired contact with others with whom they share genetic ties."<sup>709</sup> An agency director in the Northeast—an area particularly concerned with privacy and anonymity, as discussed in Chapter Three, "Divergence: Reverse Modeling"—heartily disapproved of the Donor Sibling Registry because of her perception that it severely compromises the privacy of donors.

The woman that created the Sibling Donor Registry [sic], she was like, 'well, these people [donor offspring] have a right.' And my theory is, 'well, the donors have rights, too, and they were told that they were anonymous, and it was their right to have complete anonymity, and you're violating their rights.' So I'm not in agreement with that website at all. (Director, Northeastern Agency)

Another type of donor registry is one that doesn't yet exist, but is discussed in the industry as something largely desirable (again, as discussed in more detail in Chapter Four, "National Donor Registry"). An industry-oriented donor registry, if created, would enable the exchange of information about donors among agencies, so that agencies are better equipped to monitor the total number of cycles a particular donor has completed, and to inform one another if a donor has misbehaved in some fashion. But such a registry poses serious questions for donor privacy, about both what legal uses will be permitted and the potential for donors' data to be compromised. As one Southern California agency director specified,

<sup>&</sup>lt;sup>708</sup> In recent years, it has become almost commonplace to be notified of a breach of the online security of large companies. See, e.g., Nicole Perlroth and David Gelles, "Russian Hackers Amass Over a Billion Internet Passwords," *The New York Times*, 5 August 2014, available from www.nytimes.com/2014/08/06/technology/russian-gang-said-to-amass-more-than-a-billion-stolen-internet-credentials.html?\_r=0; Internet; Accessed 9 September 2014; Jose Pagliery, "Don't Assume You're Safe from Heartbleed," CNN *Money*, 25 April 2014, available from money.cnn.com/2014/04/24/technology/security/heartbleed-security/; Internet; Accessed 9 September 2014; Violet Blue, "Change Your Passwords: Comcast Hushes, Minimizes Serious Hack," *ZDNet*, 9 February 2014, available from www.zdnet.com/change-your-passwords-comcast-hushes-minimizes-serious-hack-7000026118/; Internet; Accessed 9 September 2014; Catlin Dewey, "This is How Easy it is to Hack Someone's iCloud with their Security Questions," *The Washington Post*, 3 September 2014, available from www.washingtonpost.com/news/the-intersect/wp/2014/09/03/this-is-how-easy-it-is-to-hack-someones-icloud-with-their-security-questions/; Internet; Accessed 9 September 2014.

<sup>&</sup>lt;sup>709</sup> "About," Donor Sibling Registry, www.donorsiblingregistry.com/about-dsr/history-and-mission; Internet; Accessed 2 July 2014.

We don't think that the registry should be open to future children being able to contact the donor or that type of stuff. I don't think it should be shared with intended parents. It should just be an industry thing to prevent problems for our future intended parents. (Director, Southern California Agency)

Another Southern California agency director sympathized with donors on the issue of privacy:

Even the best of the best donors are eventually going to get tired of being contacted yearly by a place that has all of their most private information from people they don't know and—you know what I mean? Long after their memories and the money are gone. (Director, Southern California Agency)

A case manager at a Northern California agency examined the serious fallout that could result if such a registry were hacked:

I could also see it being a little bit scary, cause again, anytime you're talking about a national registry, you're talking about disclosing who you are and that you did it [donated eggs] and so many of these girls, that I see, it's clear that they are telling a few close friends but sometimes they're not telling family that they've donated their eggs because they don't want family—a backlash. It's kind of putting yourself out there and certifying that, 'Yeah, I've donated my eggs.' There's always a risk that that information out there can be compromised. I think of the privacy issues there. (Case Manager, Northern California Agency)

Many of my agency decision-maker interviewees discussed possible threats to donor privacy, whether in the form of information-dense donor profiles, pushy intended parents, advances in technology, or compromised data security.

Although the security of online information, in particular the egg donor databases in which a great deal of information about donors is stored and made accessible to putative intended parents, would seem to be a major privacy issue, only a few agency decision-makers mentioned it. And when they did, it was with brevity: a Northern California agency director said that her agency had

a password-protected donor database. (Director, Northern California Agency)

A Midwestern agency director said:

Donors apply online. It's secure; as secure as we can make it in today's world, but it is a password-protected process. (Director, Midwestern Agency)

Some agency decision-makers include information about data security in their contracts with donors:

I, [donor] ... understand that it is [agency]'s intent that their database remain secure. Therefore, only their Recipient(s) and authorized parties will have access to this database and those individuals must agree in advance to safeguard my identity. (Contract between Egg Donor and Agency, Southern Agency)

Many agencies do rely on confidentiality clauses in their contracts, and/or agreements with the intended parents that they will not breach the donor's confidentiality. At one Northeastern agency, the director reported:

We have confidentiality clauses about people not being allowed to post things on Facebook or any type of social media; we have very strict confidentiality clauses. (Director, Northeastern Agency)

Some such clauses focus on the prohibition against searching for a donor's identity through social media or engaging private investigators, with a contingency plan should the donor's identity become known to the intended parent:

The Intended Parent(s) agree that the services provided are extremely personal and sensitive to all parties concerned. Procurement of properly qualified Egg Donors is a very sensitive and private matter. The Intended Parent(s) agree not to search or try to identify their Egg Donor through Facebook, MySpace, other online search engines, private investigator or any other means either on or offline. The Intended Parent(s) understand and agree that this would be a breach of the Egg Donor's privacy and confidentiality and could cause substantial harm to her wellbeing.... In the event that Intended Parent(s) inadvertently learn of their Egg Donor's identity, they agree to respect the Egg Donor's right to anonymity and privacy and will not contact her or disclose the donor's identity to anyone. (Contract between Intended Parent and Agency, Southern Agency) Other confidentiality clauses focus on the potential disclosure of information to outside sources, including (and especially) the media:

The Parties acknowledge the sensitive and private nature of egg donation, that both Intended Parents and Donor wish the arrangement to be confidential and anonymous, and that both Intended Parents and Donor are relying on one another's agreement to maintain their anonymity. Each Party acknowledges they will not provide information to any third party (including the media) that could lead to the identity of Intended Parents, Donor or the Child, without prior written consent of each of those parties. (Contract between Egg Donor and Agency, Southern California Agency)

Or, as in this confidentiality clause, both prohibited and permitted disclosures are detailed:

All parties acknowledge the sensitive and private nature of the subject matter of this Agreement and agree to the following: a) The Intended Parents may provide information to the public, news media, or any other individual or group which could lead to the disclosure of the identity of themselves or the Child, but they may not provide information that could lead to the disclosure of the identity of the Donor may provide information to the public, news media, or any other individual or group which discloses her own identity, but she may not provide information that could lead to the discloses her own identity, but she may not provide information that could lead to the disclosure of the Intended Parents or the Child. This Paragraph shall remain in force in perpetuity, even if the remainder of the Agreement expires, is terminated or is found unenforceable. (Contract between Intended Parent and Egg Donor, Northern California Agency)

A Southern agency director worried that agreements with intended parents were insufficient to protect donors' privacy:

We try to hold our families to a standard. It's more the families than the donors, because the donor never sees a photo of the family.... It's important to kind of educate donors that as much as we can try to make sure that they're protected and that people will use the proper channels if they ever need to be reached, that I can't promise anything and that's become—that's a little disconcerting. (Director, Southern Agency)

Some agencies, particularly in the Northeast, have dealt with this uncertainty by limiting the amount of information about the donor disclosed to intended parents. First, no names are used in contracts at all; contracts are signed in counterpart:

The contracts between the parents and the donors, no one's identified by name. They're identified by donor numbers. So in the contracts ... people are referred to as 'Donor ID #xxxx.' And then the intended parents are identified by 'Intended Parent #xxxx.' (Director, Northeast Agency)

Agencies that emphasize donor privacy also prohibit semi-anonymous meetings between the parties, as being contrary to the objective of protecting donor privacy.

Most agencies in the rest of the United States, however, allow the intended parents and donors to choose the level of anonymity that feels right to them.

I, [donor], understand that my relationship with the Recipient(s) will be as anonymous as possible unless I choose to disclose personal and confidential information as indicated in [other] sections ... of this contract. (Contract between Egg Donor and Agency, Southern Agency)

Sometimes these choices encompass total anonymity, semi-anonymity, and disclosure of identifying information:

Donor acknowledges that she has been advised by [Agency] that its egg donor program allows Intended Parents and Donors to mutually determine the level of anonymity/disclosure between them, as more particularly described below.... A) 'Anonymous Donation': ... [Agency] will provide to Intended Parents: Donor's photograph and Donor's responses to [Agency]'s Donor Questionnaire, with no disclosure of identifying information about Donor; B) 'Anonymous Donation with Meeting of Intended Parents and Donor': Disclosure will be as described above in Section A. Additionally, [Agency] will arrange a meeting between Donor and Intended Parents. C) 'Non-Anonymous Donation': ... [Agency] will disclose to Intended Parents: Donor's full name, Donor's photograph(s) and Donor's responses to [Agency]'s Donor Questionnaire, specifically including disclosure of Donor's identifying information. (Contract between Egg Donor and Agency, Northern California Agency)

Some agencies allow the intended parents and egg donors to meet each other, but only under conditions of confidentiality, with the promise that no identifying information will be exchanged.

Upon mutual agreement of Donor and Recipient, Agency will arrange a private, face-to-face meeting in order for Donor and Recipient to determine whether Recipient will use Donor's eggs. Under no circumstances will the Donor and Recipient exchange any identifying information, other than first names. (Contract between Egg Donor and Agency, Northern California Agency)

"Identifying information," according to these agency decision-makers, includes:

First and last name, date of birth, and any other information that Donor and Intended Parents mutually agree to. Donor's current or past place(s) of employment and educational institutions which Donor has attended, is attending, or will attend in the future, are not considered 'identifying information.' (Contract between Egg Donor and Agency, Northern California Agency)

For another Northern California agency, non-identifying information includes:

Profiles, photos, medical history, and general education and employment history. (Contract between Egg Donor and Agency, Northern California Agency)

Agency decision-makers in the Northeast argued that disclosure of such information as places of employment and educational institutions renders the donor's identity easily ascertainable, and therefore cannot be considered anonymous donation.

If donor's privacy is threatened from the regular practices of agencies, with clients and donors who abide by their confidentiality agreements, it is even more threatened by intended parents who deliberately violate their confidentiality agreements and seek to discover their donor's identity on their own. Agency decision-makers found themselves between a rock and a hard place when dealing with difficult intended parents who have disregarded their own agreements to protect their donor's privacy.

You want to calm them down, and then you just kind of have to go, 'That's right. We also represent the donor.' You know if I were a donor ... would I be OK getting contacted like this [by the intended parents] or would I want to track down that person and kill them? (Director, Northern California Agency)

When agency decision-makers encountered intended parents who violated their confidentiality clauses, they attempted to discover how the intended parents found their donors, so as to prevent future intended parents from following in their footsteps:

I have a lot of patience, so I wasn't angry [with the intended parents], but I did say to them, 'you can't do this.' But for me, it was about I really desperately wanted to know how they had done it because I felt like I couldn't protect the donors if I didn't know how they had done it. And they never, ever told me. (Director, Southern Agency)

This agency director was frustrated because she felt like she couldn't keep the same violation of her donors' privacy from occurring again, although it could be argued that if intended parents are going to violate their confidentiality clauses by searching online or engaging private investigators, there is not much that anyone could do about it; that the only way to guarantee donor privacy would be to take the approach of the Northeastern agencies, and severely limit the amount of information disclosed to intended parents.

An agency decision-maker in Southern California took the opposite approach to donor privacy; rather than worrying about maintaining it, she believed that the very act of donating one's eggs is an implicit agreement by the donor to waive her privacy to a certain extent:

If you're talking about specifically the personal stuff they share in their history, when you're sharing your genetics with somebody and you're willing to take that step, I think that—to a certain degree —that amount of privacy and that sort of sharing is just part of what should be included. For very important reasons.... When you're giving something this significant, there is an element of privacy that you have to be willing to let go of. They [intended parents] don't have to know your name, they don't have to do anything that can expose you, but we have the donors sign a form with our agency specifically stating that we have the right to give a psychological evaluation to prospective intended parents. (Director, Southern California Agency)

Taking this view minimizes the potential exploitation of donors, since a lesser level of privacy is implied by the very decision to donate eggs. In such a way, exploitation is less likely, since in theory, the donor should take into account her own feelings about compromising her privacy when deciding to donate her eggs, and with a lower level of privacy expected, the potential for violation of that privacy is also lessened.

Two thirds of my agency decision-maker interviewees expressed concern with some aspect of maintaining egg donor privacy during and after their participation in an egg donor IVF cycle. Although they did not explicitly discuss these concerns as apprehensions about possibly exploiting donors, that is the underlying problem with violation of donor privacy. If donors are promised a certain level of privacy, up to and including anonymity, and that privacy is violated, whether accidentally, either through some insecurity in the agency's electronic data system, or the collection of "too much" information about donors, or intentionally, by means of intended parents either demanding too much information about the donor or taking it upon themselves to discover the donor's identity on their own, the donor has been unfairly taken advantage of, and thus exploited.

Agency decision-makers have, to varying degrees, taken responsibility for protecting their donors' privacy, and preventing their exploitation. In the Northeast, they do so by imposing strict conditions of anonymity on the process; in other parts of the country, they allow the donor and intended parents to choose the level of privacy with which they are comfortable. Most agencies require both donor and intended parent to sign confidentiality clauses in their contracts. Agency decision-makers who had experienced an intended parent deliberately violating the donor's privacy by seeking her out outside of the agency attempted to discover how the intended parent had made their discovery of their donor, but there is not much agency decision-makers can do to prevent such intrusions, aside from have the intended parents sign legally enforceable agreements promising that they will not seek out their donors, and warning donors that they, the agency, may not be able to protect the donor's privacy in all circumstances.

A minority opinion saw donor privacy in a different light: that by choosing to donate her eggs, the donor has of necessity waived a great deal of her privacy, and thus lowered the likelihood of violation of her privacy, and of possible exploitation. Regardless, most of the agency decision-makers with whom I spoke were concerned at some level with maintaining their donors' privacy, and by taking what steps they could to protect that privacy, they also engaged in mostly incidental prevention of exploitation.

## Medical Treatment

One of the elements of egg donation that receives a lot of media attention is the fact that egg donors are submitting themselves to otherwise unnecessary medical treatments, including taking hormones, getting blood drawn and ultrasounds done, and having a minor surgery to retrieve their eggs.<sup>710</sup> The media often exaggerates the extent of the medical risk that egg donors assume, but it is true that, as with any medical procedure, there are risks—known risks, such as possible reactions to the hormonal medications or anesthesia, and unknown risks, such as the long term effects of young women taking excess hormones in their twenties.<sup>711</sup> Perhaps the largest immediate medical risk of egg donation is ovarian hyperstimulation syndrome (OHSS). IVF necessarily involves hypersimulation of the ovaries—multiple eggs are stimulated to develop so they can be retrieved and fertilized—but OHSS occurs when the ovaries become excessively swollen, and fluid leaks into the belly and chest.<sup>712</sup> Severe OHSS can be life threatening. There are ways of preventing most cases of OHSS, such as being conservative with hormonal medications and monitoring donors closely while they take those medications, but OHSS appeared to be the biggest concern when agency decisionmakers spoke about the medical treatment of their donors.

Certainly poor medical care could lead to exploitation of donors; if they agree to act as an egg donor with the understanding that their bodies will be well cared for by the physicians to whom they are sent, and then the physicians or clinic violate that trust by pushing the donor's body more than is safe, that is taking unfair advantage of the donor. Especially when OHSS is rare today:

> I think the worst is if somebody continually hyperstimulates. Hyperstimulation is really not an option according to all the doctors that I know now. There's so many things that can be done to not cause it to happen. But I know historically, there's some doctors that—and I won't work with them, but I know that they're

<sup>&</sup>lt;sup>710</sup> Egg donors undergo part of an IVF cycle; they have their ovaries stimulated and eggs retrieved, but they do not have their uterine lining prepared for pregnancy or an embryo transferred into their uterus.

<sup>&</sup>lt;sup>711</sup> See note 6 for a summary of our current understanding of the long term medical risks to donors.

<sup>712 &</sup>quot;Ovarian hyperstimulation syndrome," Medline Plus.

not happy unless they get forty eggs [where most reputable clinics aim for about fifteen eggs].... Which is a really bad cycle and the donor's going to be uncomfortable and it's not even good for the recipients [because there's some evidence that excessive hyperstimulation diminishes egg quality]. (Director, Southern California Agency)

OHSS has become more of a concern for agency decision-makers with the advent of frozen egg banks, because:

the more eggs they [physicians who own frozen egg banks] have, the more income, so to speak. They have more property, so to speak, so they are able to make more money, and in doing so, they have to be the advocates for the patient and yet it's a conflict of interest because it's affecting their bottom line. So they may overstimulate donors, in fact. (Director, Southern California Agency)

These agency decision-makers were concerned about the possible exploitation of their donors via poor medical treatment at the clinics to which they sent them.

Several agency decision-makers discussed the steps that they take to prevent such exploitation from occurring, mostly by refusing to work with clinics who have a track record of treating donors poorly.

We also turn down doctor's offices. There are offices [that] just don't treat donors well medically; you know, we're responsible, too. (Director, Southern California Agency)

The director of another Southern California agency also takes responsibility for the level of medical care provided to her agency's donors:

We just say, it's not worth it for us. We have to be advocates for our surrogates and our egg donors, and we know this industry, so we just don't say, 'OK, well, what they're paying us, we're going to send you anywhere.' We want to make sure they're taken care of. We wouldn't be able to sleep if something happened, so it's really important for us to keep those types of—making sure that we earn their [donors'] trust. They're trusting us to find them a good match, and one of the things is their safety. (Director, Southern California Agency)

A Southern agency director sees a greater risk of OHSS for donors who participated in "shared cycles," in which the resulting eggs from a single donor are shared between two separate intended parents—a situation which presumably could lead the treating physician to push the donor to create more eggs than would be the case in a non-shared cycle.<sup>713</sup>

So I think there's a risk of that [OHSS] and I think donors are going to see that.... I've only done that two times, and it was with clinics that I have worked with that I know take great care of our donors. I would not let just any doctor say, 'here's two people, we want to share a donor,' because some of them just aren't as particular about it. (Director, Southern Agency)

Agency decision-makers take great care in vetting the clinics to which they send their donors; while the clinic is usually determined by the intended parents' choice, agencies retain the power to refuse to work with particular clinics that have a history of mistreating donors, thus compelling intended parents either to switch clinics or seek a donor elsewhere.

Another way in which agency decision-makers limit the medical risk undertaken by their egg donors is through abiding by the ASRM guideline that each donor be limited to six cycles.<sup>714</sup> Some agency decision-makers agree with the ASRM's guideline:

It's one thing to go through nine IVF egg retrievals to have your own child, because it's worth it to go through that risk. I don't think it's worth it to go through that risk for someone else. (Director, Northern California Agency)

<sup>&</sup>lt;sup>713</sup> Shared cycles, in which two sets of intended parents receive the eggs from a single donor's cycle, exist as a means of making the process of donor egg IVF less expensive. Such cycles also make it less likely to succeed, because it necessarily means that there are fewer eggs for each intended parent to work with (or, alternately, that the "sharer" will receive no eggs, if there are not enough to go around).

<sup>&</sup>lt;sup>714</sup> "[B]ecause of the possible health risks ... it would seem prudent to consider limiting the number of stimulated cycles for a given oocyte donor to approximately six..." ASRM Practice Committee, "Repetitive Oocyte Donation," S195.

Another agency decision-maker finds valid both of the ASRM's reasons for limiting each donor's number of cycles—medical risk assumed by the donor, and risk of "inadvertent consanguinity":<sup>715</sup>

I think [limiting the number of cycles an egg donor can do is good] for both. I definitely think for both reasons. (Director, Midwestern Agency)

Yet another means by which agency decision-makers try to prevent the exploitation of their donors through poor medical treatment is by the purchase of an insurance policy to cover any medical complications that donors experience as a result of donating their eggs.

The great news is that we have a very good insurance policy that we bought for our ... donors so that nobody's ever had to take a penny out of their pocket. (Director, Southern Agency)

While such insurance policies do not prevent the donor from experiencing medical problems as a result of the cycle, they can minimize any other damaging fallout from such occurrences by ensuring that donors receive complete medical care for their complications, and that they are not financially responsible for that medical care. Insurance policies for donors are more or less standard of practice among reputable agencies—though typically, those policies are bought by the intended parents, rather than by the agency itself.

Agency decision-makers attempt to prevent the exploitation of donors in part by doing their best to ensure that donors receive competent medical treatment during the course of their egg donation cycle, and by providing them with insurance in the event of a medical complication. By refusing to work with clinics that have a history of high rates of OHSS in egg donors, doing their best to limit donors to six egg donation cycles, and providing donors with medical insurance, agency decision-makers helped to prevent donors from being taken advantage of in the context of their medical treatment during an egg donation cycle.

<sup>&</sup>lt;sup>715</sup> "Inadvertent consanguinity resulting from oocyte donation could occur if: [1] a given donor has donated to two or more families and [2] the offspring were unaware of their specific genetic heritage. Previous guidelines on therapeutic donor insemination and oocyte donation, published by the American Society for Reproductive Medicine, have advised an arbitrary limit of no more than 25 pregnancies per sperm or oocyte donor, in a population of 800,000, in order to minimize risks of consanguinity." Ibid., S194.

# Legal Protection

Egg donation gives rise to many legal implications: parentage issues, disposition of embryos, and the level of anonymity or identification between the parties, to name but a few. Interestingly, the few agency decision-makers who mentioned specific legal problems were, without exception, referencing legal practices in frozen egg banking. While there are many legal issues across all aspects of egg donation—and family formation attorneys believe that all egg donors should be represented by independent legal counsel and have individualized contracts drawn up—it is the new, additional legal conundrums that have arisen with frozen egg banking that have caught the attention of agency decision-makers.<sup>716</sup>

Frozen egg banks provide more opportunity for exploitation of egg donors than do traditional fresh donor egg cycles. Several agency decision-makers felt that the lack of a direct agreement between the donor and an intended parent seriously compromises the level of legal protection a donor typically receives.

I think they're [donors are] much more likely to have better [information in a fresh cycle], yes, because intended parents draft the contract specifically between themselves and a particular donor. But in that scenario, that donor is also represented by independent counsel. But if you're just donating eggs to a fertility center, you're typically not signing a contract. What you're signing is consent to remove eggs or retrieve eggs. (Director, Midwestern Agency)

In other words, many of the donor's choices that are usually addressed in a direct agreement between the donor and intended parents are simply denied the donor in an agreement with a frozen egg bank—issues such as to how many families the eggs might be distributed, and whether or not any leftover embryos may be donated to yet another family.

Apparently, however, even donating eggs through a traditional direct agreement with intended parents does not protect donors from the grasp of egg banks; some clinics with proprietary egg banks have begun building into their contracts a provision in which the first fifteen or so eggs in a fresh donor egg cycle go to the intended parents, but any remaining eggs go to the bank to be frozen. According to the agency decision-makers,

<sup>&</sup>lt;sup>716</sup> On the topic of independent legal representation, one family formation attorney interviewee said that that's the only way to "protect ... all parties to the arrangement.... That's what the lawyers are for, they're there to give guidance and counsel and to advise them as they get into the arrangements."

this provision is so buried in the paperwork that most donors it affects are entirely unaware of it—and thus have not given their full informed consent.

They just don't read it and they sign off on it. Both the donor and the intended parents just sign off on it and later it's come to fruition that not all of the eggs were given to the recipient when they paid for all of the embryos to be fertilized. (Director, Southern California Agency)

More than one agency decision-maker mentioned this problem, and they thought that both donors and intended parents are in the dark about contract clauses giving "excess" eggs to the clinic's frozen egg bank:

> I think the most important [issue] right now is transparency. I think clinics are now starting egg banks, and they're not telling their donors about the fact that whatever leftover eggs will go to the clinic, and intended parents are signing these contracts unknowingly as well. They're paying for the full cycle, but then they have four or five eggs left over and it's going to the clinic. And donors don't know. They think they're donating to one client, and then it may go to two. (Director, Southern California Agency)

Without legal representation to guide them, donors (and intended parents) are unlikely to fully understand all the ramifications of the legal documents they sign. As another agency decision-maker put it,

in general, I think there is very limited information that goes out, and I also wonder what sort of legal access these donors have to the consent forms and contracts that they are maybe signing. (Director, Midwestern Agency)

Some legal documents that frozen egg banks ask donors to sign are simply inaccessible to donors, and they end up signing without realizing exactly to what they're agreeing. That does not constitute informed consent.

To prevent this kind of exploitation from occurring, one Southern California agency director requires all donors to have independent legal counsel:

We do frozen shared cycles with some clinics. We required that the ... donor must have an attorney represent them so it's not a waiver they just sign. (Director, Southern California Agency)

Other agency decision-makers choose not to participate in frozen egg banking, taking the stance that a direct agreement between donor and intended parent is necessary for the legal protection of all parties.

> That's an agreement that we have executed anonymously through independent legal counsel for both parties, the egg donor and the intended parent. It specifically details the things that are necessary to have a sound legal agreement between consenting parties. The financial exchange that takes place, the custodial rights and responsibilities that are bestowed upon the intended parents, all custody and control of excess embryos—eggs, embryos, or children into the future; things that are very specific and necessary in a direct agreement that you are no longer getting when you freeze eggs and they're just housed in a bank. That is something I'm not comfortable with right now. And I don't get into that. (Director, Southern Agency)

In fact, the obvious step to prevent exploitation of egg donors with regard to legal matters is to ensure that they have access to independent legal counsel for each of the cycles in which they engage.

That's why I would hope that the egg donors would use effectively the attorneys that are reviewing their contracts. (Director, Midwestern Agency)

And as a family formation attorney put it,

I get the idea of protecting all parties to the arrangement. But that's what the lawyers are for, they're there to give guidance and counsel and to advise them as they get into the arrangements. (Family Formation Attorney)

One of the problems, according to a family formation attorney, is that some clinics and agencies provide their own consent forms, without the advice of legal counsel.

They actually don't have the parties signing a direct agreement between themselves. And that is just—it's an opportunity for danger, it's an opportunity for liability and exposure that doesn't need to be there. Because really, the donor is signing medical consent forms with the clinic, and some of these forms may have a legal provision in them, which—I don't put medical provisions in my contracts. I don't think doctors should put legal provisions in there without at least letting them [donors and intended parents] speak to a lawyer. (Family Formation Attorney)

Not all agencies provide realistic access to attorneys; some pay for the donor's attorney or require that intended parents pay for it, while others require donors to pay for it if they wish to engage independent legal counsel—and while a particularly wise donor may choose to do so, the majority of donors are unlikely to because of the expense involved. Some agencies pay for the donor's legal representation themselves:

> Donor warrants that she has been offered the opportunity to obtain independent legal counsel to be advised of the terms, conditions, rights, duties, and obligations under this Agreement. Agency shall compensate Donor attorney directly and up to \$[xxxx]. (Contract between Egg Donor and Agency, Northern California Agency)

> [Agency] has agreed to pay \$[xxxx] to any legal counsel consulted by Donor prior to signing any Agreement between Donor and Intended Parents, and to make referrals to Donor should she so desire for that purpose. (Contract between Egg Donor and Agency, Northern California Agency)

Other agencies require that intended parents pay for their donor's attorney fees:

To ensure, at the Intended Parent(s) expense, any Egg Donor selected by the Intended Parent(s) has access to: An independent and impartial attorney to review and or draft an agreement between Egg Donor and Intended Parent(s), counsel, advise and negotiate the Contract on behalf of Egg Donor prior to the signing of the Egg Donor Contract by the Egg Donor. (Contract between Intended Parent and Agency, Southern Agency)

Donor further acknowledges that she has the right to consult with and have the Donor/Intended Parents Egg Donation Agreement reviewed by an attorney of her choice, at Intended Parents' expense (in the maximum amount of \$[xxxx]), prior to Donor's execution of said agreement. (Contract between Egg Donor and Agency, Northern California Agency)

Still other agencies require the donor to pay for at least part of her attorney's fees:

Donor acknowledges that prior to signing this Agreement, she has been encouraged and given ample opportunity to consult with independent legal counsel of her choice concerning the legal issues involved in egg donation in general, along with the specific terms and obligations within this Agreement at the Donor's own expense. (Contract between Egg Donor and Agency, Southern California Agency)

Donor acknowledges that she has the right to consult with and have this Agreement reviewed by an attorney of her choice, at Donor's expense, prior to Donor's execution of this Agreement. (Contract between Egg Donor and Agency, Northern California Agency)

And in fact, the agency organization SEEDS has a standard intended to ensure the egg donors have access to legal representation, but it states that such access should be paid for by the donor herself:<sup>717</sup>

The Egg Donor should always be given the option to retain legal counsel to review this agreement. If the Egg Donor chooses to exercise this option, this would be at the Egg Donor's expense.<sup>718</sup>

The draft ABA Model Act Governing ART Agencies has a similar clause, though it does not specify who covers the cost of legal representation:

No ART Agency shall permit, encourage or facilitate an egg Donor or Surrogate to begin a Cycle until the following tasks have been completed: ... (b) All Participants have each had an opportunity to consult with a licensed attorney of their own choosing.<sup>719</sup>

Agency decision-makers recognize that one way in which their egg donors are vulnerable to exploitation is the legal realm of egg donation. There are many complex issues at play, and all parties must be represented by independent legal counsel to ensure that their interests are articulated and their choices laid out for them. Otherwise, donors may end up signing legal agreements that they do not fully understand, but by which they are legally bound. Agency decision-makers try to prevent this kind of

<sup>&</sup>lt;sup>717</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

<sup>&</sup>lt;sup>718</sup> "Agency Agreements with Egg Donor," SEEDS Standards.

<sup>&</sup>lt;sup>719</sup> ABA Model Act Governing ART Agencies (DRAFT) § 304.1(b).

exploitation by ensuring that donors have access to legal counsel, a stratagem that is likely more successful when the attorney's fees are paid for by the agency or by the intended parents.

#### **Empowerment and the Avoidance of Exploitation**

The possibility of exploitation of egg donors is a topic that is often touched on in media stories about the field.<sup>720</sup> Some agency decision-makers do not believe that donors are susceptible to exploitation because they see potential donors as empowered young women who are capable of making sound decisions about egg donation for themselves.<sup>721</sup> These agency decision-makers regard the concern about exploitation common to the majority of agency decision-makers, as well as society at large, to be patronizing of donors, and an attitude that strips donors of their inherent autonomy.<sup>722</sup> In this view, as long as donors are given sufficient education about the process and their choices, they should be able to decide to donate their eggs, and they should be compensated whatever amount they are able to command.<sup>723</sup>

In a sense, however, this view is a thin notion of exploitation, almost a hijacking of feminist rhetoric, which lacks a real acknowledgment of the social justice aspect of exploitation.724 Allowing the pure market to be the arbiter of the worth of donors and their eggs raises all the issues of eugenics discussed in the Chapter Five.725 Additionally, the market may reward characteristics that are irrelevant to the outcome of a donor egg IVF cycle, the happiness of intended parents, or the health of future children. For example, women of equal intelligence may well go to Harvard and Cal

<sup>&</sup>lt;sup>720</sup> See note 676 for examples of media coverage of eggs donor exploitation.

<sup>&</sup>lt;sup>721</sup> Johnston, "Paying Egg Donors," 28-31; Mundy, *Everything Conceivable*; Shultz, "Questioning Commodification," 1841.

<sup>&</sup>lt;sup>722</sup> Johnston, "Paying Egg Donors," 28-31; Mundy, *Everything Conceivable*; Shultz, "Questioning Commodification," 1841.

<sup>&</sup>lt;sup>723</sup> In order to be truly free to participate in the market, however, donors must be educated on the medical, social, and emotional risks of egg donation. Only education will enable them to give their full informed consent.

<sup>&</sup>lt;sup>724</sup> One such concern is Debra Satz's "asymmetry thesis," which predicts that people who are systematically oppressed in a society (women, in her example, but also the poor and people of ethnic and racial minorities) cannot have the capacity to make an informed choice for themselves within the framework of oppression. Satz, "Markets in Women's Reproductive Labor," 107-131.

<sup>&</sup>lt;sup>725</sup> See Chapter Five, "Ambivalence Revealed: Justifications for, Discomfort with, and Criticism of Egg Donor Compensation" and "Implication of Eugenics." See also Kevles, *In the Name of Eugenics*.

State schools, but the market will invariably reward the Harvard student over the Cal State student, as discussed in Chapter Five, "Ambivalence Revealed: Justifications for, Discomfort with, and Criticism of Egg Donor Compensation." In that case, the name of Harvard acts as a proxy for measuring intelligence, but arguably that proxy is unreliable and misleading when it comes to evaluating donors from other schools. Furthermore, while assuming universally equal autonomy is a utopian ideal, perhaps achievable in a utopian society, the fact remains that we do not live in a utopian society, and social justice issues color everyone's decision-making ability. Some young women have better access to education and resources that allow them to make decisions free of other constraints, which can make for an uneven playing ground when it comes to choosing to become an egg donor.

More agency decision-makers than not, however, do think that exploitation is a real possibility for egg donors. These decision-makers deliberately attempt to prevent exploitation with regard to donor compensation, by limiting its amount or rejecting donor applicants who show a marked financial need. Agency decision-makers also incidentally prevent exploitation of donors by assessing their maturity before accepting them into a donor program, and by mitigating their recruiting methods (which they explicitly deem unproblematic) with psychological evaluations to assure that a donor has sufficient social support.

Other potential areas of exploitation include donor education, privacy, medical treatment, and legal protection. In all of these areas, agency decision-makers engaged in both deliberate and incidental attempts to prevent exploitation of their donors. All agencies had some sort of donor education protocol in place; some of the decision-makers explicitly discussed these programs (typically the more elaborate ones) as a means of preventing exploitation. Similarly, all agencies had some sort of provisions to protect donor privacy in place, though very few agency decision-makers also took responsibility for their donors' medical treatment, with some agencies refusing to work with clinics which have shown a disregard for donors' health—and thus the real possibility of exploitation. Finally, some agency decision-makers made available legal representation at no cost to donors; a sure way to prevent exploitation in a transaction that inherently raises many complex legal issues. Not all agencies enabled donors to engage legal counsel for free, however; some required the donors to pay their own attorneys' fees.

One final aspect of preventing donor exploitation is ensuring that donors are never financially responsible for a donor egg IVF cycle.<sup>726</sup> Since they are doing the intended parents a signal service by allowing them a chance at procreation, and because they are in fact young women, whose thoughts about donating their eggs may change over time, as they become more involved in a cycle, it is important to allow them to back out of a cycle with no repercussions. Agency decision-makers were obviously concerned with the impact on intended parents of donors backing out after the beginning of a cycle, but:

The problem is we're talking about young women who may decide at the moment that they want to be a donor, and then as they give it some more thought, just don't feel comfortable with the idea. And, frankly, if a donor doesn't feel comfortable with an idea and you force her materially to do it because you're going to hold her financially accountable if she doesn't, I mean, that's exactly what's going to prompt the crazy donor who is going to try and track you down because she knows already that she's not mature enough or emotionally responsible enough to do this. So I think there needs to be an out. (Director, Northern California Agency)

If the donor feels she must continue, because she cannot financially afford not to, this seems a sure path to exploitation.

While more agency decision-makers are explicitly concerned about the negative effects of commodification, and a minority view donors as empowered autonomous agents, in need only of education and not other means of protection, the majority of my interviewees were concerned to varying degrees about the possibility of exploitation of their egg donors. In response to that concern, they engaged in a number of strategies to prevent exploitation, some overt and some implicit.

<sup>&</sup>lt;sup>726</sup> Some agencies require a donor to pay for any completed medical procedures or testing at the time she backs out of the cycle without cause—or rather, without a cause that is non-psychological in nature.

## **CHAPTER SEVEN**

#### Suggestions for a New Regulatory Direction

#### Epilogue:727 Conceiving Meaning

After donating her eggs to a breast cancer survivor, Jennifer went on to donate to several other families. But she didn't want it to end there. She found the whole thing to be incredibly inspirational, and thought that helping people to have babies would be an unequivocal way to establish fulfilling work for herself.

She called up the agency for which she had been a donor and secured a job on their staff. After moving up the ranks in that agency, she went out on her own and founded a successful, passion-fueled agency—and a meaningful life. And breast cancer survivors? They're welcome at her agency, fees discounted.

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Amy, who thought she might have unknowingly donated her eggs to her boss, had done so without compensation. The nurses at the clinic couldn't believe that she would want to donate without compensation, and repeatedly asked her if she understood what she was doing. She did understand. And she was happy to do it, compensation or no.

Because of her generosity to the strangers who received her eggs, a friend—who had survived uterine cancer at age twenty-four—asked her to serve as a gestational surrogate. And Amy did that, too. Twins.

In the process, she realized that there were no organizations out there to help people like her and her friend. They were navigating the emotional and legal waters of surrogacy on their own. And Amy saw an opportunity to continue to help people who wanted to have babies—and to help their donors and surrogates, like herself.

So Amy established an egg donor and surrogacy agency whose mission is to make surrogacy and egg donation more accessible to those who need it. In fact, her agency's fees are so low that they prompted a competitor to accuse her of "stealing" the

<sup>&</sup>lt;sup>727</sup> Paraphrased anecdotes from two of my interviewees; names are pseudonyms.

competitor's clients, and to propose a price-fixing scheme. Amy's response? "I'm not going to screw my potential clients!"

#### **A New Regulatory Direction**

Egg donor agencies have been subject to negative media attention since their inception, most recently as a result of the controversy over Theresa Erickson's "baby-selling" scheme.<sup>728</sup> The infertility industry in general is more and more subject to scrutiny, because even basic infertility treatment intervenes in biological processes in ways that raise many ethical and legal questions. The process of egg donation alone raises questions about the moral and financial value of a human egg, whether we should commodify eggs or women's reproductive labor, and whether egg donation exploits or empowers women. States have begun to propose regulation for fertility clinics; egg donor agencies can't be far behind.<sup>729</sup> In order to think more reasonably about policy, we need to understand how individual people impact organizational meaning and values.

## The Individual within the Organization: A Theoretical Assessment

In this dissertation, I have shown that individual agency, in the form of the personal morality of agency decision-makers, forms the core of organizational behavior among egg donor agencies. Because they are relatively new organizations acting in an unregulated legal environment, and in a field that implicates many complex ethical issues, agencies might be expected to perform a great deal of modeling behavior— mimicking the behavior or standards of other, related organizations.<sup>730</sup> While agencies do engage in some modeling behavior, including "reverse modeling" of other agencies, or doing the opposite of other agencies' questionable practices, agency decision-makers

<sup>&</sup>lt;sup>728</sup> See note 508 for a summary of the media coverage following the Theresa Erickson scandal.

<sup>&</sup>lt;sup>729</sup> Vetoed bills include Ethical Treatment of Human Embryos, Georgia SB 169 (2009) (vetoed; unlawful for any person to knowingly create an in vitro embryo by any means); and California SB 674 (2009) (vetoed; would have brought fertility clinics and egg extractions sites under the jurisdiction of the California Medical Board). Since 1986, Louisiana has statutorily defined a human embryo as a juridical person. Louisiana Revised Statutes § 124. Oklahoma statute requires the consent for an embryo transfer to be executed not only by the intended parents, but also by a judge who has adoption jurisdiction. Oklahoma Statutes § 10-556(2)(2009).

<sup>&</sup>lt;sup>730</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-75; Jepperson, "Institutions, Institutional Effects, and Institutionalism;" Friedland and Alford, "Bringing Society Back In."

look first and foremost to their own individual sense of morality when they confront the many ethical issues in their businesses. Thus an "inhabited institutions" approach to understanding organizational behavior in this context is the best theoretical fit to what agencies (at least, ethically responsible agencies) are actually doing (or report they're doing).<sup>731</sup>

The primary benefit of an inhabited institutions approach is that it can bridge the gap between diffusion models of institutional change theory and the impact of the individual's decisions and actions on organizational behavior, on the one hand, and the gap between organizational behavior models and feminist legal theory addressing specific ethical issues that arise in egg donation, on the other. Diffusion models of organizational behavior suggest that organizational behavior spreads across fields as a result of modeling due to uncertainty, responses to pressures from outside the field, and the desire to normalize the field, or professionalize.<sup>732</sup> We see all of these theories in action among egg donor agencies; what is new is the basis of agencies' behavior—personal morality, invisible in diffusion models, which examine only the end behavior of organizations.

Inhabited institutions makes visible the individual actor within an organization.<sup>733</sup> In the case of egg donor agencies, it makes visible the foundation on which agency decision-makers base their decisions—their own morality. Counterintuitively, though it might seem that if each agency is guided by its director's personal moral values they would end with significantly different behavior, what I observed is a convergence of behavior to the extent that it constituted the emergence of norms and a shared moral meaning.

This is the point at which neoinstitutional organizational theory fails to fully explain decision-making in egg donor agencies. Although an inhabited institutions approach makes visible individual actions within organizations, the overarching organizational theory excels at explaining only the reproduction of organizational behavior, rather than

<sup>&</sup>lt;sup>731</sup> Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field." Theory about how individuals manage conflicting institutional logics also have a place in explaining the behavior of agency decision-makers. See Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

<sup>&</sup>lt;sup>732</sup> DiMaggio and Powell, "The Iron Cage Revisited," 70-75; Larson, The Rise of Professionalism.

<sup>&</sup>lt;sup>733</sup> See Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field."

innovation in organizational behavior. Diffusion models of institutional theory propose that organizations model themselves on other organizations and fields that are—or are perceived to be—similar or somehow relevant to them. The organizations and fields that form the basis for these models are typically successful, or at least based on entrenched underlying logics.

In the case of egg donor agencies, however, the organizations are so new that no similar or relevant models yet exist, nor are there any obvious underlying logics on which decision-makers may rely. As a result, agency decision-makers are left to throw together moral schemas and scripts from any available source, culminating in a salmagundi of moral and ethical perspectives. And yet, a convergence of norms and moral values emerges from the jumble.

The key to this paradox is the fact that the agency decision-makers' individual moralities are not in fact multiple, completely different value systems located in multiple, completely different contexts. Rather, agency decision-makers play the same roles and deal with similar problems and challenges in the course of their businesses; they are socially equivalent. Furthermore, social interaction among agency decision-makers and other players in the egg donation and infertility industries embeds them in the preexisting norms of the rest of the infertility industry, and, more importantly, in the larger social context of popular beliefs about right and wrong.<sup>734</sup> When making difficult decisions about the ethical issues they encounter in the course of business, agency decision-makers refer to their "gut" feelings, but those feelings are developed, at least in part, in the context of their social equivalence with other agency decision-makers, and their social interaction with one another and with the larger industry. Consequently, agency decision-makers' "personal" morality overlaps to a great extent.

Thus, even in the face of deliberate efforts to distinguish themselves from other agencies, agency decision-makers' organizational behavior converges. The one near-universal point of convergence is that these women have all created organizations that work toward the same goal: to act as caretakers of their charges, intended parents and donors. This is perhaps one result of agency decision-makers' social equivalence and social embeddedness: they come to believe, collectively, that a "care account" is normatively desirable.

<sup>&</sup>lt;sup>734</sup> These institutional logics are multiple and result in complexity in the ways in which agency decisionmakers use them to create meaning and translate them into organizational practices. See Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

One possible explanation for the convergence to a shared moral meaning of care taking is that such an account comes to be normatively desirable because it is what society expects of egg donor agencies, and is thus good for business. What I gleaned from speaking with agency decision-makers, however, is that their belief in their roles as caretakers is sincere, and the resulting shared moral meaning among my interviewees is the product of each decision-maker working from her individual morality—which overlaps with the morality of other agency decision-makers due to their social equivalence and embeddedness—and implementing that morality through her agency. My interviewees' shared moral meaning ultimately has its roots in their shared purpose: the joy they find in helping people to build their families.

While neoinstitutional organizational theory is insufficient to explain the development of shared moral meaning in egg donor agencies, an inhabited institutions approach to organizational behavior can still make clear how feminist theory on the ethical issues in egg donation impacts the practice of egg donor agencies. Feminist theorists have conflicting takes on the two primary ethical issues in egg donation: commodification of eggs and/or women's reproductive labor, and exploitation of egg donors. On the one hand, some feminists argue that egg donation can be a positive experience for women; it enables them to participate in the free market in a potentially beneficial way, and when the experience of commodification is embedded in the context of giving a priceless gift, even that aspect of egg donation can be spun as a benefit.<sup>735</sup> These feminists tend to see efforts to cap donor compensation and to protect egg donors from exploitation as patronizing and unnecessary; they assume that every woman, no matter her age, race, or financial situation, possesses agency that makes her competent to make a decision about donating her eggs.

Feminists on the other side of the equation argue that the very act of "donating" eggs, if a woman receives compensation, compromises her humanity, and consequently, all humanity. These feminists see the sale of eggs (or reproductive labor, more generally) as an insult to personhood, and incompatible with "human flourishing."<sup>736</sup> Similarly, these feminists see as very real the threat of exploitation, arguing that only women in lower socio-economic circumstances are likely to find the money great enough incentive to undergo an invasive and potentially risky medical procedure for the benefit of (wealthier) strangers.<sup>737</sup>

<sup>&</sup>lt;sup>735</sup> Almeling, *Sex Cells*; Johnston, "Paying Egg Donors," 28-31; Mundy, *Everything Conceivable*; Shultz, "Questioning Commodification," 1841.

<sup>&</sup>lt;sup>736</sup> Radin, "Market-Inalienability," 1851-1852.

<sup>&</sup>lt;sup>737</sup> Dickenson, *Property in the Body*; Radin, *Contested Commodities*; Satz, "Markets in Women's Reproductive Labor," 107-131.

These two feminist points of view have informed the larger social context from which agency decision-makers form their personal moralities, and they are evident in agency decision-makers' explanations for specific decisions they make about donor compensation, recruiting, education, and screening. An inhabited institutions approach to agency behavior helps us to translate the existence of these academic theories, incorporated into agency decision-makers' individual moral values, into the behavior of organizations—organizations that regularly engage with these feminist issues in the real world.<sup>738</sup>

#### Ethics on the Ground: Agency Decision-Makers in Action

In this dissertation, I show how agency decision-makers' individual actions and values have led to the beginnings of field norms for egg donation agencies, and to a shared moral meaning among them all. In essence, this is "ethics on the ground": agency decision-makers' real life use of ethics in the day-to-day running of their agencies. Agency decision-makers' individual moral beliefs are translated from their own personal belief systems, on which they base their decisions for their agencies, into organizational action via their agencies. From there, I show how agency decision-makers' personal beliefs are not entirely personal, but are contextualized within the larger infertility industry and society. Ultimately, those personal beliefs come full circle, to converge at a central point comprised of overlapping norms and a shared moral meaning of caretaking of intended parents and egg donors.

In Chapter Three, I show the beginnings of this process, that agency decision-makers, more often than not, reference their own personal morality, which they sometimes called a "gut feeling," when making decisions while running their agencies. Sometimes, agency decision-makers make decisions based on what seems right to them simply to try to differentiate themselves from those agencies they feel do not act ethically. Using their personal morality as a reference point is the major response that agency decision-makers have to the many layers of uncertainty in their field—egg donor agencies are a new type of organization, completely unregulated, and even the technology that gave

<sup>&</sup>lt;sup>738</sup> Both inhabited institutions theory and theory about managing conflicting institutional logics is relevant here: see Hallett and Ventresca, "Inhabited Institutions;" Binder, "For Love and Money;" Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; Smets, Morris, and Greenwood, "From Practice to Field;" Pache and Santos, "Inside the Hybrid Organization;" Battilana and Dorado, "Building Sustainable Hybrid Organizations;" and Greenwood et al., "Institutional Complexity."

rise to egg donor agencies is itself only decades old.<sup>739</sup> For the most part, rather than model their agencies on other agencies or other, analogous organizations, agency decision-makers look inward, at their individual values, when running their agencies.

In Chapter Four, I show how agency decision-makers respond to pressures from without by acting to secure their agencies' legitimacy and beginning to professionalize.<sup>740</sup> Pressures from organizations and professionals within the infertility industry, the cultural expectations of society (often experienced by egg donor agencies as negative press coverage of collaborative reproduction), including societal backlash after revelations of unethical or even criminal behavior from other agencies, and market pressure brought to bear by savvy intended parents, all affect agency decision-maker actions.<sup>741</sup> In response to those pressures, agency decision-makers claim legitimacy by securing their associations with the medical profession and its well-established legitimacy (including attempting to protect intended parents and egg donors from clinics they feel act unethically), affiliating themselves with respected infertility support organizations, and undermining the stigma surrounding egg donation by encouraging open communication between intended parents and egg donors, and disclosure to children. Agency decision-makers make a further claim to legitimacy through their nascent effort at professionalization, or at least the creation of a professional body and a code of conduct.<sup>742</sup> Agency decision-makers' claims to legitimacy and effort at professionalization all speak to the image they would like to project for those outside the field: an image of ethical caretaking that is consistent with the overlapping norms and shared moral meaning discovered in Chapter Three.

In Chapter Five, I focus in on perhaps the most contested aspect of egg donation, commodification. The biological imperative of reproduction—intended parents' insatiable desire for a child—creates a particularly strong market for donor eggs, and understandably, young women are far more likely to donate their eggs when they are compensated. I show that most agency decision-makers experience some amount of ambivalence about this substance of their business, perhaps because of the implication of eugenics in paying a woman for her eggs (usually based on desirable genetic traits) and the threat egg donation poses to traditional concepts of family, in that it blurs the

<sup>&</sup>lt;sup>739</sup> DiMaggio and Powell, "The Iron Cage Revisited," 69-75. See Thornton, Ocasio, and Lounsbury, *The Institutional Logics Perspective*; and Battilana and Dorado, "Building Sustainable Hybrid Organizations," for more on how organizations manage conflicting institutional logics.

<sup>&</sup>lt;sup>740</sup> DiMaggio and Powell, "The Iron Cage Revisited," 74-75; Larson, *The Rise of Professionalism*; Scott, "Lords of the Dance."

<sup>&</sup>lt;sup>741</sup> For examples of negative press coverage of collaborative reproduction, see note 494.

<sup>742</sup> DiMaggio and Powell, "The Iron Cage Revisited," 70-75; Binder, "For Love and Money."

definition of what makes a woman a mother. Agency decision-makers use a number of strategies to ameliorate the negative consequences of commodification, including carefully designating that donor compensation is for her services, not for her eggs, and structuring donor compensation such that it is based on her experience as a donor, rather than her particular genetic traits. Some agency decision-makers also ensure that egg donors' choices, such as the choice not to donate to an unmarried intended parent, are respected. Agency decision-makers frame the whole experience of egg donation, for donors and intended parents alike, in terms of a gift—the biggest gift one could give or receive—which deeply impacts the experience of commodification for the parties for the better. Finally, agency decision-makers try to counter the negative consequences of commodification by humanizing the parties to one another—making donors and intended parents see each other as real people. All of these strategies are ways that agency decision-makers counter their ambivalence about the commodification aspect of egg donation to improve the experience of their donors and clients, in order to achieve the ultimate good, the one that outweighs the moral risks of commodification—helping people to build their families.

Finally, in Chapter Six, I explore the ways in which agency decision-makers think about and act on the risk of exploitation of egg donors. On this topic, more so than others, agency decision-makers demonstrated a division of opinion. A minority felt that egg donors were not at risk for exploitation by participating in egg donation; these decisionmakers believed that as long as they are well educated about their choices, all young women are capable of making good decisions for themselves, and in fact, any attempts to protect them from exploitation are nothing more than patronizing. The majority of agency decision-makers recognized that there was some risk of exploitation to donors, but they were less concerned about it than about the possible negative consequences of commodification. Nonetheless, I show that agency decision-makers take action to prevent exploitation, sometimes purposefully, and sometimes incidentally. They set caps on their compensation (per ASRM guidelines), they require psychological evaluations to ensure donor maturity, they use ethical recruiting practices, they provide thorough education to their donors, they protect their donors' privacy, and they ensure that their donors receive competent medical care and legal representation. However, whether they believe wholeheartedly in young women's autonomy, or they are concerned about exploitation, all of the agency decision-makers with whom I spoke do what seems right to them, referencing their own personal morality to inform the decisions they make for their agencies, and in this case, on behalf of their egg donors.

All of the topics explored in this dissertation—from agency decision-makers' efforts to establish legitimacy to the ways in which they deal with the feminist issues of commodification and exploitation—demonstrate that agency decision-makers refer to

their personal moral values when running agencies. Those personal moral values are actualized through their agencies, and eventually converge at a central point, which comprises the emergence of field-wide norms and the creation of a shared moral meaning of caretaking of intended parents and egg donors. This "ethics on the ground"—agency decision-makers' real-life use of ethical values to run their agencies, and all of the repercussions thereof—exists in concert with agency decision-makers' shared goal: to help people build their families.

## Where To? Suggestions for a New Regulatory Direction

There is general agreement among agency decision-makers and, based on media coverage (including online comments on internet articles), the general public, that the infertility industry in general, and egg donation and surrogacy agencies in particular, are in need of some minimum standards.<sup>743</sup> Nobody likes to see egg donors or intended parents taken advantage of or subjected to disrespectful treatment, or worse. And agency decision-makers worry about how poorly unethical organizational behavior reflects on their agency and on the field as a whole. If it wasn't already obvious, the case of Theresa Erickson made clear that the law has a long way to go to catch up with the industry; an on-point criminal charge doesn't even exist for what she did and she was prosecuted under a wire fraud statute.<sup>744</sup>

Regulation is both necessary and inevitable—at some point, the public will demand it in reaction to yet another scandal. Many of my interviewees expressed concern about the possibility that such regulation would come down from above, created by legislators who have no familiarity with the field, and who are just trying to satisfy frightened constituents—most of whom also know nothing about the ins and outs of running an egg donor agency.

After speaking with many decision-makers in reputable agencies in California and across the country, I argue for a mixed regulatory approach, including greater professionalization of agencies, with minimal state oversight to ensure compliance with agency self-regulation. I propose the establishment of a state licensing agency, similar to

<sup>&</sup>lt;sup>743</sup> For media coverage of regulation of egg donation, see, e.g., Alyona Minkovski, "Why Isn't Egg Donation Regulated?" *HuffPost Live*, 10 June 2014, available from live.huffingtonpost.com/r/segment/ egg-donation-regulation/53906f1402a760c53a000250; Internet; Accessed 9 September 2014; Michelle Norris, "Egg Donation and the Free Market," *All Things Considered*, *NPR*, 28 July 2005, available from www.npr.org/templates/story/story.php?storyId=4775655; Internet; Accessed 9 September 2014.

<sup>&</sup>lt;sup>744</sup> See note 508 for a summary of the Theresa Erickson scandal.

the Medical Board of California, which oversees licensing and enforcement of the laws relating to medical practice in the state. The majority of agency standards, however, should be created by the agency professional organization.

As described in this dissertation, egg donor agencies have made a start at professionalization. The Society for Ethics in Egg Donation and Surrogacy is attempting to establish practice standards, which, if successful, would consist of two of the theoretical criteria for professionalization, the establishment of a professional organization and the creation of a code of conduct.<sup>745</sup> Ideally, the mission of SEEDS would continue and be expanded, such that they are able to reach a consensus on agency practice standards, which should be made enforceable by the state licensing body.

I suggest that the declared ethics of my interviewees—ethics developed from the convergent personal moral values of each agency decision-maker—form a solid foundation for appropriate self-regulation for the benefit of intended parents, egg donors, and society. My interviewees are a self-selected group of people willing to speak with me after learning my stated interest in thinking about regulation for their field; the goal with self-regulation is to give cause to all agencies to act like the best of them—or, perhaps, like the best of them represent their actions to an outsider. Either way, their rhetoric is good.

Adding a layer of state oversight to egg donor agencies is a difficult balancing act; agency decision-makers are not wrong to worry that state involvement might prove to be an inconvenience at best, and detrimental to their ability to provide services at worst. Yet some amount of state oversight is, I argue, necessary to reassure a suspicious public, to give the public confidence in what would mostly be the field's self-regulation. State oversight would also force compliance with the field's self-regulation from the less ethical/more reluctant agency decision-makers (including some of those who refused my request for an interview); criminal penalties for noncompliance would, in theory, help to solidify the professionalization of egg donor and surrogacy agencies more quickly than the professional body's shaming mechanisms alone.

Ideally, this state oversight would consist of a licensing agency, with authority to limit access to entry to the field and authority to enforce a few basic regulations. Such regulations should be based on the draft ABA Model Act Governing Reproductive Technology Agencies, or some similar set of suggested laws, which themselves have been developed by attorneys active in the collaborative ART industry, in concert with

<sup>&</sup>lt;sup>745</sup> Society for Ethics in Egg Donation and Surrogacy (SEEDS), www.seedsethics.org.

agency decision-makers and other industry professionals.<sup>746</sup> Such a set of laws, as it is currently envisioned, would work synergistically with agency professional self-regulations.

As with any legislative project, this approach faces some real obstacles. First, since it requires each state to pass its own legislation, there would certainly be issues of consistency across states, and that is only if all states could be convinced to adopt a similar approach.<sup>747</sup> Of course, it could be argued that such regulation is more important in states that have a denser population of agencies—such as California—so perhaps it is unnecessary for every state to pass it. Still, even among states that have a significant number of agencies, it is unlikely that they would all agree on the best approach to the problem.

The second potential problem with this approach is also situated in its state-by-state nature. Most of the agencies with whose decision-makers I spoke work not only in their home state, but also all over the country, and sometimes all over the world. Intended parents come to them from states less friendly to collaborative reproduction, and they recruit egg donors from many different states other than their own. The regulation and licensing would have to take into account the prevalence of what amounts to interstate commerce among egg donor agencies.<sup>748</sup>

My hope is that this dissertation will contribute to reshaping discourse on reproductive technology policies. Egg donor agencies are a new type of organization unaddressed by even the meager laws aimed at the medical side of the infertility industry. With greater professionalization and the establishment of a state licensing agency for egg donor and surrogacy agencies, agencies will have a set of best practices standards, based on the convergent moralities of agency decision-makers, and intended parents and egg donors will have a baseline against which to evaluate their agency of choice. In a best case scenario, this mixed regulatory approach, combining minimal state legislation, a state licensing body, and professional self-regulation, will also prevent the specter of eugenics

<sup>&</sup>lt;sup>746</sup> See Appendix IV for the ABA Model Act Governing ART Agencies (DRAFT).

<sup>&</sup>lt;sup>747</sup> This is a similar problem to gay marriage being legal in some states and not recognized in others—the most important thing is that recognition of legal parentage of children born through collaborative reproduction arrangements is consistent across states.

<sup>&</sup>lt;sup>748</sup> In California, physicians are licensed and disciplined by the Medical Board of California, which is a state government agency. For telemedicine practice, in which a physician gives medical advice from a distance to a patient in another state, some states require that the physician be licensed in the state in which the advice is delivered, but many states have created certain exemptions for telemedical practice. If egg donor agencies were regulated by state government, each state would decide whether agencies licensed in other states could recruit donors and provide services in their state.

from manifesting any further. It is a fine line between intended parents choosing what is best for them and their families, and "designer babies" meant to take advantage of socially favored physical and intellectual traits, but with legislative and self-regulated standards to reference, agencies can (and will be forced to) avoid engaging in practices deemed unacceptable by the donor egg agency industry and society as a whole. Ultimately, I hope this dissertation contributes to protecting the health, safety, and liberty of everyone involved.

#### **Avenues for Future Research**

This dissertation is aimed at understanding what egg donor agencies are doing, what normative regulations they are creating for themselves, what meaning they give to their work, and what meaning that creates for others. The practice of egg donation implicates social meanings of family, gender, medicine, and the market—each of which has its own, often contradictory, perspective. This dissertation lies at the intersection of institutional change theory and feminist legal theory, informed by an inhabited institutions approach; consequently, it fills a gap in the literature about how small organizations in new fields navigate tricky ethical waters in order to create norms for themselves, and how the actions of individuals—in the context of their interactions with other individuals, organizations, professional guidelines, and society in general converge to create shared moral meanings across organizations.

This dissertation is limited, however, by the constraints of time, space, and the necessary limitations imposed by the use of a non-representative, self-selected sample. Going forward, it would be informative to talk to even more agency decision-makers, particularly representatives of other types of agencies, such as start-ups run out of garages, or agencies that have been accused of or have a reputation for unethical behavior. A larger sample of agencies would also enable analysis of regional variations in practice or standards, something I found some evidence of with regard to the East Coast, but that possibly exists in more nuanced form among other geographic regions as well.

Another potentially fruitful avenue of inquiry is in-house programs. I would like to know in greater detail how these organizations-within-organizations differ from their independent counterparts. Are they greatly more subject to medical professional norms, since they conduct their business under the umbrella of infertility clinics? Do the inhouse program decision-makers have the same level of impact on their organizations? Do they look to their personal morality to make those decisions? Or are the decisions made for them by the physicians? How does that impact the creation of norms and moral meaning in the field? How do physicians tackle difficult ethical issues in their infertility practices? What impact does physician decision-making have across the field?

In addition to inquiries about particular types of egg donor organizations, I suspect that there is much to be learned from an analysis of the ways in which egg donor organizations interact with each other, and a comparison of how they interact with other organizations and professionals. Do agencies function as a network of agencies? Do in-house programs? Do network structures have different bureaucracies associated with them? In other words, does morality and internal regulatory structure vary according to agency/program structure? Is organizational form related to the form of its morality?

It would also be useful to perform an analysis of the development of norms and creation of moral meaning in analogous and/or related organizations, such as sperm banks and adoption agencies. Rene Almeling has looked at the gendered differences between egg donor agencies and sperm banks, and how those organizations frame the experience of commodification for gamete donors.<sup>749</sup> The research I would propose takes that analysis a step further to examine whether those organizations share moral meaning, and the origins of their norms and moral meanings.

As frozen egg banks develop and settle, it will be interesting, too, to ask what the differences are between egg donor agencies and frozen egg banks. Because of the relatively simple process of obtaining sperm, sperm banks did not go through a similar progressions with "fresh donor sperm agencies" preceding the emergence of frozen sperm banks.<sup>750</sup> Therefore, the differences in the development of egg banks and sperm banks—their norms and creation of meaning—may be enlightening.

A final area ripe for analysis is egg donation for stem cell research. It would be enlightening to ask how recruiting happens in the context of research, how donors feel about their experience, and any differences in qualifications to donate for research versus infertility treatment. Stem cell research is a much more highly regulated environment, so presumably the development of norms within the context of research is much more heavily influenced by interactions with the law than it is in the context of egg donation for infertility treatment.<sup>751</sup>

<sup>749</sup> Almeling, Sex Cells.

<sup>&</sup>lt;sup>750</sup> For a short history of sperm banks, refer to Chapter Two, "A Brief History." See also Spar, *The Baby Business*, 36-37; California Cryobank, "Sperm Banking History."

<sup>&</sup>lt;sup>751</sup> For a brief discussion of stem cell research, particularly in California, see Chapter Two, "A Brief History."

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Independent egg donor agencies, as represented by the people who head them, have one critical thing in common: the desire to help intended parents become actual parents. Agency decision-makers develop the internal ethical guidelines by which they run their agencies based on gut feelings and personal experience—their own personal moral values. They are concerned about the public perception of their field, and wish to establish legitimacy by distancing themselves from the unethical practices in the industry and engaging in a project of professionalization. Agencies contextualize the experience of commodification for donors and intended parents alike by encouraging a positive, human connection between donors and intended parents. And agencies try to minimize the possibility of exploitation of their donors both intentionally and incidentally through means such as donor education and deferral to medical professional standards. Agency decision-makers frequently express some ambivalence about working in a field with so many potential ethical issues through statements of nonjudgment: "Who am I to judge?" But in the end, agency decision-makers come back to their shared moral meaning, taking care of intended parents and egg donors, and the joy they take in helping people to build their families.

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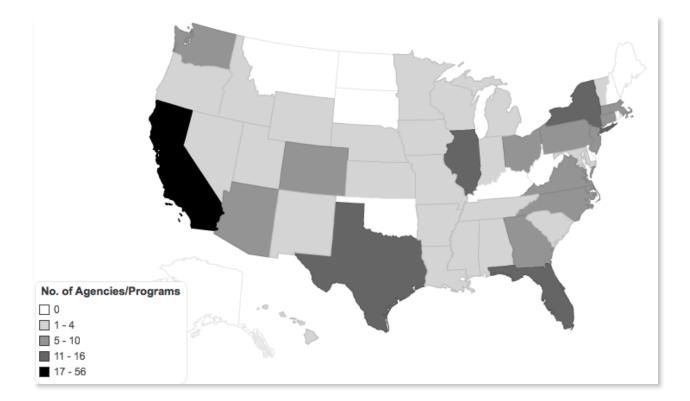
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## **APPENDIX I**

# Geographic Distribution of Egg Donor Agencies

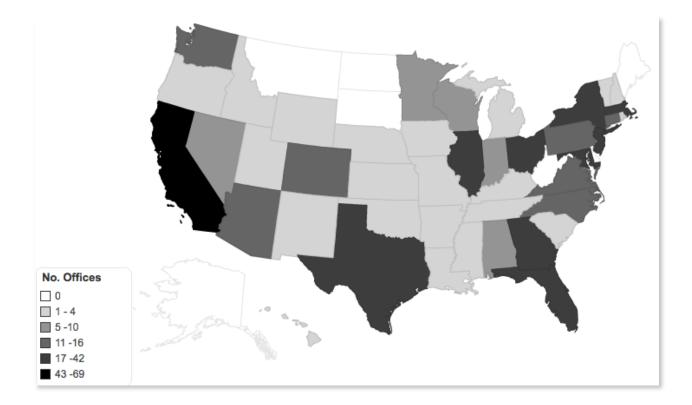
and In-House Egg Donor Programs in the United States

# Total Independent Egg Donor Agencies & In-House Egg Donor Programs, Primary Office by State according to data available online as of March 4, 2014



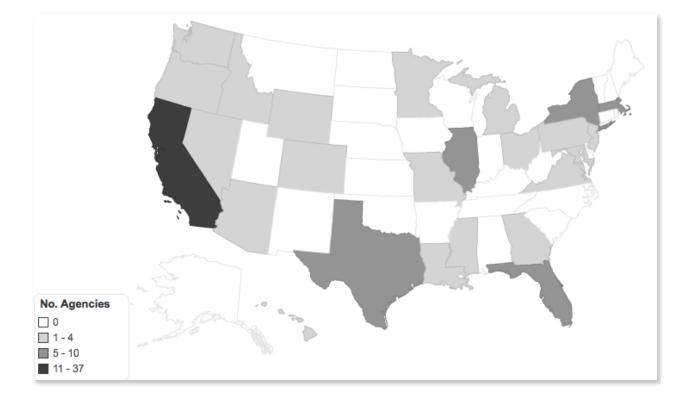
Total agencies/programs:	229
In-house programs:	120
Independent agencies:	104
Search services:	4

# Independent Egg Donor Agencies & In-House Egg Donor Programs, All Branch Offices by State according to data available online as of March 4, 2014



Agencies with multiple branches in one state:	60
Agencies with branches in multiple states:	27
Agencies with international branches:	3
(6 branches)	

# **Independent Egg Donor Agencies by State** according to data available online as of March 4, 2014



# **In-House Egg Donor Programs by State** according to data available online as of March 4, 2014



# Number of Independent Egg Donor Agencies & In-House Egg Donor Programs by State according to data available online as of March 4, 2014

State	Main Offices	Branches	Indep. Agencies	In-House Programs
AL	2	5	0	2
AK	0	0	0	0
AZ	6	12	1	5
AR	1	1	0	1
СА	56	69	37	19
СО	5	16	2	3
СТ	5	13	0	5
DE	0	0	0	0
DC	0	5	0	0
FL	16	40	8	8
GA	7	22	3	4
HI	2	2	2	0
ID	1	1	1	0
IL	14	36	6	8
IN	2	7	0	2
IA	1	1	0	1
KS	2	2	0	2
КҮ	0	1	0	0
LA	2	2	1	1
ME	0	0	0	0
MD	4	18	2	2
МА	10	23	7	3
МІ	3	3	2	1
MN	4	5	2	2

State	Main Offices	Branches	Indep. Agencies	In-House Programs
MS	1	1	1	0
МО	2	3	1	1
МТ	0	0	0	0
NE	1	1	0	1
NV	3	5	2	1
NH	0	2	0	0
NJ	8	24	4	4
NM	1	2	0	1
NY	15	42	5	10
NC	6	11	0	6
ND	0	0	0	0
ОН	6	17	2	4
ОК	0	1	0	0
OR	3	4	1	2
PA	6	12	2	4
RI	0	2	0	0
SC	1	2	0	1
SD	0	0	0	0
TN	3	4	0	3
ТХ	14	34	8	6
UT	2	3	0	2
VT	1	1	0	1
VA	6	14	1	5
WA	7	12	2	5
WV	0	0	0	0
WI	1	8	0	1
WY	1	1	1	0

# Number of Independent Egg Donor Agencies, In-House Egg Donor Programs, & Egg Donor Search Services by Census Region according to data available online as of March 4, 2014

NORTHERN CALIFORNIA:	15
In-house Programs:	8
Independent Agencies:	6
Search Services:	1

SOUTHERN CALIFORNIA:	38
In-house Programs:	6
Independent Agencies:	31
Search Services:	1

WEST (including California):	84
In-house Programs:	33
Independent Agencies:	49
Search Services:	2

MIDWEST:	36
In-house Programs:	21
Independent Agencies:	13
Search Services:	2

NORTHEAST:	45
In-house Programs:	27
Independent Agencies:	18
Search Services:	0

SOUTH:	63
In-house Programs:	39
Independent Agencies:	24
Search Services:	0

### **APPENDIX II**

## A Comprehensive Listing of Egg Donor Agencies

and In-House Egg Donor Programs in the United States

# Independent Egg Donor Agencies, In-House Egg Donor Programs, & Egg Donor Search Services by Type, Geographic Region, & Name according to data available online as of March 4, 2014

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Donor Concierge	Search Service	CA-North	CA (1)	www.donorconcierge. com
Baby Steps Fertility	Search Service	CA-Southern	CA (1)	babystepsfertility.com
Fertility Bridges	Search Service	Midwest	IL (1); CA (1)	www.fertilitybridges. com
Lotus Blossom Consulting	Search Service	Midwest	IL (1)	lotusblossomconsulting. com
California Registry of Egg Donors	Independent	CA-North	CA (1)	www.asianeggdonor. com
Fertility Connections	Independent	CA-North	CA (1)	www.fertilityconnections .com
Jackie Gorton Nurse Attorney	Independent	CA-North	CA (1)	www.jackiegortonnurse attorney.com
My Donor Cycle	Independent	CA-North	CA (1)	www.mydonorcycle. com
San Francisco Donor Network	Independent	CA-North	CA (1)	www.sfdonors.com
Woman to Woman Fertility Center	Independent	CA-North	CA (1)	www.womantowoman fertilitycenter.com
A Perfect Match	Independent	CA-Southern	CA (1)	www.aperfectmatch. com
Alternative Conceptions	Independent	CA-Southern	CA (1)	www.alternative conceptions.com
Beverly Hills Egg Donation	Independent	CA-Southern	CA (2); MA (1)	www.bhed.com
Conceptual Options, LLC	Independent	CA-Southern	CA (2)	www.conceptualoptions .com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Cori's Egg Donor and Surrogate Services, Inc.	Independent	CA-Southern	CA (1)	www.coriseggdonor services.com
Creative Conception Inc.	Independent	CA-Southern	CA (1)	www.creative conceptioninc.com
Egg Donation and Surrogacy Center	Independent	CA-Southern	CA (1)	www.findadonor.com
Egg Donation, Inc.	Independent	CA-Southern	CA (1)	www.eggdonor.com
Egg Donor and Surrogacy Institute	Independent	CA-Southern	CA (1)	www.eggdonoronline. com
Egg Donor Conceptions, Inc.	Independent	CA-Southern	CA (1)	www.eggdonor conceptions.com
Egg Donor Program, The	Independent	CA-Southern	CA (1)	www.eggdonation.com
Elite Fertility Solutions	Independent	CA-Southern	CA (1)	www.elitefertility.com
Extraordinary Conceptions	Independent	CA-Southern	CA (1)	www.extraconceptions. com
Family Creations LLC	Independent	CA-Southern	CA (1)	www.familycreations. net
Fertility Alternatives, Inc	Independent	CA-Southern	CA (1)	www.fertilityalternatives. com
Fertility Miracles	Independent	CA-Southern	CA (1)	www.fertility- miracles.com
Genesis Group	Independent	CA-Southern	CA (1)	www.genesisegg donation.com
Gifted Journeys	Independent	CA-Southern	CA (1)	giftedjourneys.com
Global Egg Donors	Independent	CA-Southern	CA (1)	www.globaleggdonors. com
Global Fertility Services	Independent	CA-Southern	CA (1)	www.familyfertilitycenter .com
Golden Egg Donation, Inc.	Independent	CA-Southern	CA (1)	goldeneggdonation.com
Growing Generations	Independent	CA-Southern	CA (1); NY (1); OH (1)	www.growing generations.com
Heart to Heart Donations	Independent	CA-Southern	CA (1)	www.fwdonoreggs.com
Miracles Egg Donation & Surrogacy, Inc.	Independent	CA-Southern	CA (1)	www.miraclesinc.net

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Peas in a Pod	Independent	CA-Southern	CA (1)	www.peasinapodinc. com
Premier Egg Donors	Independent	CA-Southern	CA (1)	www.premiereggdonors .com
Reproductive Solutions	Independent	CA-Southern	CA (1)	www.eggreproductive. com
Select Surrogate, The	Independent	CA-Southern	CA (1)	www.selectsurrogate. com
Surrogate Alternatives, Inc.	Independent	CA-Southern	CA (1)	www.surrogate alternatives.com
West Coast Egg Donation	Independent	CA-Southern	CA (1)	www.westcoastegg donation.com
Donor SOURCE, The	Independent	CA-Southern (HQ Irvine)	CA (4), AZ (1); CO (1); FL (1); GA (1); IL (1); MA (1); NV (1); NY (1); NC (1); OR (1); SC (1); WA (1); TX (1)	www.thedonorsource. com
Alternative Reproductive Resources	Independent	Midwest	IL (1)	www.arr1.com
Center for Egg Options	Independent	Midwest	IL (1)	www.egg411.com
Compassionate Beginnings	Independent	Midwest	OH (1)	www.donoragency.net
ConceiveAbilities	Independent	Midwest	IL (1); CO (1)	www.conceiveabilities. com
Egg Donor Creations	Independent	Midwest	MO (1)	www.eggdonorcreations .com
Egg Donor Program of Michigan	Independent	Midwest	MI (1)	www.eggdonorof michigan.com
Family Source Consultants LLC	Independent	Midwest	IL (2)	www.familysource surrogacy.com
Graceful Conceptions	Independent	Midwest	IL (1)	www.graceful conception.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Happy Beginnings, LLC	Independent	Midwest	IL (1)	www.happybeginnings eggdonation.com
International Assisted Reproduction Center	Independent	Midwest	MN (1)	www.fertilityhelp.com
My Donor Connection	Independent	Midwest	MN (1)	mydonorconnection. com
Reproductive Assistance, Inc	Independent	Midwest	OH (1); TX (1); CO (1)	www.reproassistinc. com
Stork Society, LLC, The	Independent	Midwest	MI (1); WI (1); GA (1); FL (1); CA (1); OK (1)	www.thestorksociety. com
A Woman's Gift	Independent	Northeast	NJ (1)	awomansgift.com
Asian Egg Donation LLC	Independent	Northeast	NJ (1); NY (1)	www.asianeggdonation. com
Center for Surrogacy and Egg Donation, Inc.	Independent	Northeast	MA (1)	csedinc.com
Choices LLC	Independent	Northeast	MA (1)	www.choicesdonations. com
Circle Egg Donation	Independent	Northeast	MA (1); CO (1); CA (1); United Kingdom; Sweden	www.circleeggdonation. com
Diversity Fertility Services LLC	Independent	Northeast	NJ (1)	dfsdonors.com
Donor Services of New York	Independent	Northeast	NY (1)	www.donorservicesofny. com
Indian Egg Donors	Independent	Northeast	NY (1)	www.indianeggdonors. com
Intended Parents, Inc.	Independent	Northeast	NJ (1)	intendedparents.com
My Donor	Independent	Northeast	NY (1)	www.mydonor.net
National Exchange for Egg Donation and Surrogacy (NEEDS)	Independent	Northeast	MA (1); TX (1)	fertilityneeds.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Northeast Assisted Fertility Group	Independent	Northeast	MA (1); NY (1); DC (1); GA (1); FL (1); TX (1)	www.assistedfertility. com
NY LifeSpring	Independent	Northeast	NY (1)	nylifespring.com
Prospective Families	Independent	Northeast	MA (1)	www.prospective families.com
Rite Options	Independent	Northeast	NY (1)	www.riteoptions.com
Seeds Center	Independent	Northeast	PA (1)	www.seedscenter.com
Surrogate Services International Inc.	Independent	Northeast	PA (1)	www.surrogateservices international.com
Tiny Treasures	Independent	Northeast	CA (1); NY (1); MA (1)	www.tinytreasures agency.com
A Jewish Blessing	Independent	South	FL (1)	www.ajewishblessing. com
Advocates for Surrogacy	Independent	South	FL (1)	www.advocatesfor surrogacy.com
Beginning Families	Independent	South	LA (1)	beginningfamilies.com
Bundles of Joy LLC	Independent	South	FL (1)	www.bundlesofjoyllc. com
Creative Family Connections LLC	Independent	South	MD (1)	www.creativefamily connections.com
Creative Love Egg Donor and Surrogate Agency LLC	Independent	South	FL (1)	www.cledp.com
Donor Solution, The	Independent	South	TX (2); CA (1)	thedonorsolution.com
Earthly Angels Consulting	Independent	South	MS (1)	www.earthlyangels consulting.com
Egg Donation Center of Dallas, Inc	Independent	South	TX (1)	www.eggdonorcenter. com
Egg Donor America	Independent	South	VA (1)	www.eggdonoramerica. com
Egg Donor Solutions	Independent	South	TX (1)	eggdonorsolutions.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Eggceptional Donor Group	Independent	South	GA (1); FL (1)	www.eggceptional donors.com
Eggspecting, Inc.	Independent	South	GA (1)	eggspecting.com
Family Building Center, Inc.	Independent	South	MD (2)	familybuild.com
Family Inceptions International	Independent	South	GA (2)	www.familyinceptions. com
Fertility Resources of Houston LLC	Independent	South	TX (1)	www.fertilityresources houston.com
Future Angels Egg Donation, LLC	Independent	South	FL (1)	futureangelsegg donation.com
Giving Hope Egg Donation Inc.	Independent	South	TX (1)	www.givinghopeinc. com
Loving Donation, Inc.	Independent	South	FL (1)	lovingdonation.com
Open Arms Consultants, Inc.	Independent	South	FL (1)	www.openarms consultants.com
Our Fairy Godmother	Independent	South	FL (1)	www.ourfairygodmother .com
Prime Genetics LLC	Independent	South	TX (1)	www.prime- genetics.com
Simple Donations	Independent	South	TX (1)	www.simpledonations. com
TLC Egg Donation	Independent	South	TX (3)	tlceggdonation.com
An Eggceptional Match LLC	Independent	West	CO (1)	www.donatedeggs.com
Angel's Gift	Independent	West	CO (1)	www.angeleggdonation. com
Conceptions Center for Ovum Donation	Independent	West	HI (1)	www.conceptionscenter .com
Creating New Generations	Independent	West	OR (1)	www.creatingnew generations.com
Egg Donor Select, Inc.	Independent	West	WA (1)	www.eggdonorselect. com
Heartfelt Egg Donation	Independent	West	NV (1)	heartfelteggdonation. com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Las Vegas Egg Donation	Independent	West	NV (1)	www.lasvegasegg donation.com
Nationwide Egg Donation	Independent	West	ID (1)	www.nationwideegg donation.com
NW Fertility	Independent	West	WA (1)	www.nwfertility.com
Pacific Egg Donors	Independent	West	HI (1)	www.pacificeggdonors. com
Precious Wonders	Independent	West	AZ (1)	www.preciouswonders. com
Premium Egg Donation, Inc.	Independent	West	WY (1)	www.premiumegg donation.com
Alta Bates Donor Egg Program	In-house	CA-North	CA (1)	abivf.com
California IVF Fertility Center	In-house	CA-North	CA (2)	www.californiaivf.com
Fertility and Gynecology Center/Monterey Bay IVF Egg Donor Program, The	In-house	CA-North	CA (1)	www.montereybayivf. com
Fertility Physicians of Northern California Egg Donor Program	In-house	CA-North	CA (2)	www.fpnc.com
Northern California Fertility Medical Center Egg Donation Program	In-house	CA-North	CA (2)	www.ncfmc.com
Pacific Fertility Center Egg Donor Agency	In-house	CA-North	CA (1)	www.pfcdonoragency. com
Reproductive Science Center	In-house	CA-North	CA (2)	rscbayarea.com
UCSF Egg Donor Program	In-house	CA-North	CA (1)	coe.ucsf.edu/ivf
Coastal Conceptions – Newport Fertility Center	In-house	CA-Southern	CA (1)	www.coastal conceptions.com
Egg Donor For You—San Diego Fertility Center	In-house	CA-Southern	CA (2)	www.eggdonor4u.com (clinic website = www.sdfertility.com)
Fertility Specialists Medical Group	In-house	CA-Southern	CA (1)	ivfspecialists.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Reproductive Specialty Medical Center	In-house	CA-Southern	CA (1)	www.drary.com
Santa Monica Fertility	In-house	CA-Southern	CA (1)	www.santamonica fertility.com
USC Fertility	In-house	CA-Southern	CA (1)	www.uscfertility.org
Advanced Fertility Center of Chicago	In-house	Midwest	IL (1)	www.advancedfertility. com
Aurora Fertility Services	In-house	Midwest	WI (7)	www.aurorahealthcare. org/services/womens- health-care/aurora- fertility-services/egg- donor-program
Bethesda Fertility Center	In-house	Midwest	OH (1)	bethesdafertility.com
Center for Reproductive Medicine Minnesota	In-house	Midwest	MN (2)	www.ivfminnesota.com
Chicago IVF	In-house	Midwest	IL (4); IN (2)	www.chicago-ivf.com
Egg Donors Change Lives	In-house	Midwest	IN (1)	www.eggdonorschange lives.com (clinic website: www.midwestfertility. com)
Fertility Centers of Illinois	In-house	Midwest	IL (12)	fcidonor.com
Heartland Center for Reproductive Medicine, PC	In-house	Midwest	NE (1)	www.heartlandfertility. com/egg-donation
Institute for Reproductive Health	In-house	Midwest	OH (2); KY (1)	www.cincinnatifertility. com
InVia Fertility	In-house	Midwest	IL (4)	www.inviafertility.com
IVF1 Match	In-house	Midwest	IL (2)	www.ivf1match.com
Mid Iowa Fertility	In-house	Midwest	IA (1)	www.midiowafertility. com
Midwest Center for Reproductive Health	In-house	Midwest	MN (1)	www.mcrh.com
Midwest Reproductive Center, PA	In-house	Midwest	KS (1)	www.midwest reproductive.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Reproductive Care of Indiana	In-house	Midwest	IN (4)	www.reprocareindiana. com
Reproductive Medicine Associates of Michigan	In-house	Midwest	MI (1)	www.rmami.com
Reproductive Resource Center of Greater Kansas City, PA	In-house	Midwest	www.rrc.c om	www.rrc.com
UC Health Center for Reproductive Health	In-house	Midwest	OH (1)	uchealth.com/fertility
University Hospitals Egg Donation	In-house	Midwest	OH (10)	www.uhhospitals.org/ services/obgyn/uh- fertility-center/ treatment-options/egg- donation
University of Illinois Hospital and Health Sciences System Egg Donor Program	In-house	Midwest	IL (3)	hospital.uillinois.edu/ Patient_Care_Services/ Obstetrics_and_Gynec ology/Our_Services/ Reproductive_ Endocrinology_and_ Infertility/Egg_Donation
Washington University Infertility and Reproductive Medicine Center at Barnes- Jewish Hospital	In-house	Midwest	MO (2)	infertility.wustl.edu
Baystate Medical Center	In-house	Northeast	MA (2)	www.baystatehealth. com/Baystate/Main +Nav/Clinical+Services/ Departments/Obstetrics +%26+Gynecology/ ma-ct-fertility-ivf-clinic
Center for Advanced Reproductive Technologies	In-house	Northeast	CT (3)	fertilitycenter-uconn.org
Center for Human Reproduction	In-house	Northeast	NY (1)	www.centerforhuman reprod.com
Center for Human Reproduction, North Shore University Hospital	In-house	Northeast	NY (7)	www.northshorelijivf. com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Columbia University Center for Women's Reproductive Care	In-house	Northeast	NY (2)	columbiafertility.org
Cornell Center for Reproductive Medicine	In-house	Northeast	NY (4)	ivf.org
CT Fertility	In-house	Northeast	CT (1); NY (1)	www.ctfertility.com
Family Fertility Center	In-house	Northeast	PA (1)	www.familyfertility.com
Fertility Center, LLC, The	In-house	Northeast	PA (2)	www.thefertilitycenter. com
Fertility Solutions of New England	In-house	Northeast	MA (4); RI (1)	www.fertilitysolutionsne. com
IRMS Reproductive Medicine at Saint Barnabas	In-house	Northeast	NJ (5)	www.sbivf.com
IVF New Jersey Fertility Care	In-house	Northeast	NJ (5); NY (1)	www.ivfnj.com/egg- donation
Kofinas Fertility Institute	In-house	Northeast	NY (2)	www.kofinasfertility.com
Long Island IVF Egg Donor Program	In-house	Northeast	NY (6)	www.longislandivf.com
Main Line Fertility and Reproductive Medicine	In-house	Northeast	PA (1)	www.mainlinefertility. com
New England Fertility	In-house	Northeast	CT (2)	www.nefertility.com
New Hope Fertility Center	In-house	Northeast	NY (1); Mexico, China, Russia	www.newhopefertility. com
NYU Langone Oocyte Donation Program	In-house	Northeast	NY (1)	www.nyufertilitycenter. org/egg_donation
Ovatures Egg Donation Program—RMA of NJ	In-house	Northeast	NJ (7); PA (1)	www.ovatures- eggdonation.com (Clinic website: www.rmanj.com)
Penn Fertility Care	In-house	Northeast	PA (1)	www.pennmedicine.org/ fertility/patient/clinical- services/donor-egg- program

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Reproductive Medicine Associates of CT	In-house	Northeast	CT (4); NY (1)	www.rmact.com
Reproductive Science Center of New England	In-house	Northeast	MA (8); NH (2); RI (1)	www.rscnewengland. com
Reproductive Science Center of New Jersey	In-house	Northeast	NJ (3)	fertilitynj.com
RMA of New York	In-house	Northeast	NY (4)	eggdonationny.com (Clinic website: rmany.com)
University of Rochester Medical Center Strong Fertility Center	In-house	Northeast	NY (1)	www.urmc.rochester. edu/ob-gyn/fertility- center/treatment/donor- oocytes
Vermont Center for Reproductive Medicine	In-house	Northeast	VT (1)	www.fletcherallen.org/ services/ womens_health/ specialties/infertility
Yale Fertility Center	In-house	Northeast	CT (3)	www.yaleobgyn.org/yfc
A Woman's Center for Reproductive Medicine	In-house	South	LA (1)	www.ivflouisiana.com
Advanced Fertility and Reproductive Endocrinology Institute LLC	In-house	South	SC (1)	www.ivfwecare.com
Arkansas Fertility & Gynecology	In-house	South	AR (1)	www.arkansasfertility. com
ART Fertility Program of Alabama	In-house	South	AL (4)	artprogramal.com/node/ 114
Atlanta Center for Reproductive Medicine	In-house	South	GA (4)	www.atlantainfertility. com
Brown Fertility	In-house	South	FL (3)	www.brownfertility.com
Carolina Conceptions	In-house	South	NC (1)	www.carolina conceptions.com
Center for Assisted Reproductions <u>embryo.net</u>	In-house	South	TX (4)	www.embryo.net
Center for Reproductive Medicine	In-house	South	FL (1)	ivforlando.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Center of Reproductive Medicine (CORM)	In-house	South	TX (2)	www.infertilitytexas. com
Cooper Institute for Advanced Reproductive Medicine	In-house	South	TX (1)	www.houstonfertility solutions.com
Dallas Fertility Donor Egg Program – Dallas-Fort Worth Fertility Associates	In-house	South	TX (2)	www.dallasfertility.com/ donor-eggs
Dominion Fertility	In-house	South	VA (2); DC (1); MD (1)	www.dominionfertility. com
Duke Fertility Center	In-house	South	NC (1)	dukefertilitycenter.org/ treatments/donor-egg- recipient-program
Emory Reproductive Center	In-house	South	GA (1)	www.emoryhealthcare. org/reproductive-center
Fertility Associates of Memphis	In-house	South	TN (1)	fertilitymemphis.com
Fertility C.A.R.E.	In-house	South	FL (2)	www.myfertilitycare. com
Fertility Center	In-house	South	TN (2)	www.myfertilitycenter. com
Fertility Center of San Antonio	In-house	South	TX (1)	www.fertilitysa.com
Florida Institute for Reproductive Medicine	In-house	South	FL (8)	www.fertilityjacksonville. com
Genetics & IVF Institute	In-house	South	VA (1); MD (1); China	www.givf.com
Georgia Reproductive Specialists	In-house	South	GA (3)	www.ivf.com
Houston Fertility Institute	In-house	South	TX (9)	www.hfi-ivf.com
Huntsville Reproductive Medicine, PC	In-house	South	AL (1)	huntsvilleivf.com
IVF Florida Reproductive Associates	In-house	South	FL (6)	www.ivfflorida.com
Johns Hopkins Fertility Center	In-house	South	MD (1)	www.hopkinsmedicine. org/fertility

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Nashville Fertility Center	In-house	South	TN (1)	www.nashvillefertility. com
North Carolina Center for Reproductive Medicine (NCCRM)	In-house	South	NC (2)	www.nccrm.com
Piedmont Reproductive Endocrinology Group (PREG)	In-house	South	NC (3)	www.pregonline.com
Reproductive Biology Associates	In-house	South	GA (7)	rba-online.com/ivf
Reproductive Endocrinology Associates of Charlotte (REACH)	In-house	South	NC (2)	www.northcarolina fertility.com
Reproductive Medicine and Surgery Center of Virginia, PLC	In-house	South	VA (1)	www.rmscva.com
Reproductive Medicine Group, The	In-house	South	Tampa (2); FL (1)	www.floridafertility.com
Shady Grove Fertility Reproductive Science Center	In-house	South	DC (2), MD (11), PA (4), VA (4)	www.shadygrovefertility. com
South Florida Institute for Reproductive Medicine	In-house	South	FL (5)	www.ivfmd.com
UNC Fertility	In-house	South	NC (1)	uncfertility.com
University of Florida Reproductive Medicine	In-house	South	FL (1)	repro.med.ufl.edu/ eggdonation/ overview.php
Virginia IVF & Andrology Center	In-house	South	VA (1)	www.vaivf.com
Washington Fertility Center	In-house	South	VA (4); DC (1); MD (1)	www.washingtonfertility. com
Advanced Fertility Care	In-house	West	AZ (3)	www.azfertility.com
Advanced Reproductive Medicine at University of Colorado	In-house	West	CO (2)	arm.coloradowomens health.com
Arizona Center for Fertility Studies	In-house	West	AZ (1)	www.acfs2000.com

Organization Name	Туре	Geographic Region	Branch locations by state (# offices)	Website
Arizona Reproductive Medicine Specialists	In-house	West	AZ (2)	www.arizonafertility.com
Colorado Center for Reproductive Medicine	In-house	West	CO (3)	www.colocrm.com
Conceptions Reproductive Associates of Colorado	In-house	West	CO (4)	www.eggdonorcolorado .com (Clinic website: www.conceptionsrepro. com)
Donor Branch of FCLV	In-house	West	NV (2)	thedonorbranchoffclv. com
Exceptional Donors, at Oregon Reproductive Medicine	In-house	West	OR (1)	www.oregon reproductivemedicine. com/solutions/ exceptional-donors
Fertility Treatment Center	In-house	West	AZ (2)	www.fertilitytreatment center.com
OHSU Fertility Consultants	In-house	West	OR (1)	www.ohsu.edu/xd/ health/services/women/ services/fertility
Overlake Reproductive Health	In-house	West	WA (1)	fertileweb.com/ bellevue-fertility-clinic
Pacific NW Fertility	In-house	West	WA (1)	www.pnwfertility.com
Reproductive Care Center	In-house	West	UT (2)	www.fertilitydr.com
Reproductive Medicine & Fertility Center New Mexico	In-house	West	NM (2); CO (1)	www.ivfnewmexico. com
Seattle Reproductive Medicine	In-house	West	WA (5)	seattlefertility.com
SRM Spokane	In-house	West	WA (1)	www.srmspokane.com
Troché Fertility Centers	In-house	West	AZ (2)	www.wvfc.com
Utah Center for Reproductive Medicine	In-house	West	UT (1)	healthcare.utah.edu/ womenshealth/utah- center-for-reproductive- medicine
Washington Center for Reproductive Medicine	In-house	West	WA (1)	www.seattleivf.com

### **APPENDIX III**

**SEEDS Standards (Proposed)** 

#### SEEDS

### Society for Ethics in Egg Donation and Surrogacy

#### eggdonationethics.wordpress.com

visited April 24, 2014

Welcome to the official blog for the Surrogacy and Egg Donation Ethical Society (SEEDS)

Posted on April 17, 2012

Standards and Ethics for Egg Donation and Surrogacy (SEEDS) was created by owners of egg donation and surrogacy agencies to define and classify a set of standards that are intended to apply to all such agencies in the United States. SEEDS will not have legislative authority, only advisory status. It is, however, the intention of SEEDS's founding members to expand the organization in size and outreach to the point that SEEDS's recommendations will have a major influence and impact on future egg donation and surrogacy legislation.

SEEDS's goal is to raise the standards by which agencies carry out their work in order to transcend any negative impressions that may have developed from the poor practices of a small number of agencies. Our intention is to reassure potential donors, their families, intended parents and the general public that egg donation and surrogacy can be safe, ethical options for all parties involved to overcome the problem of infertility.

SEEDS's founding members (and hopefully other contributors) will use this blog as a forum to address issues and questions that arise about the ethics and practices of egg donation and surrogacy, as well as to post new information about these subjects. As with all areas of medicine, egg donation and surrogacy are constantly advancing and growing through the research and development of doctors and scientists all over the world. We will do our best to present and comment upon new developments and their implications on the industry as well as the impact that increased government regulation could have on the practices of egg donation and surrogacy.

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What medical information should agencies provide to donors about risks of donation?

Posted on June 11, 2012

### Background

While it is important to provide medical information and risks with the donor, how and when is the appropriate information provided? Most agencies do not have a doctor on staff, so should not give actual medical advice, but to what extent and when shall that information get to the donor.

### II STANDARD

There are various stages where information sharing can occur. Initial contact is a good place to share some information because it is important a donor has some idea of risks before agreeing to be a donor. This is not because they must proceed once they have submitted their application (there are obviously stages they can decide not to donate) but it is because we want to reduce the likelihood a donor will decline to donate after her profile has been shared with a possible recipient.

This information sharing is done by providing a link to the NY State Department of Health pdf file on "Becoming a Donor" and requesting the potential donor read fully prior to application submission. Once the donor applies, offer the donor an option to speak with someone at your agency who has been a previous donor, or put her in touch with a previous donor. Additionally, and if possible, arrange a conversation with a nurse or reproductive endocrinologist.

When a donor is contacted about a potential cycle, reminding her about the medical process and expectations is vital in being sure she is mentally prepared to move forward. A donor should also be reminded that there are general side effects, such as: bloating, feeling of fullness, headaches, possible mood swings, bruising around the injection site, etc. Encourage them to come up with a list of questions for the doctor for their first patient appointment, including bigger risk factors such as ovarian hyperstimulation, torsion or rare reactions to the medications. It is also suggested to remind the donor that she may back out of the contract prior to any medical procedures taking place should she feel she is not ready or willing to make this commitment.

For best practices, the below steps are recommended:

First contact made with donor should include link to unbiased information on risks of egg donation

Opportunity to discuss the "donor experience" should be provided

Opportunity to speak with a nurse or doctor should be provided

Donor should be encouraged to create a list of questions for first patient appointment upon being chosen as an egg donor

Contract should reflect an "out" (without consequence) if information provided to donor on first patient appointment is not something donor can feel comfortable with.

For agencies who do not have a prior donor on staff, they could request (and/or compensate) prior donors to complete the "donor experience" discussion with a first time donor.

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Psych and Genetic Guidelines

Posted on September 18, 2012

Background

Most clinics require a psychological evaluation and some require a genetic consultation. The open issues as I see them for this subject are:

What is the value of genetic consults?

Should we require genetic consults for each donor regardless of the clinic requirement?

Does a couple need a new genetic consult with each cycle?

Can psych evaluations be completed remotely?

Should the psychologist need to see the donor or is a teleconference sufficient?

What events should trigger an updated psych? (time, events, etc)

#### II STANDARD

The value of a genetic consult is to make a couple aware of a donor's extended health history as well as the possible duplication of genetic traits with that of the intended father. It would be a very positive thing to order for each cycle as it can provide important information and additional insight. Several clinics indicate family history is not something they spend much time looking at and clinics are not as qualified as a licensed geneticist to determine risk factors. They leave it to the recipients to evaluate themselves while seldecting a donor.

Recently, some clinics have made the determination that a donor needs an updated genetic consult with each cycle. If a clinic does not require updated genetic histories with each subsequent cycle, the agency should ask the donor when a cycle is pending (before contracts) if there have been any known changes in her or her family's health history. If there have been, she should be required to do a follow-up genetic counseling session for an updated genetic report. A recipient should talk with a geneticist about the genetic profile of their donor in relation to that of the intended father (or sperm donor).

Genetic evaluations should be shared with the intended parent(s) and clinic prior to medical screening to determine if any additional testing may be required.

Psychological evaluations and donor education should include both a written test (such as the Minnesota Multiphasic Personality Inventory (MMPI), or Personality Assessment Inventory (PAI), along with a scheduled appointment with a licensed therapist. Ideally, psych evaluations should be completed in person. Written evaluations are considered out dated one year from date of test, while in-person evaluations are considered out dated after two years. Both written and in-person psych evaluations, however, should be re-done after any life-altering events. These events include (but are not limited to) things like: marriage, birth of a child, death in the family, divorce, or loss of a job or home.

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Ethical Standards for Advertising for Egg Donors

Posted on September 19, 2012

Background

Egg Donor and/or Surrogacy Agencies frequently advertise in print and Internet media and also to a lesser extent in other media (TV, Radio, Trade Shows, Seminars, etc.). This SEEDS Ethics Principle is intended to refer particularly to Print and Internet media, but the principles embodied in the standards can likely be applied to all media.

Advertising by Egg Donor and/or Surrogacy Agencies may be targeted at egg donors and present anticipated compensation arrangements for the egg donor. The SEEDS Ethics Standard for Compensation in Advertising for Egg Donors will be established by applying the principles of honesty, clarity, disclosure, propriety, professionalism, non disparagement, and non exploitation.

Advertising targeted at egg donors is generally designed to inform them of an opportunity to donate their eggs under certain conditions and for a certain fee or fee range. Where possible, these ads are written in such a way as to inform the donors about the process they will be exposed to and the fee(s) they will earn.

The medium for ads targeted at egg donors is often print of on line publications, generally periodicals, less often dailies (such as newspapers) or Internet media (particularly web sites and blogs). Space in print media advertising is generally limited and there is usually little room for extensive messages. Space in Internet media is generally much more generously available and gives place for much more extensive information.

For purposes of this standard, Advertising is considered to be all information presented by agencies to potential donors that can be construed as information designed to attract those donors to consider donating their eggs for the agencies' Intended Parents.

#### II STANDARD

#### Monetary

Egg donor ads do not have to state the compensation intended to be paid to the donor. To the extent that such ads do state fees, they must be the fees relevant to the donor opportunities being advertised. For example, it is not ethical to state a fee for a donation to take place in New York City if the donation is expected to be in Arizona. It is also not ethical to state a single fee if the actual fee will vary dependent upon location or other factors. If a range of fees or varying fees are presented in the ad, it must clearly be stated what conditions will govern the actual fee. If fees are contingent in any way, i.e. depend on any condition, e.g. repeat donor, location, etc. those factors must be explained in the ad. If fees are to be paid in segments, those facts must clearly be explained in the ad. It is presumed that donor fees will be paid at the time of egg retrieval unless otherwise stated.

Payments to the egg donor that are not expressly part of the actual egg donor fee should be presented in the ad, e.g. travel expenses. Specific amounts do not have to be identified, but the ad should state that donor's travel expenses, etc. will be reimbursed.

Monetary arrangements should be presented in an appropriate professional manner, not dominating the ad nor in presentation format to call undue attention over other elements of the ad. The monetary information should not be presented in comparative manner to any other agencies' fees.

#### Presentation and Display

Ads should be placed in appropriate media or in appropriate locations within web sites or blogs. Media selected should be reputable and non exploitative. Placement within media should be appropriate. Ads should be professionally and tastefully designed and not be overly ostentatious.

#### Content

To the extent possible within the confines of the ad/Internet space available, the following should be presented: Why an egg donation is important; Qualifications to be an egg donor; Description of the egg donation process; Compensation for the Egg Donor; Risks of Egg Donation; Description of the Agency and its People. Testimonials are permitted as long as they are genuinely written by prior donors, not written by agency staff, and not excessive.

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Emotional Disclosure for Egg Donation to IP's and ED

Posted on September 27, 2012

Agency's responsibility regarding Emotional Disclosure

#### I Background

Egg Donor Agencies work with all types of personalities when it comes to both the donors and the intended parents. As most cycles are considered anonymous or, in some cases, "open" (with slight degrees of variation), there is limited information that an egg

donor or a recipient parent has with regards to one another. The agency has a responsibility to reveal personality traits that may affect the decision of all parties to move forward with one another. This SEEDS Ethics Principle is intended to refer to the information agencies should be required to share regarding personality traits of either the egg donor or the intended parents.

Disclosure to egg donors or intended parents should be limited to information that allows all parties to make an honest, informed decision without revealing identifying information that would breech confidentiality. The goal of the SEEDS Ethics Standards for emotional disclosure is to honestly identify and share information that could have emotional long-term effects on either the egg donor or intended parent(s) going through the cycle, or the possible risk to the cycle or offspring as a result.

II Standard

### Donors

Emotional Disclosure of information to egg donors regarding the intended parents during the matching process of the cycle should include non-identifying information that allows the egg donor to make an informed decision about the family she is donating to. For example, an egg donor should know if they are working with a single parent, a gay family, a heterosexual couple and/or the marital status. She should be informed of the following:

They are capable of supporting a family.

Intent for future contact.

That the agency, clinic and / or licensed psychologist feel they are emotionally prepared to move forward with this process.

They have not shown signs of verbal abuse to the agency and / or their staff.

There is no known criminal record of drug or physical abuse.

There are no signs of instability or obvious mental illness present.

Intended Parents

Emotional Disclosure of Information to intended parents regarding the egg donors during the matching process of the cycle should include non-identifying information

that allows the IP's to make an informed decision about the egg donor they are using. The IP's should be informed of the following:

Job, moves, school and/or other obligations that are causing stress and/or fear (i.e. loss of a job, failing a class, moving to another location, etc.).

Donors perceived enthusiasm and/or response and understanding of questions, obligations and appointments (including promptness of returned phone calls/emails/ texts, etc).

Donor's social support system.

New relationship within the time-frame of being chosen.

Donor's empathetic response to the intended parents.

They have not shown signs of verbal abuse to the agency and/or their staff.

There is no known criminal record, drug or physical abuse.

There are no signs of instability or obvious mental illness present.

For the purposes of this standard, Emotional disclosure is considered to be all important non-identifying personal information that could be a deciding factor in the egg donor's and/or intended parent(s) comfort level in moving forward with the cycle.

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Agency Agreements re Egg Donation with Intended Parents

Posted on October 17, 2012

Agency Agreements re Egg Donation with Intended Parents

I Background

Egg Donor and Surrogacy Agencies enter into contractual relationships with their "customers", known as Intended Parents (IP). Intended Parents may be a heterosexual or homosexual couple or may be a single person (technically an "Intended Parent").

The contractual relationship whose terms are embodied in the Agency's agreement with IPs ("Agency Agreement") is intended to define the responsibilities of and risks

undertaken by the IPs and the Agency, in relationship to a specific egg donation transaction between the IPs and an egg donor.

It is anticipated that some of the responsibilities and risks identified in the Agency Agreement may also be included in an Agreement between the IPs and the Egg Donor ("Legal Agreement"). Where the terms specified in the Agency Agreement differ from those in the Legal Agreement, the latter generally take precedence.

The IPs and the Egg Donor are generally represented by separate counsel in the drafting and negotiation of the Legal Agreement. Though the IPs may be represented by counsel in the drafting and negotiation of the Agency Agreement, that is not usually the case.

### II STANDARD

Agency Agreements should generally include at least the following sections:

- \* Purpose of the Agreement
- \* Representations of the Parties
- \* Services Provided by the Agency
- \* Responsibilities of Intended Parents
- \* Agency Fee, Payment, and Refunds Schedule and Policy
- \* Donor Fees and Expenses Details
- \* Parental Rights of IPs and Release of Rights by Donor
- \* Assumption of Risks by IP
- \* Confidentiality
- \* Maintenance of Records by Agency and Future Contact Between IP and Donor
- \* Independent Legal Counsel Advice
- \* Term of Agreement
- \* Disclosure and Waiver of Agency's Potential Conflict of Interest

\* Process for Dispute Resolution

Agency Agreements should be written in language readily understood by non attorney IPs, be as inclusive as necessary without being overly lengthy, and very legible. IPs should be given sufficient time to review the Agency Agreement and be allowed to ask any questions they may have before being expected to execute the Agreement and provide any payment.

If IPs choose to be represented by counsel regarding the Agency Agreement, Agency should entertain all questions asked and modifications requested by counsel before expecting IPs to execute the Agreement.

The Agreement should provide for signatures of all IP parties and an authorized representative of the Agency as well as for initials of all parties on each page of the Agreement.

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Anonymous VS Known Egg Donation

Posted on October 19, 2012

KNOWN VS ANONYMOUS Egg Donation Terms

Background Egg Donor Contracts are created to legally represent agreements and understandings between Egg Donors and Intended Parents. The success of a contract depends on clear, concise and thorough representations. In the Egg Donation industry there are typically two options to define the relationship status between an Egg donor and an Intended parent. It is defined in black and white terms. The Intended Parents are contracting with an "anonymous" Egg Donor or a "known" Egg Donor. This type of categorization may have been common in the past, but today Agencies are facilitating relationships that range in communication and expectation. As such, the definition and terms should stay relevant. For practical reasons, we have defined 5 types of relationship definitions for legal contracts.

#### STANDARDS

ANONYMOUS: Describes an arrangement in which the Intended Parents and the Egg Donor do not know each other's identities. Aliases such as "Intended Mother", "Intended Father", and "Donor ID Number/ First Name" are used in the legal agreement. The Intended Parents will typically only view a donor's profile through an agency website.

SEMI ANONYMOUS- RESTRICTED: Describes an arrangement in which the Intended Parents and the Egg Donor do not know each other's identities, but may have restricted communication facilitated by the agency or an attorney. Communication is limited to finding out basic information via emails, letters or Agency correspondence. The Intended Parents and Egg donor do not communicate directly with one another.

SEMI ANONYMOUS – LIMITED/OPEN: Describes an arrangement in which the Intended Parents and the Egg Donor see each other face to face. They can meet in person, have a video call, and/or communicate via telephone. They exchange first names but limited identifying information beyond that. Generally they do not communicate beyond this interaction and do not exchange contact information.

OPEN: Describes an arrangement in which the Intended Parents and the Egg Donor can meet, have a video call, and/or a telephone consult. They exchange full names and contact information. The level of communication beyond this interaction will vary. Some relationships may continue to grow during the pregnancy. Some people will leave the door open to communication only if medically necessary or if the resulting child wishes to know more about the Egg Donor at age of 18.

KNOWN: Describes an arrangement in which Intended Parents and an Egg Donor have an existing relationship. The egg donor could be a friend, sibling, distant family member, or even a neighbor.

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Agency Agreements with Egg Donor

Posted on October 20, 2012

Ethics Standard of Agency Agreements with Egg Donor

#### BACKGROUND

In any egg donation arrangement 3 contracts should be executed: Contract between the Egg Donor and Agency (Egg Donor Understanding Agreement), Contract between the Intended Parents and Agency (Agency Agreement), and Contract between the Egg Donor and the Intended Parents (Legal Agreement).

The Egg Donor and Agency contract should be the first to be executed. This contractual agreement between both parties should be endorsed when the Egg Donor decides to be represented by the Agency. The Egg Donor and Agency agreement should state Egg Donor's responsibilities, risks, and expectations of both parties to one another. These representations should be clearly delineated in layman's term. The Agency contract with the egg donor should be written in a way that legal representation would not be necessary. However, the Egg Donor should always be given the option to retain legal counsel to review this agreement. If the Egg Donor chooses to exercise this option, this would be at the Egg Donor's expense.

The agreement should be initialed and signed by the Egg Donor. A copy of the Egg Donor's Identification and Social Security card should be taken with the agreement. If the Egg Donor is married or has a domestic partner he/she will also be responsible to sign off on the agreement.

#### STANDARDS

Egg Donor and Agency Agreements recommendations index:

Agency responsibility to the Egg Donor

Egg Donor's expectations of the Agency

Disclosure of Egg Donor's information

Possible financial, psychological and physical risks

**Donor Compensation** 

Verifying information

Possibility of background check

**Cancellation Policy** 

**Delayed Cycle Policy** 

Egg Donor's bill of rights

Agency exclusivity

Egg Donor Benefit Package

Egg Donor Insurance

Tax Liability

Responsibility of Husband / Sexual Partner

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Agency's responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors.

Posted on October 21, 2012

Agency's responsibility in Gauging the Emotional Maturity and Commitment of Egg Donors.

I Background

Egg Donor Agencies work with very diverse groups of egg donors who have widely varying personality types as well as current situations in their lives. It is the agency's responsibility to ask specific questions to determine the emotional maturity, readiness and/or current life circumstances that would allow for the donation to move forward to the best of their ability. This is to work in conjunction with the psychological evaluation of the egg donor.

II Standard

Lifestyle Questions To Determine Suitability

An Egg Donation Agency should ask a series of questions to each egg donor to determine her suitability to move forward with the process. These questions should include the following considerations to access her readiness to move forward:

Does the donor have a social support system that includes at least one close friend, family member or significant other that she has confided in about her choice to donate her eggs. If there is an unforeseen complication has she considered what she would tell those closest to her?

Will the donor be able to take off work, school, travel or family obligations to be able to commit to the cycle. Does she risk losing her job or failing a class to be an egg donor? Does she further understand that her recovery could be longer if she has complications from the retrieval process (such as hyperstimulation, pain or discomfort)?

Does the donor understand that there will be another family(ies) who will have her genetic material? Has she considered how she will feel about this now? In the future? If she chooses not to or cannot have her own children some day?

Will the donor be willing to meet the family who chooses her? What about the child(ren) that result from the donation?

Does the donor understand that she will be taking daily injections, making multiple appointments, and have a semi-invasive retrieval/surgery at the end? Does she feel confident she can give herself injections? Does she feel confident that she can give blood several times? Does she know that she will have several vaginal ultrasounds? Does she understand one missed injection or appointment is breech of contract and she would not be paid her fee if the cycle is compromised?

Emotional or Lifestyle Disqualifiers

1.) Donor's significant other and/or family member is not supportive of her choice to donate.

2.) Donor has an inflexible work and/or school schedule that would cause her to fail a class or lose her job if she took time off.

3.) Donor has phobia of needles.

- 4.) Donor does not feel comfortable having a genetic child in the world.
- 5.) Donor would regret donation if she does not have her own children.
- 6.) Donor does not feel she could emotionally handle hormonal changes.

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Ethical Business Practices Among Agencies

Posted on May 6, 2013

Agency Ethical Business Practices

Egg Donors

## I BACKGROUND

This SEEDS Ethics Principle is intended to refer specifically to ethical business practices among agencies in which donors are being shared between programs, are registered with more than one agency, or have personal information online that could be accessible to competing agencies within the industry.

#### II STANDARD

### Donor Matching

There are situations in which a donor has registered with more than one agency in order to optimize her chances of becoming an egg donor. This is not illegal and the donor has a legal right to do this, so competing agencies will often present the same donor to intended parents. SEEDS Ethical Standards would suggest the following business practices be applied:

1.) Whichever agency has matched the donor first, inclusive with paperwork confirmed by both the egg donor and the intended parent(s), has the ethical right-of-way to continue with this cycle first. The second agency may work with the donor for the subsequent cycle should the donor confirm her desire to do so.

2.) Should a donor apply to a second or third agency and is honest about having previously applied to competitors, the agency(ies) should not tell the donor she is currently matched, when she is not, in order to keep her from being matched elsewhere.

#### Donor Fees

In order to maintain good business practices among agencies on behalf of the families we work with, SEEDS Ethical Standards suggests that the following business practices among agencies should not be used:

1.) Offering a donor who is currently matched with another agency a higher fee if she switches agencies;

2.) Creating a "bidding war" between intended parents for the same egg donor to see who is willing to pay the highest fee;

3.) Encouraging a donor to request or accept a fee higher than other agencies she has applied with.

### **Agency Boundaries**

Agencies should not visit sites of their competitors or work with intended parents who have access to competitor donor profiles with the intent of finding information out about the donor and contacting them independently. This includes but is not limited to:

Finding the donor(s) on Facebook or other social media sites with the intention of having them donate with their agency.

Obtaining access to competitors' websites, either by legal or illegal means, in order to obtain personal information about specific donors with the intent to contact them regarding egg donation.

# APPENDIX IV

ABA Model Act Governing Reproductive Technology Agencies (DRAFT)

## AMERICAN BAR ASSOCIATION MODEL ACT GOVERNING ASSISTED REPRODUCTIVE TECHNOLOGY AGENCIES (*DRAFT VERSION* October 2013)

#### PREFATORY NOTE

The materials contained herein represent the opinions of the authors and editors and should not be construed to be those of either the American Bar Association or the Section of Family

Law. Nothing contained herein is to be considered as the rendering of legal advice for specific cases, and readers are responsible for obtaining such advice from their own legal counsel. These materials are intended for educational and informational purposes only. This proposed Model Act has not yet been approved by either the Section of Family Law, any other ABA section, or the ABA Board of Governors.

Assisted Reproductive Technologies (ART) is the intersection of various professions. There are aspects that are addressed by psychologists, physicians, and attorneys. Each of these professions is guided and regulated to some extent by the substantive and ethical rules of their various professional organizations and their licensing requirements.

Third party ART (gamete and embryo donation and surrogacy) is also impacted by the services provided by certain recruiting and matching agencies that receive and manage prospective intended parents' funds for the purpose of matching them with desirable donors/surrogates and administering various aspects of their ongoing fertility program. Such agencies can be owned and operated by anyone without professional training or affiliation. There have been documented cases in which the owners of such agencies have misappropriated and absconded with client funds and otherwise inadequately or negligently administered their programs to the detriment of their clients and their donors/surrogates. Regarding such agencies there is a significant gap in the licensing and regulation that governs most other aspects of the ART process, and the authors and editors, members of the American Bar Association Family Law Section Assisted Reproductive Technology Committee, believe that such licensing and regulation should be proposed and adopted. That is the purpose of the following Model Act Governing Assisted Reproductive Technology Agencies.

ARTICLE 1. DEFINITIONS SECTION 101. SHORT TITLE SECTION 102. DEFINITIONS

ARTICLE 2. LICENSING

SECTION 201. APPLICATION FOR LICENSE SECTION 202. DISCIPLINARY ACTION SECTION 203. FAILURE TO COMPLY

ARTICLE 3. RESPONSIBILITIES OF ART AGENCIES SECTION 301. LICENSING REQUIRED

SECTION 302. AFFIRMATIVE DUTIES AND OBLIGATIONS SECTION 303. SERVICE AGREEMENTS

SECTION 304. PREREQUISITES FOR CYCLE COMMENCEMENT SECTION 305. RECORDKEEPING

SECTION 306. CONTINUING EDUCATION

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ARTICLE 4. MISCONDUCT

SECTION 401. UNLICENSED OPERATION

SECTION 402. AUTHORIZATION OF CIVIL ACTION SECTION 402. AUTHORIZATION OF CIVIL ACTION SECTION 403. FUNDS HELD IN ESCROW

SECTION 404. FALSE OR MISLEADING INFORMATION PROVIDED TO COURT SECTION 405. PAYMENT FOR GAMETES

SECTION 406. REMEDIES NOT EXCLUSIVE

ARTICLE 5. MISCELLANEOUS PROVISIONS SECTION 501. AUDITS

SECTION 502. RULEMAKING

# ARTICLE 1. DEFINITIONS SECTION 101. SHORT TITLE

This Act is entitled a Model Act Governing ART Agencies. SECTION 102. DEFINITIONS

1. "Assisted Reproductive Technology" or "ART" means a variety of clinical treatments and laboratory procedures which include the handling of human oocytes, sperm, or Embryos, with the intent of establishing a pregnancy. This includes, but is not limited to, in vitro fertilization (IVF), Gamete intrafallopian transfer (GIFT), zygote intrafallopian transfer (ZIFT), Embryo biopsy, preimplantation genetic diagnosis (PGD), Embryo cryopreservation, oocyte or Embryo donation, and gestational surrogacy. This definition, for purposes of this Act, does not include artificial insemination, the process by which a man's fresh or frozen sperm sample is introduced into a woman's vagina, other than by sexual intercourse.

2. "Assisted Reproductive Technology Agency" or "ART Agency" means any Person that facilitates Collaborative Reproduction by:

(a) Planning or arranging the details of agency services with the Intended Parent(s); (b) Setting the timeline for the services; establishing the type of services to be rendered; acquiring or coordinating the services of third party licensed professionals; (c) Recruiting and/or obtaining personal information regarding Donors, Gametes or Surrogates;

(d) Making, negotiating, or completing the financial arrangements;

(e) Directing, being in charge or apparent charge of, or supervising, directly or indirectly, the matching process between the Intended Parent(s) and Donors, Gametes or Surrogates;

(f) Directing, being in charge or apparent charge of, or supervising, directly or indirectly, the services to be provided by another licensed Person;

(g) Using in connection with one's name or employment the words or terms "Agency," "agency owner," or any other word, term, title, or picture, or combination of any of the above, that when considered in the context in which used would imply that such Person is engaged in the practice of agency ownership or that such Person is holding herself or himself out to the public as being engaged in the practice of providing services related to matching egg Donors or Surrogates; provided, however, that nothing in this paragraph shall prevent using the name of any Owner, department, or corporate director of an agency, who is not a licensee, in connection with the name of the agency with which such individual is affiliated, so long as such individual's affiliation is properly specified; or

(h) Managing or supervising the operation of an agency, except for administrative matters such as budgeting, accounting and personnel, maintenance of buildings, equipment and grounds, and routine clerical and recordkeeping functions.

(i) A Person who performs a function in Collaborative Reproduction shall not be considered an ART Agency under this Act, so long as that Person is not also performing actions detailed above in (a)-(h).

3. "Client" means Intended Parent(s) working with an ART Agency.

4. "Collaborative Reproduction" involves any assisted reproduction in which an individual other than the Intended Parent(s) provides genetic material or agrees to act as a Surrogate. It can include, but is not limited to: (1) attempts by Intended Parent(s) to create a child through means of a Surrogacy agreement, with or without the involvement of Donors; and (2) assisted reproduction involving Donors where a Surrogate is not used.

5. "Cycle" means an attempt to establish pregnancy through the use of medical techniques or therapies including but not limited to ART through IVF or artificial insemination6. "Department" means [insert agency name].

*Legislative Note:* States should determine the department under the state's own organizational scheme that is best suited to oversee ART Agencies.

7. "Donor" means an individual who produces eggs or sperm used for assisted reproduction, whether or not for consideration. The term does not include: (a) an Intended Parent who provides Gametes, to be used for assisted reproduction; (b) a woman who gives birth to a child by means of assisted reproduction; or (c) an Intended Parent. An embryo Donor means an individual or individuals with dispositional control of an Embryo who provide(s) it to another for gestation and relinquish(es) all present and future parental and inheritance rights and obligations to a resulting individual or individuals.

8. "Embryo" means a cell or group of cells containing a diploid complement of chromosomes or group of such cells (not a Gamete or Gametes) that has the potential to develop into a live born human being if transferred into the body of a woman under conditions in which gestation may be reasonably expected to occur.

9. "Escrow Account" means an independent, insured, bonded escrow depository maintained by a licensed, independent, bonded escrow company; or an insured and bonded trust account maintained by an attorney.

(a) For purposes of this section, a non-attorney ART Agency may not have a financial interest in any escrow company holding client funds. A non-attorney ART Agency and any of its directors or employees shall not be an agent of any escrow company holding client funds; and

(b) Client funds may only be disbursed by the attorney or Escrow Agent as set forth in the assisted reproduction agreement and the fund management agreement between the Intended Parent(s) and the Escrow Account holder.

10. "Escrow Agent" means the trustee for an Escrow Account.

11. "Gamete" means a cell containing a haploid complement of DNA that has the potential to form an Embryo when combined with another Gamete. Sperm and eggs are Gametes. A Gamete may consist of nuclear DNA from one human being combined with the cytoplasm, including cytoplasmic DNA, of another human being.

12. "Intended Parent" means an individual, married or unmarried, who manifests the intent as provided in this Act to be legally bound as the parent of a child resulting from assisted or Collaborative Reproduction.

13. "Medical Errors" mean any and all medical errors that have any potential for adverse effects

for patients, even if the mistakes are seemingly minor. Any use of the wrong Gametes or Embryos is a medical error. Errors affecting the number or quality of Gametes or Embryos available are Medical Errors.14. "Owner" means any and all Persons who, directly or indirectly, or acting by or through one or more Persons, owns an interest in an ART Agency.

15. "Participant" means any Intended Parent, Donor or Surrogate, whether or not a written contractual relationship exists with the ART Agency.

16. "Person" means any and all persons, associations, businesses, corporations, partnerships, institutions, agencies, medical centers, and other organizations.

17. "Record" means information inscribed in a tangible medium or stored in an electronic or other medium that is retrievable in perceivable form.

18. "Service Agreement" means an agreement between an ART Agency and Intended Parent(s) describing the services to be performed.

19. "Surrogate" means an adult woman, not an Intended Parent, who enters into

a surrogacy agreement to bear a child, whether or not she has any genetic relationship to the resulting child. Both a traditional surrogate (a woman who undergoes insemination and fertilization of her own eggs *in vivo*) and a gestational surrogate (a woman into whom an Embryo formed using eggs other than her own is transferred) are surrogates.

20. "Surrogacy" means an arrangement between Intended Parent(s) and a Surrogate.

# ARTICLE 2. LICENSING

# SECTION 201. APPLICATION FOR LICENSE

1. Every Applicant for a license as an ART Agency must submit a written application for a license to the Department, in such form as prescribed by the Department.

2. The Department's application, shall, at a minimum, require the following information, to be provided in a sworn statement:

(a) The business name, each business address, tax ID number, and date of incorporation if applicable, or the true full legal name of the primary agent for the business, date of birth, driver's license number, social security number, and each place of business address;

(b) The true name, date of birth, driver's license number, social security number, and home address of all Owners;

(c) Degrees and certifications and licenses or other professional designation of primary agent for the business and for all Owners;(d) Each business or occupation engaged in by all Owners during the five (5) years immediately preceding the date of the application, including place of employment and the location thereof;

(e) The previous experience of all Owners as it relates to the field of assisted reproduction;

(f) A description of formal and informal education in the field of ART completed in the two years immediately preceding the application date by all Owners;

(g) Proof of applicable professional liability insurance, if available;

(h) The applicant's Conflict of Interest Policy (disclosure procedure/waiver procedure);

(i) Statement of whether the applicant or any Owner has been convicted or found guilty of a felony. If so, provide an explanation of the nature of the crime and a certified copy of the relevant court records;

(j) Whether the applicant or any Owner, regardless of adjudication, has been convicted or found guilty of, has entered a plea of guilty or a plea of nolo contendere to a felony and, if so, the nature of the felony;

(k) Whether the applicant or any Owner, regardless of adjudication, has previously been convicted or found guilty of, has entered a plea of guilty or a plea of nolo contendere to racketeering or any offense involving fraud, theft, embezzlement, fraudulent conversion, or misappropriation of property;

(1) Whether there has ever been a judicial or administrative finding that the applicant has previously been convicted of acting as an agency without a license, or whether such a license has previously been refused, revoked, or suspended in any jurisdiction;

(m) Whether the applicant or any Owner has worked for, or been affiliated with, a company that has had entered against it an injunction, a temporary restraining order, or a final judgment or order, including a stipulated judgment or order, an assurance of voluntary compliance, or any similar document, in any civil or administrative action involving racketeering, fraud, theft, embezzlement, fraudulent conversion, or misappropriation of property or the use of any untrue, deceptive, or misleading representation or the use of any unfair, unlawful, or deceptive trade practice;

(n) Whether the applicant or any Owner has had entered against him/her/it an injunction, a temporary restraining order, or a final judgment or order, including a stipulated judgment or order, an assurance of voluntary compliance, or any similar document, in any civil or administrative action involving racketeering, fraud, theft, embezzlement, fraudulent conversion, or misappropriation of property or the use of any untrue, deceptive, or misleading representation or the use of any unfair, unlawful, or deceptive trade practice;

(o) Whether the applicant or any Owner has had any convictions for child abuse or neglect or sexual misconduct;(p) A statement from each Owner specifying that he/she is not currently using any illegal drugs, and is able to fulfill the duties of his/her job description;

(q) A statement of affirmative duties as further described under this Act;

(r) A statement of intent to comply with Department's audit and review policy;

(s) Whether there have been any judicial or administrative findings that applicant or any Owner has been previously denied a license in the area of providing medical, adoption, child-care, assisted reproductive services or counseling services;

(t) Any material change in business following date of initial or renewal of licensure (as specified below);

(u) Whether Applicant or any Owner has previously been convicted of acting as an agency without a license, or whether ANY such a license has previously been refused, revoked, or suspended in any jurisdiction. If so, provide a detailed explanation;

(v) Whether the Applicant or any Owner has worked for, or been affiliated with, a company that has had entered against it an injunction, a temporary restraining order, or a final judgment or order including a stipulated judgment or order, an assurance of voluntary compliance, or any similar document, in any civil or administrative action involving racketeering, fraud, theft, embezzlement, fraudulent conversion, or misappropriation of property or the use of any untrue, deceptive, or misleading representation or the use of any unfair, unlawful, or deceptive trade practice. If so, provide detailed explanation; and

(w) Whether the Applicant or any Owner has had entered against her or him an injunction, a temporary restraining order, or a final judgment or order, including a stipulated judgment or order, an assurance of voluntary compliance, or any similar document, in any civil or administrative action involving racketeering, fraud, theft, embezzlement, fraudulent conversion, or misappropriation of property or the use of any untrue, deceptive, or misleading representation or the use of any unfair, unlawful, or deceptive trade practice. If so, provide detailed explanation.

3. The Department shall implement procedures to obtain the following information regarding each

Owner:

(a) State and federal criminal records;

(b) Child abuse and neglect check for all states of residency from the age of eighteen

(18); and

(c) Sex offender registry check for all states of residency from the age of eighteen (18)

as well as the federal database.

4. Upon the filing of an application for a license and payment of all applicable fees, unless the application is to renew or reactivate an existing license, the, Department shall:

(a) Review applicant's policy for client file structure and management;

(b) Review applicant's written Service Agreement for clients to ensure compliance with this Act;

(c) Review applicant's accounting process;

(d) Review the applicant's system for protection of Participant funds in accordance with this Act; and

(e) Review applicant's Record retention policy.

5. The Department shall issue the license unless the application is incomplete, or grounds for denial of the license exist.

6. The Department may implement any application fees or other fees necessary or convenient to carry out the provisions of this section.

7. The Department may permit applicants to operate on an interim basis while license applications are pending.

8. Each licensee shall report, on a form prescribed the Department, any change to the information contained in any initial application form or any amendment to such application not later than thirty (30) days after the change is effective.

9. Each licensee shall report any changes in the Owners, partners, departments, members, joint venturers, directors, or venturers, or directors of any licensee of any licensee, or changes in the form of business organization, by written amendment in such form and at such time as the Department specifies by rule.

(a) When such change causes a new Person to acquire a controlling interest as the term is defined above, such Person must submit an initial application for licensure before such purchase or acquisition at such time and in such form as the Department prescribes.

10. Licenses are not transferable or assignable. A licensee may invalidate any license by delivering it to the Department with a written notice of the delivery, but such delivery does not affect any civil or criminal liability or the authority to enforce this chapter for acts committed in violation thereof.

11. A licensee who is the subject of a voluntary or involuntary bankruptcy filing must report such filing to the Department within seven (7) business days after the filing date.

12. A licensee that has been convicted or found guilty of a felony or has had entered against her or him an injunction, a temporary restraining order, or a final judgment or order, including a stipulated judgment or order, an assurance of voluntary compliance, or any similar document, in any civil or administrative action involving racketeering, fraud, theft, embezzlement, fraudulent conversion, or misappropriation of property or the use of any untrue, deceptive, or misleadingrepresentation or the use of any unfair, unlawful, or deceptive trade practice must immediately report such filing to the Department, together with a full explanation.

13. The Department shall implement procedures for the renewal of licenses.

14. Streamlined License Procedure

(a) Any Owner who is a professional subject to regulation under other departments may opt for streamlined licensure requirements under this Act.

(b) The Department shall determine categories of professionals that qualify for streamlined licensure. Such professionals shall include, but not be limited to, physicians, attorneys, registered nurses, licensed psychologists and licensed social workers.

(c) An inactive, suspended or otherwise not active professional license shall not qualify for the streamlined licensure requirements.

(d) The streamlined licensure procedure shall be determined by the Department.

15. This Chapter does not prevent a licensee from providing services to residents of any part of this state or any other state or country.

# SECTION 202. DISCIPLINARY ACTION

1. The following acts are violations of this chapter and constitute grounds for disciplinary action. (a) A material misstatement of fact in an application for a license.

(b) Failure to demonstrate financial responsibility, experience, character, or general fitness, such as to command the confidence of the public and to warrant the belief that the business operated at the licensed or proposed location is lawful, honest, fair, efficient, and within the purposes of this chapter.

(c) The violation, either knowingly or without the exercise of due care, of any provision of this chapter, any rule or order adopted under this Act, or any written agreement entered into with the Department.

(d) Any act of fraud, misrepresentation, non-waived conflict of interest, or deceit, regardless of reliance by or damage to a client, or any illegal activity, where such acts are in connection with providing agency services under this chapter. Such acts include, but are not limited to:

(i) Willful imposition of charges in violation of this Act, or previously undisclosed charges, or charges in excess of 10% over the amount originally disclosed in the Service Agreement without reasonable cause;

(ii) Misrepresentation, circumvention, or concealment of any matter required to be stated or furnished to a third Person;(iii) The use of false, deceptive, or misleading advertising; and

(iv) Failure to disclose material information in its possession to Participants. (e) Failure to maintain, preserve, and keep available for examination, all books, accounts, or other documents required by this Act, by any rule or order adopted under this Act, or by any agreement entered into with the Department.

(f) Refusal to permit inspection of books and Records in an investigation or examination by the Department or refusal to comply with a validly issued subpoena issued by the Department. (g) Pleading nolo contendere to, or having been convicted or found guilty of, a crime involving fraud, dishonest dealing, or any act of moral turpitude, regardless of whether adjudication is withheld.

(h) Allowing any Person other than the licensee to use the licensee's business name, address, or telephone number in an advertisement in an attempt to mislead another.

(i) Failure to pay any fee, charge, or fine imposed or assessed pursuant to this chapter or any rule adopted under this chapter.

(j) Using the name or logo of another institution when marketing or soliciting existing or prospective customers if such marketing materials are used without the consent of that institution and in a manner that would lead a reasonable individual to believe that the material or solicitation originated from, was endorsed by, or is related to or the responsibility of that institution or its affiliates or subsidiaries.

(k) Payment to the Department for a license or permit with a check or electronic transmission of funds that is dishonored by the applicant's or licensee's financial institution.

(1) Failure to maintain continuing education as otherwise set out in this Statute.

# [Legislative Note: Optional, depending on adoption of continuing education requirements]

(m) Failure to meet and/or maintain minimum standards as set forth above constitute grounds for denial of an application.

2. Under this section, a licensee is responsible for acts of its Owners, members of the partnership, any department or director of the corporation or association, or any Person with power to direct the management or policies of the partnership, corporation, or association.

3. Under this section, a licensee is responsible for the acts of its employee or agents if, with knowledge or reckless disregard of such acts, the licensee retained profits, benefits, or advantages accruing from such acts or ratified the conduct of the employee or agent as a matter of law or fact.

4. Disciplinary action that may be imposed under this section includes:

(a) Denial of the issuance of a license or renewal of a license;

- (b) Issuance of a probationary or conditional license;
- (c) Fines up to \$25,000 per violation;
- (d) Suspension of a license;
- (e) Revocation of a license; and

(f) Ordering restitution to aggrieved Participant(s) to the full extent of their financial damages. Restitution includes, but is not limited to, all amounts paid by the aggrieved Participant(s) to the ART Agency as well as consequential and incidental losses incurred by the aggrieved Participant(s) as a result of the ART Agency's and/or Owner's misconduct.

5. The Department shall follow the state's administrative procedures act when exercising its duties under this Section, and all remedies available under the administrative procedures act shall be available to the Department and licensee or applicant.

6. In the event that the Department takes action under this Section, it shall arrange for the provision of ongoing services to the active Participants.

# SECTION 203. FAILURE TO COMPLY

1. The Failure of any ART Agency or any other Person to comply with any provision(s) of this Act shall not affect the validity and enforceability of any lawful direct agreement(s) among the Participants.

2. Action taken by the Department against any licensee shall not impair the obligation of any lawful agreement(s) between the licensee and Participant(s).

# ARTICLE 3. RESPONSIBILITIES OF ART AGENCIES SECTION 301. LICENSING REQUIRED

1. ART Agencies must be licensed under this Act to operate in this state.

# SECTION 302. AFFIRMATIVE DUTIES AND OBLIGATIONS

1. Provide services to its Participants in a non-discriminatory manner. Nothing herein shall inhibit the ART Agency's ability to accept or decline prospective Participants based on its own policies and screening procedures.

2. Respect the autonomy of Participants by not engaging in coercion, fraud, misrepresentation, or unethical behavior.

3. An ART Agency shall not provide legal, medical, psychological or other advice that it is not licensed or otherwise qualified to give.

4. Medical Errors committed by or known to an ART Agency or Operator shall be immediately reported to the affected Participant(s) in the assisted reproduction arrangement to enable them to decide on a course of action.

5. An ART Agency shall not present a Surrogate or Donor for matching to Intended Parent(s), that they reasonably know or should know is not qualified or is unavailable.

SECTION 303. SERVICE AGREEMENTS

1. Prior to entering into a Service Agreement, an ART Agency shall provide the following:

(a) A detailed description of the services to be provided by the ART Agency;

(b) The estimated costs of the services to be provided by the ART Agency;

(c) An explanation of refund and cancellation policies; and

(d) The estimated timing for the services to be provided by the ART Agency, as well as a statement that the projected time frame may be subject to variables outside of the control of the ART Agency.

2. All Service Agreements must be in writing and include the following provisions: (a) The information required by Article 3, Section 303 of this Act;

(b) The name and address, phone number and email of Agency, the corporate identity if any, the main contact person of the agency, and the license number, if one has been provided by the Department;

(c) The full legal names, addresses, phone numbers and emails for the Intended Parent(s);

(d) A detailed description of the services to be provided by the ART Agency;

(e) A detailed description of the estimated costs of the services to be provided by the

ART Agency;

(f) A description of other known fees and expenses that may be incurred, including, but not limited to, legal fees and medical costs;

(g) A timetable for the payment of known costs, fees and expenses;

(h) The name and address, phone number and email of the Escrow Agent;

(i) The estimated time for completion of the services to be provided, as well as a statement that the projected time frame may be subject to variables outside of the control of the ART Agency;

(j) Notification of the right, and an opportunity, to have the Service Agreement reviewed by independent legal counsel, and right to separate counsel for applicable agreements with third parties for each Participant involved;

(k) An explanation of recordkeeping procedures for Records required to be kept under Section 305 of this Act;

(1) An explanation of the ART Agency's policies regarding future contact between the Participants following the completion of the direct agreement between the Participants or a statement that the ART Agency does not provide such services;

(m) Disclosure of any and all relationships, activities, financial or other interests of the Owners of the ART Agency that may constitute an actual or potential conflict of interest and waiver of the same;

(n) The name of the ART Agency's professional liability insurance carrier(s) or a statement that the ART Agency does not carry professional liability insurance where none is applicable; and

(o) A litigation or alternative dispute resolution clause which provides attorney's fees and costs be paid by the unsuccessful litigant.

SECTION 304. PREREQUISITES FOR CYCLE COMMENCEMENT

1. No ART Agency shall permit, encourage or facilitate an egg Donor or Surrogate to begin a Cycle until the following tasks have been completed:

(a) A Service Agreement has been signed by the Intended Parent(s);

(b) All Participants have each had an opportunity to consult with a licensed attorney of their own choosing;

(c) A direct agreement between the Participants has been executed;

(d) The Intended Parent(s) have made the deposit to the Escrow Account, in accordance with the direct agreement(s) between the Participants.

(e) The Participants are informed to seek advice regarding their life insurance and health insurance/benefits policies and the respective coverage of the fertility treatment, complications, and obstetric costs and fees;

(f) The Participants are informed to seek advice from medical, psychological, legal, and any other relevant third party professionals to discuss the potential risks and outcomes of the process; and(g) The Participants are informed to seek advice regarding their guardianship and estate planning options.

# SECTION 305. RECORDKEEPING

1. The ART Agency shall create and maintain reasonable and ordinary business Records.

2. The ART Agency shall maintain copies of direct agreements between Participants, unless the Participants decline to share their direct agreement with the ART Agency.

3. All Records required to be kept under this section shall be maintained for a minimum of eighteen (18) years following the completion of the Service Agreement.

4. The ART Agency shall have and follow a written policy that covers the following:

(a) The protocol for creating, storing, backing up, accessing, transferring and disposing

Records under the ART Agency's control; and

(b) The policy for transfer of such Records in the event that the ART Agency ceases to exist or is otherwise unable to continue to maintain the Records for the required time period.

5. Such Records shall be held in strict confidence by the ART Agency and only released upon the written permission of the Participant(s) whose information is stored in such Records. This provision applies even when the information is identified and used in a database, for archival research, educational purposes, advertising, or for any other purpose.

6. Such Records shall be confidential and the Records and their contents shall not be disclosed nor shall disclosure be compelled except as follows:

(a) For the ART Agency Owner to carry out any and all duties under a Service Agreement;

(b) With the consent of the Participant(s) whose information is contained in the Record to be disclosed; or

(c) Pursuant to a valid court order or subpoena. SECTION 306. CONTINUING EDUCATION

*Legislative Note:* States can choose to implement alternative educational requirements in lieu of yearly continuing education

1. Owners of ART Agencies must complete \_\_hours of continuing education each calendar year.2. Such continuing education may consist of such topics as ethics, communicable diseases, FDA screening, financial responsibility, psycho-social aspects of assisted reproduction, reproductive medicine/biology and reproductive law or other relevant topics. To the extent that the subject matter is identical, licensees that hold other professional licenses may satisfy these requirements through continuing education approved by their respective licensing authority.

SECTION 307. MANAGEMENT AND DISBURSEMENT OF FUNDS

1. All unearned or undisbursed funds of Intended Parent(s) must be held in an Escrow Account pursuant to this Act.

2. An ART Agency must provide proof of insurance and bonding as required pursuant to this Act, as may be required by the Department.

# SECTION 308. PROFESSIONAL LIABILITY INSURANCE

1. An ART Agency must carry professional liability insurance coverage, if available.

## ARTICLE 4. MISCONDUCT

*Legislative Note:* States should customize this article to comport with the state's criminal code.

## SECTION 401. UNLICENSED OPERATION

1. No ART Agency shall operate without a license in accordance with this Act. Violation of this paragraph shall be punishable by a civil penalty.

2. No Person shall knowingly operate or permit the operation in this state of an ART Agency that is not licensed in accordance with this Act. Violation of this paragraph shall be punishable by a civil penalty.

*Legislative Note:* States should incorporate the existing statutory scheme for civil penalties for unlicensed activities.

# SECTION 402. AUTHORIZATION OF CIVIL ACTION

1. In the event of negligent conduct or misappropriation of funds by an ART Agency or Owner, the aggrieved Person may bring an action against the ART Agency.

2. In the event of knowing or purposeful misconduct, an award of punitive damages is authorized. SECTION 403. FUNDS HELD IN ESCROW

1. No ART Agency or Owner shall permit unearned client funds to be held in an account other than an Escrow Account

# SECTION 404. FALSE OR MISLEADING INFORMATION PROVIDED TO COURT

1. No ART Agency or Operator shall provide, attempt to provide, or solicit another to provide false, misleading or incomplete information to another with the purpose to influence a court order relating to parentage of a child born, or expected to be born, as a result of assisted reproduction. Violation of this section shall be a felony and punishable accordingly.

# SECTION 405. PAYMENT FOR GAMETES

1. No ART Agency or Owner shall compensate or permit a Donor to be compensated based on the number or quality of Gametes or Embryos donated. Violation of this section shall be a misdemeanor and punishable accordingly.

#### SECTION 406. REMEDIES NOT EXCLUSIVE

1. This Article is not intended to limit the rights of any Person or government entity to bring an action against the ART Agency or Owner under any other provision of law or equity.

### ARTICLE 5. MISCELLANEOUS PROVISIONS SECTION 501. AUDITS

1. The Department may audit the ART Agency to ensure compliance with any and all provisions of this Act and the ART Agency shall fully cooperate in any such audit.

#### SECTION 502. RULEMAKING

1. The Department shall, adopt rules to implement the Department's responsibilities under this

Act, in accordance with the State administrative procedures act, if any.

# APPENDIX V

Interview Transcriptionist Non-Disclosure Agreements

I, Christine M. Jaber , transcriptionist, on behalf of CS Administrative 474 Inman St., Akron, OH 44306 agree to Services, located at , maintain full confidentiality in regards to any and all digital audio files received from Janette Catron related to her research study entitled "Decision-Making in Egg Donor Agencies." Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of digitally recorded interviews, or in any associated documents.

2. To not make copies of any audio files or computerized titles of the transcribed interview texts, unless specifically requested to do so by the researcher, Janette Catron.

3. To store all study-related digital audio files, transcripts, and materials safely and securely as long as they are in my possession.

4. To delete all digital audio files and and transcripts from my computer hard drive and any back-up devices, and to destroy all study-related materials in a complete and timely manner at the conclusion of the transcription services or at their termination by Janette Catron.

5. None of the content of the digital audio files or other materials provided by Janette

Catron will be forwarded to any third party under any circumstances.

6. Title to, and all rights emanating from, the ownership of all confidential information disclosed under this agreement remains vested in Janette Catron.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the digital audio files and/or files to which I will have access.

Transcriber's name (printed) Christine M. Jaber

Transcriber's Signature Date 3/12/2014

I,Paula Allen, transcriptionist, on behalf of CS AdministrativeServices, located at7601 N. Leonard Ave, Clovis, CA 93619, agree tomaintain full confidentiality in regards to any and all digital audio files received fromJanette Catron related to her research study entitled "Decision-Making in Egg DonorAgencies." Furthermore, I agree:

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Transcriber's name (printed)		Paula S. Allen	
Transcriber's signature	Date	March 9, 20014	

*1, Mary Y o u n g ,* transcriptionist, on behalf of CS Administrative

# Services, located at

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Transcriber's name (primed) Mary foun	Transcriber's name	(printed)	Mary Young
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Transcriber's signature Date 3/10/2014

I, Karen Everett, transcriptionist, on behalf of CS Administrative

#### Services, located at

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Transcriber's name (printed) Karen Everett\_\_\_

Transcriber's signature Date 3/10/2014\_

I, Kimberly Harkins, transcriptionist, on behalf of CS Administrative

# Services, located at

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Transcriber's name (printed) Kimberly K. Harkins

Transcriber's signature \_\_\_\_\_ Date <u>3/12/14</u>