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Anticipating Autism:
Navigating Science, Uncertainty, and Care in the Post-Genomic Era

by

Martine Danielle Lappé

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

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Sociology

in the

GRADUATE DIVISION

of the

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by
Martine Danielle Lappé

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DEDICATION

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ABSTRACT

Anticipating Autism:
Navigating Science, Uncertainty, and Care in the Post-Genomic Era

By: Martine Danielle Lappé

In the United States, diagnosed cases of autism have increased more than ten fold over the past four decades. This dramatic change has become the source of considerable controversy, raising questions about what lies behind these rising numbers. These debates have spurred new directions in research on the causes of autism, including epidemiologic studies focused on environmental factors and gene-environment interactions. This dissertation provides a sociological study of the emergence, practices, and consequences of autism gene-environment interaction research. Using participant observation, document analysis, and interviews with scientists, advocates and mothers of children diagnosed with autism, I argue that autism gene-environment interaction research is situated within a larger social and scientific process I call *anticipating autism*. Building on scholarship in medical sociology, science and technology studies and social theory, this process captures how autism is increasingly being produced as a possible future that should be preemptively considered, acted upon and engaged in the present.

My findings detail how this process is taking place across sites of knowledge production, scientific practice, autism diagnosis and family life. In particular, I describe how advocacy efforts, science, and family experiences of autism facilitated new approaches to the study of the condition. Following a prospective epidemiologic study focused on autism risk factors during fetal development and early childhood, I show how gene-environment interaction research is shifting understandings of autism both spatially

and temporally. Finally, I describe how, for mothers of children diagnosed with autism who are expecting another child, research participation becomes a practice in caring for specific children, being a "good mother," and preparing for the future. These findings reflect changing relationships between science, uncertainty and care in the post-genomic era. This dissertation contributes to the fields of sociology and science and technology studies.

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CHAPTER 1:
ANTICIPATING AUTISM

> *Autism is a uniquely good place to listen in on conversations about the role of affect in biomedicine and about the ethics of empathy. It is, however, far from the only place where these conversations take place. They happen every time children develop in ways different from what their parents expected and the parents seek out experts for advice.*
> (Silverman 2011:233)

Setting the Scene

Flash Back: October 9, 2011. *Autism Votes*, a policy and lobbying initiative developed through the advocacy organization *Autism Speaks*, issues a press release on the signing of SB.946. This law requires insurance coverage for autism treatments in California, making the state the twenty-eighth in the nation to mandate insurance coverage for autism treatments.[1] The press release provides a financial and statistical backdrop for the law:

> Thousands of California families, in the absence of insurance coverage, have been forced to pay out-of-pocket or rely on taxpayer-funded programs for behavioral health treatments, which can cost $50,000 a year or more. Autism Speaks has helped lead the fight in statehouses across the nation to end such insurance company discrimination. This year alone, laws have been enacted in Arkansas, Virginia, West Virginia and Rhode Island; and a bill passed this summer by the New York Legislature awaits Gov. Andrew Cuomo's signature.
>
> Since 2006, the prevalence of autism has risen to 1 in 110, including 1 in 70 boys, prompting the national Centers for Disease Control and Prevention to call autism a public health challenge. Estimates of the annual cost of autism to the nation have ranged as high as $90 billion. The number of California children with autism has not been calculated precisely, but estimates range at 30,000 children.
>
> "The use of early intervention treatments, such as ABA [Applied Behavioral Analysis], can substantially increase a child's independence, thereby reducing future taxpayer costs for special education and social services," said Peter Bell, Autism Speaks' executive vice president for programs and services. "In states that have enacted autism insurance reform, actual experience has demonstrated the impact on premiums has been far below estimates offered by insurance industry lobbyists."

This narrative of financial hardship, the promises of intervention and state regulation, provides a glimpse into the contemporary discourse that surroundings autism in the

[1] What are biomedical interventions including diets, supplements or "alternative" interventions, such as chelation, are not covered by insurance under the new law.

United States, and the landscape families must navigate following the diagnosis of a child with an autism spectrum disorder (Autism Votes 2011).

Flash Back: July 4, 2011. Newspapers and television broadcasts are abuzz with reports on findings from the largest twin study to explore the genetic contributions to autism (Hallmayer et al. 2011). The headline on the University of California–San Francisco website – "Study Debunks Autism as a Primarily Genetic Disorder" – discursively turns previous causal understandings of autism on their head. During the course of the next day, headlines flash across newspapers and television programs: "Environment Blamed for Autism," "Environment May Be Especially Key to Autism," and "Autism Risk: Genes May Not Play Biggest Role." In the *New York Times*, *Los Angeles Times*, *Washington Post*, and prominent autism advocacy websites including *Autism Speaks*, the tone of the coverage is similar: when it comes to autism, the environment plays more of a role than we thought, genes play less, and this changes everything.[2] In the words of the authors: "children's environment represents more than half of the susceptibility — 55 percent in the most severe form of autism and 58 percent in the broad spectrum of the disorder — while genetics is involved in 37 percent and 38 percent of the risk, respectively" (Hallmayer et. al 2011:1095). In other words, autism has more to do with the environment than we thought.

A second study's findings also feature prominently in the coverage, reflecting a

[2] As I have argued elsewhere (Lappé, Newschaffer, Yudell and Tabor N.d.), these popular accounts eclipse a long history of research on environmental factors and autism, and the burgeoning work that I describe in this dissertation. The findings also say little about the potential relationships *between* genetics and the environment (as the authors make clear in the article), and nothing of the conditions of possibility for this kind of scientific work. The emphasis of the news stories, while more sensational than the article itself, is important in illustrating the shifting social and scientific discourse that surrounds contemporary understandings of autism.

key dimension of what is at stake in conversations about autism and "the environment." This study (Croen et al. 2011) reports on the relationship between antidepressant use during pregnancy and children's risk of autism, noting that "exposure [to antidepressants], especially during the first trimester, may modestly increase the risk of ASD" (Croen et al. 2011:1104). These findings, their accompanying comment – "Is Autism, at Least in Part, a Disorder of Fetal Programming?" – and related media coverage, reflect the kinds of environments that are becoming more and more central in accounts of autism risk. In these publications and related news stories, what emerges is the "womb as environment" (Lajonchere 2011). Here, and elsewhere, pregnancy is positioned as a concentrated and *consequential* space and time for autism.[3]

Flash Back: June 1, 2010. I sit across from Eleanor in her living room as she cradles her six-week old daughter, Deana, in her arms.[4] Together, Eleanor and Deana are participating in several autism studies. In one – the one I will follow for my research – Deana will be observed until age three for signs of autism. During that time, researchers will collect data on possible genetic and environmental risk factors for the condition. Researchers have already begun to do so, following Eleanor throughout her pregnancy. Eleanor's oldest son was diagnosed with autism nearly six years ago, and while Deanna seems alert, happy and healthy, Eleanor finds herself keenly observant of the little girl – as she has been with each of her children since her son's diagnosis. She remembers his first few months, comparing and contrasting them with Deana's. The similarities and

[3] Since these publications, there have been several other high profile publications illustrating the relationships between mothers' health during pregnancy and risk of autism in their children (Zerbo et al. 2012; Krakowiak et al. 2012) and studies that indicate genetic mutations related to fathers' age (see Sanders et al. 2012; O'Roak et al. 2012; Neale et al. 2012).

[4] All mothers' names and children's names have been changed to protect anonymity.

differences between the two children punctuate her feelings about the future and whether or not Deana will have autism. For now, all she can do is wait, and watch.

* * *

Anticipating Autism

This dissertation is about family, science and uncertainty. It is about anticipation and the unexpected, about care and the conditions of possibility that structure ways of knowing about the body, health and illness in the United States. It is about autism. The moments above provide glimpses of the cultural and scientific conditions that structure life for families whose children have been diagnosed with an autism spectrum disorder in the United States. What is at stake in each of these moments is not only the biological but also, simultaneously, the social. This includes the availability of resources for families and the conditions of care surrounding autism, as well as the historical conditions that shape its diagnosis. As I argue in this dissertation, relationships between the biological and social are becoming more central in articulations of autism as a disease category. Reflected in questions about the interactions between genes, environmental factors, timing and their consequences, bio/social relationships have developed as central to understandings of autism in recent years (Engel and Daniels 2011; NIEHS 2011).[5] Central to, and simultaneously emanating from these, is a changing landscape of personal experiences and scientific knowledge production surrounding autism (see Eyal et al. 2010; Silverman 2011).

[5] I use bio/social here to indicate that these two realms remain distinct in discourse about autism. While the bio and social each signal distinct arenas, these are increasingly being joined in interesting and consequential ways that I explore in this dissertation.

In the pages that follow, I focus on autism science as a historically situated social world and a lens onto the interactions among family, uncertainty and care. I detail how the interactions among family experiences of autism and scientific research are shifting cultural and personal meanings of the condition as a disease category and social experience. Throughout the dissertation, I detail how autism is mobilized socially and scientifically, constructed as a disease entity and experienced by families and scientists. I argue that through these movements, autism is drawn into new spatial and temporal configurations that both reflect and are productive of changing understandings of genes, environments, and their relationships to risk and responsibility.

In order to trace the intended and unintended consequences of these movements, I follow the emergence, practices and consequences of epidemiologic sciences focused on autism risks during pregnancy and early childhood. I contend that through these sciences and families' interactions with them, autism reflects new social and biological relationships among bodies, environments and behaviors. The result is an extension of existing relationships that have characterized the disorder since its naming, and current models of causation. The openness of these relationships is particularly well illustrated in how they are being articulated vis-à-vis "the environment" and genetics. These categories – and increasingly gene-environment *interactions* – have become socially and biologically meaningful "boundary objects" (Star and Griesemer 1989) within autism science and experiences related to it.

Through tracing these objects and their meanings, I argue that domains of both scientific research and family life are increasingly characterized by a process I call *anticipating autism*. Drawing on scholarship in science and technology studies (Hacking

2007; Adams, Murphy and Clarke 2009) and medical sociology (Clarke et al. 2008; Jutel and Nettleton 2011; Timmermans and Buchbinder 2010, 2012), this concept frames how autism is being produced as a possible future that should be preemptively considered, acted upon and engaged in the present. As the scientific studies noted above illustrate, the future of autism has started to matter at earlier and earlier points in human development, expanding autism risk both spatially and temporally, as describe in Chapter Two. Anticipating autism reflects this qualitative shift in the politics of classification and in the experiences of families, clinicians and scientists alike.

The concept of anticipating autism involves three key processes. The first process involves the shifting relationships among health, illness, science and citizenship that have intensified over the past several decades (see Epstein 1995, 1996, 2008; Brown et al. 2004; Bucchi and Neresini 2007; Klawiter 2008; Silverman 2011; Cooper and Waldby forthcoming). This process reflects how patients and organized advocacy efforts have increasingly come to shape scientific agendas surrounding their illness experiences. In the case of autism, this has involved particular demands on both the state and scientific researchers to more fully account for concerns raised by autistic self advocates (Orsini 2010) and parent advocates (Silverman 2011; Eyal et al. 2010; Singh 2010). These efforts have changed how research is conducted (see Tabor and Lappé 2011; Singh 2010) and the questions being pursued.

This dovetails with the second process, which details the changing conditions surrounding scientific work and disease classification in the post-genomic era. These include calls for increased data sharing, technologies that can facilitate this, and interdisciplinary approaches. These reflect larger shifts in the content, volume,

institutional infrastructures and relationships of post-genomic science and take a particular shape and pace when called upon to address parent experiences of their children's autism (see Tabor and Lappé 2010). Importantly, these shifts are increasingly molecular (Rose 2007; see also Navon 2011) and expansively social (Gibbons and Novas 2008).

Finally, anticipating autism involves the shifting temporal and spatial configurations of risk (see Clarke et al. 2010) and their relationships to family experiences of illness. This includes not only the shifting qualities of autism science reflected in the first two processes, but also the emotion work (Hochschild 1983) and biolabor (Cooper and Waldby forthcoming) of mothering children who experience affective, cognitive or physical challenges. The residual effects of blame attributed to mothers of children early in the history of autism also impacts views of autism risk today (see Landsman 2009). These dynamics position traditional gender roles and relationships within the family and society as part and parcel of the scientific theories that now characterize autism today (see also Silverman 2011 on love as an analytic). As I detail throughout this dissertation, these bio/social experiences of autism are deeply entangled with autism science (see also Silverman 2008, 2011; Singh 2010).

All three processes are occurring within a situation (Clarke 2005) where information, attention and action related to autism are being "ratcheted up" throughout society (Adams, Murphy and Clarke 2009). This occurs in the form of scientific press releases, media reports on insurance coverage, vaccine debates and personal stories. It travels vis-à-vis advice columns and talk show segments, blog posts, testimonials and memoirs. It is woven into daily conversations, character arcs in prime time television,

intimate choices about when to have children, and how to care for them. In many ways, autism has become ubiquitous. Together with the expanding amount of information about autism are increasing campaigns calling for parents to "learn the signs" of autism and act early. These efforts situate the possibility of intervention in the keen observations of parents and physicians, carers and educators. Simultaneously, this attention to autism, its rising numbers in the population, and what should be done around it, are doing cultural work: they produce autism as a new normal that is accompanied by continued controversy.

Statement of the Problem

Autism refers to a spectrum of development disorders including autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome (APA 1994). These diagnoses range in severity, but are joined by their common features, including impairments in socialization, abnormal verbal and nonverbal communication, and restricted, stereotyped behaviors and interests (Filipek et al. 1999). Beyond these seemingly straightforward diagnostic criteria, however, is a diverse range of symptoms and co-occurring conditions that make each individual diagnosis of autism unique. This heterogeneity dovetails with larger questions surrounding autism's rising prevalence in the population, and what lies beneath those numbers (see Harmon 2012).[6]

Over the past several decades, diagnoses of autism spectrum disorder (ASD) have risen from 1 in 2000 in 1966 (Lotter 1966) to 1 in 88 in the United States (CDC 2012). In California, for example, recorded cases of autism have risen steadily. Between 1987 and

[6] New findings also suggest that diagnoses along the autism spectrum may reflect distinct disease categories, each with their own pathways and various phenotypic expressions (for example, see Navon 2011).

1998 the number of children with autism enrolled in the California Department of Developmental Services (DDS) grew 210%, from 3,864 to 11,995 (Schechter and Grether 2008:21).[7] New studies (CDC 2012) indicate that national prevalence rates have risen 23% from 2006-2008. What lies behind this significant increase has been the source of considerable debate, raising questions about the role of changing diagnostic criteria (Croen et al. 2002), increased awareness of autism, and the possible impacts of environmental factors in the etiology of the condition (Szpir 2006).

Together, these prevalence estimates and their underlying questions conjure up an image of autism as a moving target, mired in uncertainty, and at the same time of increasing personal and public importance. These statistics have been central to public awareness campaigns, calls for increased funding and efforts to facilitate more transparent dialog and decision making surrounding federal funding (IACC 2011). Over the past several decades, science on autism spectrum disorders has proliferated. The explosion of federal and private support has run the gamut, but is more extensive in some areas than others (NIH 2012). The favored sites have largely focused on the biological causes of autism, especially genetics research. Recently, however, research related to the role of "the environment" in autism has gained significant social and political attention.[8] This domain of knowledge production is one site where definitions of what is meant by the category have shifted and changed over time, leading to what I argue is a vast space most often defined by what it is not (genes), rather than what it explicitly *is*.

Throughout these developments, the public image of autism has in many ways remained one of controversy, competing interests and worldviews, often articulated vis-à-

[7] This prevalence was reported for children aged 6 years and born in the year 2000 (Schechter and Gretcher 2008:21).
[8] In Chapter Two I detail how this took place, and its consequences for understandings of autism's causes.

vis views about causation (see Offit 2008). Most private experiences of autism, however, offer a messier though no less passionate portrayal of what is at stake when it comes to conversations about autism's causes. Through depicting the practices of autism science, family, uncertainty and care as co-constructed, this dissertation seeks to place hyperbole on balance with the everyday. It is the everyday where autism is lived and lived with, and where its social realities are produced. Understanding how this takes place is one of my central concerns.

I focus on one area of autism science that sits at the intersection of public and private, questions of cause and social conditions surrounding autism. This is the proliferation of research on environmental and genetic risk factors for autism – much of which raises new questions about autism, what should be done about it, and when. In particular, I focus on the sociological dimensions – including the multiple actors, motivations, and meanings – involved in research on gene-environment interactions and autism. This research posits an interaction between environmental factors and biomarkers of susceptibility (Hertz-Picciotto et al. 2006), marking a new domain of research related to the etiology and progression of autism (see also Singh and Rose 2009 on ethics of biomarkers in psychiatric research).

In considering the emergence of autism gene-environment interaction research, I focus specifically on prospective cohort studies that explore the effects of genetic and environmental factors during pregnancy and early childhood (Lawler 2008).[9] This model of research recruits women who have already had one child diagnosed with autism during

[9] To date, there are no known biological markers for autism (Herbert et al. 2006). However, Newschaffer and colleagues (2007:236) report that, "a number of endogenous biomarkers associated with autism risk have been investigated, and these may help identify significant biologic pathways that, in turn, will aid in the discovery of specific genes and exposures."

the early stages of a subsequent pregnancy (or often before they become pregnant).[10] During this pregnancy and for three years following that child's birth, information about each participant's genetics and environmental exposures are collected through a variety of specimens.[11] These include "blood, urine, hair, saliva, and breast milk (if the mother is breast feeding), dust samples from the participant's home" and meconium, placenta and cord blood following the delivery. These are collected in order to better understand the "biological and environmental triggers that children are exposed to prenatally and post-partum" and their possible relationship to autism (MARBLES 2012, see also EARLI 2012).[12]

These studies and other prospective epidemiologic studies exploring risk factors for autism during pregnancy and early child development (ABC 2012) are touted as holding the potential to provide clues about the environmental, genetic and timing factors that lead to autism (Stoltenberg et al. 2011). These studies include a growing number of projects initiated at the turn of the twenty-first century (see Lawler 2006).[13] These are by and large prospective epidemiologic investigations. I choose to follow this particular trend in autism science because these research projects provide several important vantage points in examining the production of scientific knowledge related to autism.

---

[10] See Miranda R. Waggoner's Dissertation (2011) for a contemporary history and sociology of pre-conception care.

[11] Participants include biological mothers and fathers, siblings diagnosed with autism and the new child. However, very few samples are taken from fathers and siblings. The majority of attention is placed on mothers' activities, behaviors and exposures during pregnancy, and their new child's environment and development following birth.

[12] A more in-depth description of research practices and study rationale is provided in the Methods section of this chapter and throughout Chapter Three.

[13] The article provides an overview of studies within the United States and elsewhere that consider the role of environmental factors in autism's etiology and progression. A snapshot of studies at this point in time leaves out the most recent advances in the field (see Lawler and Daniels 2010), but nevertheless gives a good sense of the networks of research exploring the potential environmental and gene-environment interactions related to autism.

First, these studies are uniquely positioned at the center of changing politics surrounding environmental research on autism at the turn of the twenty-first century (as well as environmental research more broadly). As such, they provide resources for continued questions about autism's multiple, complex causes, and are an avenue for other relationships among families and researchers (detailed in Chapter Three). Second, as others (Halladay 2012) have described, these studies provide researchers both the challenge of recruiting and sustaining participants over an extended period of time, and the potential to identify the relationships between genetics and environmental factors through collecting data in real time (Newschaffer et al. 2007; Stoltenberg et al. 2010). Finally, I chose these studies because they offer a window into changing knowledge surrounding autism and motherhood, a topic that has been central to cultural narratives about autism since its first descriptions (see Sousa 2011).

As the results of these and other studies continue to generate publications, and data continue to be collected, stored and analyzed, their meanings remain "in formation." As a result of these constantly moving targets, autism science and questions about the environment present challenging subject matter for social scientists (Beck and Niewöhner 2006). Rather than attempt to provide an assessment of the 'state of the science,' this dissertation considers the conditions of possibility (Foucault 1973) in which these sciences dwell, and what they are productive *of*. It also catches these projects at a moment when their roots and futures can be seen in *relation* – through the interactions imaged and produced between genes and environmental factors, experiences of risk and social realities among families and scientists.

In exploring these dynamics, I see autism science as an example of what Franklin and Roberts (2006:79 emphasis in original) have called "*a condensed node of social action*, or a nodal point of exchange between different 'streams' of social action." Within prospective pregnancy studies exploring the causes of autism, these "streams" of social action include science, technology and prevention, as well as social structures of funding, notions of motherhood and family. Importantly, these studies orient questions of cause simultaneously into bodies and outward into the environment.

This dissertation describes the cultural, political, and scientific contexts in which these studies developed as projects (Chapter Two), the multiple social worlds involved in these endeavors (Chapter Three), and their intersections with autism family life (Chapters Four and Five). I also consider how various interests and perspectives buoy decisions made about autism research, the various forms of knowledge and claims-making involved in the construction of causal explanations for autism, and the always already changing consequences of this research for how we understand the complex relationships between the body, the environment and time, as well as science, family and uncertainty.

Throughout, I consider this matrix of human and nonhuman actors (Clarke 2005) with particular reference to women and their families. In particular, I see women as mothers as central figures in these forms of scientific knowledge production. This is for three reasons that are further detailed in the chapters of this dissertation. First, mothers of children diagnosed with autism are central actors in the care work (Hochschild 1979; Landsman 2009; Mol 2008) of raising children with developmental disabilities in the United States. In the past several decades, this work has taken the form of everything

from everyday activities to organized advocacy efforts. Their practices shape autism both publically and privately, personally and politically.

Second, and importantly for the connections I trace between scientific practices and mothers' experiences of autism, it is women's bodies that are increasingly providing the spaces of connection between genes, environmental factors and autism. In prospective studies of autism and environmental factors, it is pregnant women whose bodies and lives have become central in the generation of knowledge. These studies connect research practices to the intimate labor (Boris and Salazar Parreñas 2010) of motherhood through their focus on fetal development and early childhood.[14]

Third and finally, in the pages of this dissertation it becomes clear how the commitments of women as mothers structure opportunities for *both* science and for children diagnosed with autism. Despite these contributions, the breadth of women's work within autism science and as mothers of children diagnosed with autism remains largely eclipsed by statistics, assumed obligations or unarticulated efforts (see Sousa 2011). While many accounts have highlighted the important role of families in scientific advocacy surrounding autism (Silverman 2011; Eyal et al. 2010; Singh 2010), the extent to which mothers are embedded in the social and *biological* explanations for autism remains largely unexamined. This dissertation positions these relationships as central to changing understandings and experiences of autism.

Considering the Literature: Bio/Social Ways of Knowing

As I detail in Chapter Two, genetic understandings of autism have dominated scientific thinking in the field since the 1970s. Considerations of and scientific

[14] I discuss these connections further in Chapter Two.

investments in research exploring the role of environmental factors in autism are situated within this history. For example, across my interviews with scientists, advocacy leaders and mothers of children diagnosed with autism, the environment was often defined as 'everything but genes,' and environmental factors characterized as 'triggers' that influenced pre-existing genetic vulnerabilities.[15] Because the environment is always already defined in relation to genetics, I provide an overview below of social science scholarship that considers how genetics, genomics and post-genomics have shaped and are shaped by understandings and experiences of health and illness. This scholarship offers tools for considering the emergence, practices and relationships engendered by prospective autism gene-environment interaction research. This is followed by a section on "Biomedicine, Risk and Life Itself," perspectives related to "Public Participation in Science" and literature addressing the theme of "Motherhood in the Post-Genomic Era."

The New Genetics, Genomics and the Post-Genomic Era

Genetic sciences have motivated significant social science attention over the past several decades (see Tutton and Hallowell 2009 for a review), and especially since the launch and completion of the Human Genome Project (HGP). This attention is well documented in scholarship addressing "the new genetics" (see Conrad and Gabe 1999; Finkler et al. 2003) and in accounts that detail the meanings and actions related to genetic knowledge (Rabinow 1992; Fujimura 1996; Wailoo 1997; Rapp 1999; Kay 2000; Shostak 2003; Silverman 2004; Kerr 2004; Lindee 2005; Reardon 2005; Gibbons and Novas 2008; Taussig 2009). These include detailed accounts of how social, scientific and

[15] In commentaries, articles and reviews, as well as during my interviews, individuals often described the causes of autism using statements such as the following: "if genetics load the gun, then the environment pulls the trigger." This and similar descriptions always struck me as strange and unnecessarily violent.

medical landscapes are configured by and come to shape experiences of risk and responsibility related to health and illness (Rapp 1999; Finkler 2001; Lock et al. 2006; Lock et al. 2007), and sociological and anthropological accounts that highlight the complex nature of these changing relationships and experiences. Together, these accounts reflect how genetic ways of knowing and the "gene" itself have become flexible objects whose meanings and interpretations are co-produced (Jasanoff 2006; Niewöhner 2011).

Several analytic approaches articulate distinctions within social science and science studies perspectives on genetics and medicine in particular. The first is most closely aligned with the notion of "geneticization" (Lippmann 1991). This concept describes "the ongoing process by which differences between individuals are reduced to their [DNA] codes, with most disorders, behaviors and psychological variations defined, at least in part as genetic in origin" (Lippmann 1991:19). Applications of this approach have largely concentrated on the consequences of genetics for medicine and experiences of illness (Conrad and Gabe 1999; Fox-Keller 2002). For example, in their review of sociological work on the new genetics, Conrad and Gabe (1999:1) argue that a "rising genetic paradigm" is "influencing how we think about life, including disease and disability, human capacities and failings, social problems, kinship and the quality of life" (Conrad and Gabe 1999:3). Additional scholarship taking up the concept of geneticization has explored how scientific approaches and new technologies shift our cultural and individual understandings and experiences of 'choice' (Parsons and Atkinson 1992, 1993), and cultural representations of genes (Duster 1990; Nelkin and Lindee 1995; Shakespeare 1995; Conrad and Weinberg 1996; Conrad 1997). While the concept of geneticization emphasizes genetic determinism, other analyses have highlighted the more

nuanced, complex and multiple ways that genetic knowledge becomes meaningful in local sites and situations.

A second analytic approach highlights the multiple ways that genetic information is employed and negotiated in clinical settings (see Latimer et al. 2006; Rabeharisoa and Bourrett 2009). Through their concept of "bioclinical collectives" Rabeharisoa and Bourrett (2009:693) detail how collectives both within and outside of the clinic negotiate the medical relevance and biological significance of genetics for patient care. Rather than affirming the process of geneticization, these findings instead reflect the complex ways that genetic information is evaluated both within and beyond the clinic, where both phenotypic and molecular observations inform one another and co-constitute clinical practices. Latimer also examines how the clinic (Latimer 2012) and the body (Latimer 2007) become central figures in family and medical negotiations of the meanings of genetics, arguing that medical dominance over reproduction is being reconstituted through genetics. Still other scholarship, (Heath, Rapp and Taussig 2004:152) highlights something pivotal about genetics and genomics: that it is "both productive, and productive of resistance." This work signals how genetics is called upon, remade and cast aside in complex ways that shift understandings and experiences of the self, family and illness (see also Finkler 2000). The unique ways that this takes its shape is also illustrated in earlier scholarship comparing lay, scientific, and clinical perspectives on genetics (see Richards 1993, 1996; Kerr et al. 1997, 1998), as well as work taking up the concept of biosociality (Rabinow 1992, 2008; Gibbons and Novas 2008). Many patient movements also explicitly challenge genetic characterizations of disease, fostering more critical

analyses of the impacts of environmental factors for health and illness (e.g. Brown et al. 2004).

Alongside these two areas of scholarship is recent work concerned with the changing character of genetic sciences per se. This literature critically explores genomics, changing models of disease, and clinical conditions that characterize what has been deemed the post-genomic era (Ommen 2000; Rajan 2006). The concept of the post-genomic era signals a shift from Mendelian models of disease that characterized early genetics, to those emphasizing the complex relationships among "non-genetic" factors and genes in the etiology and progression of common, complex diseases including cancer, heart disease, diabetes and psychiatric conditions, among others. The post-genomic era also signals the changing character of scientific knowledge practices following the HGP.

These technological and methodological shifts in the landscape of common, complex disease research have also raised questions about the effects of environmental factors and epigenetic changes in disease progression and etiology. These questions have been accompanied by technological innovations and new approaches in the collection, analysis, and interpretation of data, including DNA microarray analyses, genome wide association studies (GWAS), exome sequencing, and increased attention on the epigenome and toxicogenomics (see Shostak 2003; Shostak 2005; Fortun and Fortun 2005). Social science scholarship addressing these changes explores how complex models may reproduce, shift or alter understandings of risk and what constitutes medicine and prevention (Landecker 2011). This scholarship also considers how the post-genomic era may usher in old and new questions about time, the body and vulnerability when it

comes to health and illness (Lock et al. 2006; Lock et al. 2007; Beck and Niewöhner 2006; Shostak 2010). It is to these recent conversations that my analysis of autism science, uncertainty and care, contributes.

Importantly, these analytic approaches have not supplanted earlier social science perspectives on genetics or the environment, but rather offer changing perspectives on the shape of contemporary biosciences. Of particular interest in this dissertation are how these more general shifts in research on health and illness have taken form within the fields of autism science, and the intersections of these with family experiences. To this end, I consider the multiple levels – from the social to the molecular (see Beck and Niewöhner 2006) – where relationships between bodies and environments are being constructed, and examine the unique practices that constitute these relationships. Below, I consider some of the empirical and theoretical accounts that provide tools for considering prospective research on autism, genes and the environment.

Biomedicine, Risk and Life Itself

Clarke and colleagues (2010) define biomedicalization as "the increasingly complex, mulitsited, multidirectional processes of medicalization that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine" (Clarke et al. 2010:46). Through illustrating the interconnected nature of scientific knowledge production, biomedical classification, risk and surveillance, biomedicalization offers a unique lens through which to view contemporary autism science. The theory builds on the concept of medicalization, which describes how the jurisdiction of medicine has expanded to redefine moral, social, or legal problems as medical (e.g., Zola 1972; Conrad and Schneider 1980). While

medicalization is indeed intensifying, the authors contend that it is doing so "in new and complex, usually technoscientifically enmeshed ways" (Clarke et al. 2010:46).

Clarke and colleagues (Clarke et al. 2010:46) state that the "bio-" in biomedicalization signals the transformation of both the "human and nonhuman made possible by technoscientific innovations such as molecular technology and genomization." These innovations also underscore approaches in the study of gene-environment interactions explored in this dissertation. Describing one of the five processes of biomedicalization – the "focus on health, risk and surveillance" – the authors state that "health itself and the proper management of chronic illnesses are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help and biomedical goods and services" (Clarke et al. 2010:62). As I point out in this dissertation, the intensifying regimes of participation *in science* have also become an extension of the focus on health, risk and surveillance and a means of caring for the self and others. In this way, as the authors contend, "risk and surveillance mutually construct one another" (Clarke et al. 2010:63).

This dissertation, in many ways, is a case study of biomedicalization: an in-depth analysis of how one particular area of science emerged at a particular time, and its local meanings as related to classifications of autism and experiences of contemporary motherhood. In particular, this study highlights the increasing technoscientization of everyday life, from the surveillance of childhood behaviors (as illustrated in Chapter Four), to the comparisons of bodies and embodied experiences that situate the complex and diffuse knowledge of autism risks (addressed in Chapter Five). Importantly, my

analysis contributes to the focus on health, risk and surveillance an emphasis on care practices, which become primary in mothers' relationships with autism and gene-environment interaction science (see also Silverman 2011).

The enmeshing of technoscience and biomedicine highlighted in the theory of biomedicalization is also reflected in Rose's work on "life itself." Rose (2007:5) considers his project a "preliminary cartography of an emergent form of life, and a draft of a history of the potential futures it embodies." Building on Foucault (1973), he argues that this emergent form of life involves five specific 'mutations': molecularization, optimization, subjectification, somatic expertise, and economies of vitality (Rose 2007:5-6). For Rose, these mutations reflect a "style of thought" (Fleck 1935) that involves new ideas of what human beings are, can do, and should hope for. Though all five mutations are potentially at work within contemporary autism science, I focus on subjectification and its relationship to "somatic ethics" here. These concepts provide tools for thinking through the relationships between risk, surveillance and participation in science (further detailed below).

Rose argues that *subjectification* reflects novel relationships with the self and the emergence of what he calls "somatic ethics." Somatic ethics reflects how health and wellbeing are increasing enrolled in our ethical and moral choices as individuals. Rose contends that these choices involve perceptions and experiences of risk that are intimately bound up with forms of biological knowledge. The concept of somatic ethics therefore involves "a new informed ethics of the self – a set of techniques for managing everyday life in relation to a condition, and in relation to expert knowledge" (Rose and Novas 2005:450-451). Rose describes how individuals increasingly consider and interact

simultaneously with personal, corporeal, and expert knowledge in their thinking about themselves, their families and their future, often taking on forms of activism and responsibility in light of new biological understandings of the body.

In this context, Rose (2007) argues, contemporary risk politics increases the obligation that individuals act toward their own imagined future in the present, and with hope for the future. This obligation now permeates understandings of self and others. These complex obligations resonate in practices surrounding autism, where early intervention efforts call on parents to monitor their children's development in order to intervene at earlier time periods, influencing neural pathways to establish new patterns of behavior from the outside in. Following diagnosis, myriad treatment options and the necessary tinkering they require, position parents and other carers as experts in their children's symptom management and treatment regiments (as I describe in Chapter Four). Importantly though, these practices become more than means of surveillance. As I argue in Chapter Three, they become forms of *care*. This emphasis reveals the affective dimensions of somatic ethics, a feature highlighted in feminist accounts (see Chapter Three and Silverman 2011) and in the history of autism and parent advocacy (see Nadesan 2005; Eyal et al. 2010; Silverman 2011). This history sits within a larger field of studies emphasizing forms of collective action and identity related to biological knowledge and science, to which I now turn.

Public Participation in Science

Over the past several decades, scholars have turned their attention toward the role of social movements (Brown et al. 2004), collective efforts (Epstein 1996, 2008) and citizen action in the sciences that surround health and illness. Since the 1980s in

particular, there has been upsurge in citizen activism and political inventiveness around issues of health and illness (Rose and Novas 2005:452). Understanding this sea change is particularly important for this dissertation because of its relationship to the emergence of autism gene-environment interaction research (as I detail in Chapter Two), and due to the critical role of parents of children with autism in changing social and scientific understandings of the condition (Silverman 2011).

Co-Producing Scientific Knowledge

Public participation in science has been defined as, "the diversified set of situations and activities, more or less spontaneous, organized and structured, whereby non-experts become involved, and provide their own input to, agenda setting, decision-making, policy forming, and knowledge production processes regarding science" (Bucchi and Neresini 2008:449). This phenomenon remains emergent. Its boundaries – in particular between experts and non-experts – remain in formation. At its roots are core sociological questions about how we come to value and define knowledge and its meanings in science and society.

While past theoretical perspectives considered expert and lay understandings of science as distinct and separate, with experts exhibiting advanced understandings of science and lay perceptions at a deficit,[16] recent work emphasizes knowledge production

[16] Studies and theorizing on public participation in science has seen heightened attention in recent years in part in response to critiques launched at the public *understanding* of science model, also called the 'deficit model'. Bucchi and Neresini (2008:450) note that critics including Wynne (1991, 1995) and Michael (2002) argue that this model "emphasized the public's inability to understand and appreciate the achievements of science." While more recent studies (Callon et al. 2001; Jasanoff 2005) have promoted a co-production model for studying and understanding the construction of both public and scientific knowledge, former programs and studies were largely based on improving what was perceived as the public's 'deficit' and such work continues today. Such research operates under three general assumptions (Bucchi and Neresini 2008): first, that *public understanding of science* largely coincides with *scientific*

as both locally situated and socially and culturally contingent for experts *and* lay individuals alike. This perspective, known as "critical/interpretative public understanding of science" (Wynne 1995; Michael 2002), reinterprets the gap between lay and expert knowledge as one of location, rather than deficit. Building on this concept, Michel Callon (1999) has called for a more substantial shift to a model of knowledge "co-production" (see also Jasanoff 2005), which views lay and expert knowledge as mutually co-produced and continually under construction (Jasanoff 2005; Callon and Rabeharisoa 2008). Co-production also reflects an increasing demand by organized groups of citizens for "closer involvement in decisions concerning the development of research and technical-scientific innovation" (Bucchi and Neresini 2008:454). While there have long been patients' organizations and support groups, today such groups are much more likely to form direct alliances with scientists (Brown et al. 2004; Rose and Novas 2005; Heath, Rapp and Taussig 2004), and to be central in formations of scientific knowledge. This is in part because of the roles that scientific research and innovation have come to play in constructing personal experiences and social action related to illness, a theme I turn to next.

Biology and Belonging: Biosociality and Forms of Citizenship

Rose's (2007) notion of the "collectivizing moment" of biological citizenship reflects what Rose and Novas (2005) describe as the active role some patients and patient

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literacy (Layton et al. 1986); second, it assumes that once scientific literacy is achieved, it will guarantee positive public attitudes toward science and technological changes; and finally, the tendency to problematize only the public side of the "science and public relationship" (Bucchi & Neresini 2008:450). All these assumptions have been heavily critiqued since the early 1990s, with critics calling for more in depth analyses of the processes involved in *both* scientific and public knowledge about science, rather than merely viewing public understanding as "an impoverished or quantitatively inferior version of expert knowledge" (Bucchi and Neresini 2008:451).

groups now take in shaping the direction of science in relation to both their *experience* of biological information (or as the result of diagnosis) as well as their *hopes* for the treatments and cures it may provide (see also Epstein 2007). This collectivizing spirit has played a significant role in the changing character of autism science (see Silverman 2011), therapeutic relationships (see Eyal et al. 2010) and the meanings of biological information (see Singh 2010). This spirit is also expressed in Heath, Rapp and Taussig's (2004) concept of "genetic citizenship." This concept describes emergent networks based in part on genetic science and shifts within the public sphere that give rise to "new forms of democratic participation, blurring the boundary between state and society, and between private and public interests" (Heath et al. 2004:152). These include direct partnerships between lay disease groups and scientists. Heath, Rapp and Taussig (2004:152) argue that as more and more human, and human health, differences are being understood as "genetically influenced or controlled," forms of citizenship oriented around those distinctions are gaining salience. The many manifestations of these collectivities and their strategies for action, however, illustrate the complex ways that "difference" comes to matter for collective action (Heath et al. 2004:152). This can be seen in collective efforts on the part of autism self-advocates, as well as parents of children with autism and their allies. In each of these instances biological and social experiences of autism are made meaningful in relationships to social conditions. These help to shape both the need for and the targets of collective action (Shakespeare 2006).

Providing an additional example of the intersections of science, illness and citizenship, Petryna (2002) details how biological citizenship can "embody a demand for particular protections, for the enactment or cessation of particular policies or actions,

or… access to special resources" directly related to corporeal experiences. Her research charts how post-Chernobyl sufferers use the calculus of risk to construct particular physical, psychological and medical identities and histories for themselves in order to receive compensation from the state. Her work illustrates how corporeal experience serves as one basis for citizenship claims, a theme echoed in Brown and colleagues conceptualization of embodied health movements (EHMs). This concept highlights the critical role that embodied experience and claims about environmental causation play in collective participation in science. The concept of embodied health movements (EHMs) (Brown et al. 2004) provides a particularly useful example of public participation in science and one that underscores forms of advocacy related to the environment that I discuss in Chapter Two.

Brown explains that EHMs are based on "the emergence of a collective identity as a mobilizing force," one that relies heavily on the knowledge garnered from embodied experience (Brown et al. 2004:55). Further, these movements form when individual, embodied disease experience meets the limits of medical and scientific explanations. Thus, "embodied health movements address disease, disability or illness experience by challenging science on etiology, diagnosis, treatment and prevention" and EHMs include 'contested illnesses' that are "either unexplained by current medical knowledge or have purported environmental explanations that are often disputed" (Brown et al, 2004:52). As a result of their relationships to environmental causation, and the engagement of individuals with science on the basis of their own "intimate, firsthand knowledge of their bodies and illness" (Brown et al. 2004:56), EHMs provide a particularly useful

framework for thinking about public engagement in science related to autism and the emergence of gene-environment interaction research.

Motherhood in the Post-Genomic Era

Finally, I want to consider how motherhood has been taken up in relation to the biomedical shifts considered above. In particular, this project is engaged with literature grounded in feminist and cultural studies of science, medicine and contemporary motherhood (see Hays 1996; Landsman 2009). Within this field, I am interested in contributing to scholarship that explicitly considers the medicalization of motherhood (see Armstrong 2003; Waggoner 2011), and studies of pregnancy as a time of intense medical and social meaning when surveillance of women's bodies is heightened (Casper 1999; Armstrong 2003). These and other feminist accounts consider the intersections of the body, medicine and science, thereby troubling assumptions of 'choice' and 'control' that permeate American reproductive culture (Rapp 1999; Armstrong 2003).

For example, Rapp's (1999) *Testing Women, Testing and Fetus* provides an exemplar of changing relationships among technology, the body, and choice related to reproduction, and offers one lens through which to consider experiences of contemporary motherhood. Rapp offers an ambitious and thoughtful account of women's experiences of amniocentesis that challenges any simple understanding of science, technology or the body. Rapp details how amniocentesis – a form of prenatal genetic screening – becomes imbued with the power of "positing the genetic future" (Rapp 1999:306) in ways that shift and change women's experiences of pregnancy and how 'choices' about fetal and personal/familial futures are constructed.

As amniocentesis has become commonplace, the possibilities of this knowledge presents pregnant women with inescapable choices that must be made about their fetuses, families and the future. 'Choice' becomes both a burden and a freedom in the particularly gendered and embodied experience of pregnancy and during decisions of whether to abort an affected fetus. Rapp (1999:222) identifies this as the "forced choice" brought upon by amniocentesis. Rapp (1999:306) argues that women become "moral pioneers" and "our moral philosophers of the private." In particular, the women in Rapp's study are pioneers because,

> in their relation with their bodies, with their choices, with experts, with others in analogous situations, and with their destiny, they must shape new ways of understanding, judging, and acting upon themselves, and must also engage in a kind of re-imagining of those to whom they owe responsibilities – their progeny, their kin, their medical helpers, their co-citizens, their community, their society (Rose and Novas 2005:450) .

As Rapp and many others have now made clear, this 're-imagining' is always, already social. It is structured in relation to the information and new technologies of intervention make possible as well as each individual's particular familial, community and personal histories and their hopes for the future.

In both the public discourse and scientific research on autism, motherhood has been central. Beginning with psychogenic theories that blamed "refrigerator mothers" for their children's autism (Bettelheim 1963), mothers have historically been saddled with responsibility for autism, and often ridiculed for their advocacy (see Offit 2008 on vaccine concerns). A poignant article charts what Sousa (2011) calls "the cultural identity transformation of mothers raising children with intellectual disabilities." This article describes a transition from an image of mothers as "refrigerator mothers" to that of "warrior-heroes" (p.220). Citing Sharon Hays (1996), Sousa reflects on the paradigm of

"intensive mothering" wherein today's American mothers are "expected to devote limitless time, energy, and resources to their children's development," often leaving their own self-interest by the way side while raising children with intellectual disabilities (Sousa 2011:220). Through a discourse analysis of mothers' published memoirs, Sousa argues that the cultural image of such mothers has become one of "warrior-heroes" who wage "battle against social and political forces to gain medical and educational interventions for their children despite the high personal and financial costs to themselves and their families" (Sousa 2011:221). My analysis of mothers' experiences of autism diagnosis (Chapter Three) and autism risk (Chapter Five) resonates with Sousa's findings. Such broader cultural narratives also help condition mothers' relationships to autism science.

Positioning these responsibilities and their effects within the context of reproduction, Landsman (2009) notes that the cultural obsession with the "perfect baby" further implicates mothers of children with disabilities. She notes the pervasive ways that "choice" and "control" orient experiences of pregnancy:

> Reproduction in North America is saturated in the discourse of choice and control. Widespread availability of prenatal screening tests, selective abortion for disability, new conceptive technologies, publicized breakthroughs in knowledge of genetics, and the broad dissemination of health information about what women should consume and how they should conduct themselves during and even before pregnancy to ensure a 'good' outcome frame the contemporary American experience of procreation (Landsman 2009:3).

Landsman, herself the mother of a daughter with a disability, provides a feminist anthropological analysis of "mothers' ongoing reinterpretations of disability" following their children's diagnosis (2009:3). She writes that, "the potential disabled baby imagined by a pregnant women as she contemplates prenatal screening is… the 'Other'." However,

"for a *mother* of a child newly diagnosed with an impairment, the 'Other' is neither hypothetical nor located in an exotic, distant land… the Other is—sometimes quite suddenly—a member of the family" (emphasis in original, Landsman 2009: 3). Her account of "reconstructing motherhood" insists on hearing mothers as experts on their own lives and experiences, a most useful approach in my project.

In the sections above, I have considered how social science scholars have approached genetics and the useful tools provided in theories of biomedicalization (Clarke et al. 2010) and "life itself" (Rose 2007). I pointed to the focus on health, risk and surveillance as a particularly salient nexus for thinking about the emergence, practices and consequences of autism gene-environment interaction studies. Further, I considered how studies of public participation in science, health social movements and collective identities forged through biological forms of knowledge, provide important context for understanding the practices and politics of autism science today. Finally, I considered motherhood and its intersections with science, technology and disability in the post-genomic era. These sections provide an overview of approaches from which I draw inspiration and on which my analysis pivots. Below, I discuss the methods I employed in my research.

Methods

Following the Science

This dissertation focuses on the emergence, practices and consequences of research on autism and gene-environmental interactions. This includes their infrastructures, logics, practices and the relations they engender. It also explores the social situations in which they developed as projects and how they are productive of not

just knowledge about autism, but shifting relationships of anticipation, expertise and care. Through focusing on the production of knowledge surrounding autism's causes, my research considers the conditions of possibility that have enabled these studies. I detail the multiple actors, motivations, and meanings involved in research on the role of environmental factors in autism, how this research has come about and, centrally, the possibilities that conducting research on autism and the environment opens up for our contemporary understandings of health and illness.

The scientific research I follow throughout this dissertation is part of a larger arena of autism science that aims to understand the genetic and environmental causes of autism. The specific studies I consider are the Markers of Autism Risk in Babies – Learning Early Signs (MARBLES) and Early Autism Risk Longitudinal Investigation (EARLI). These two studies share a prospective, longitudinal design, though the scale of each study, its recruitment, protocol and research questions, are distinct. Together, MARBLES and EARLI are the first United States based epidemiological studies to prospectively study environmental and genetic causes of autism by collecting data during pregnancy and early childhood. Both studies specifically enroll women who have biological children diagnosed with autism during a subsequent pregnancy and for three years afterward. During this time, researchers collect biological and environmental samples to consider relationships between these factors and autism. These samples then become part of a large database from which multiple investigators may draw for future analyses.[17]

[17] The underlying logic of enrolling this group is also a shared characteristic of the two research studies, as well as several other international studies (ABC 2012). This logic, which I discuss in more detail in Chapter Five, reflects the up to 30% recurrence rate (i.e., the likelihood that a future child will have autism or developmental delay) in families who already have a child with autism (Constantino et al. 2010).

The scientific practices of these studies warrant sociological investigation because of their connection to uncertainties surrounding autism, the extended nature of subject participation in the studies, and their potential implications for understandings of autism causation.[18] Importantly, these studies are positioned within a larger landscape of autism knowledge production that includes scientific conferences, social and professional meetings and symposia, autism walks, fairs and information sessions, advocacy efforts and family support groups. They also sit within a vast sea of literature – both popular media and academic publications – that grapples with similar questions of cause and care that are at the core of my research endeavors. My findings are therefore informed by a network of data sources related to autism gene-environment interaction research that I detail below.

A Multi-Sited Ethnography

A multi-sited approach "moves out from the single sites and local situations of conventional ethnographic research designs to examine the circulation of cultural meanings, objects, and identities in diffuse time-space" (Marcus [1995] 1998:79). It allowed me to track multiple actors, objects, discourses, and meanings across various domains and time. Using this approach, and the analytic tools of grounded theory (Strauss 1987; Charmaz 2006) and situational analysis (Clarke 2005), I collected data

[18] As I contend in Chapter Three, it is the prolonged nature of MARBLES and EARLI that ushers in the possibility of support and exchanges of knowledge that move beyond the biological and hopeful to include both material and affective dimensions of care. Rather than a single donation, samples and assessments are collected over a series of many years. As a result, the work of participation means that women must provide samples that extend beyond their and their children's bodies, to their partners, their behaviors, their environments and their activities. And they must do so on an ongoing basis. This invites mutual entrée: for researchers, into families' lives and for participants, into the process of research. It also invites mutual responsibility: for researchers, to provide information on child developmental assessments and connections to early services if deemed necessary, and for participants, to a whole host of possible care practices whose effects remain largely uncertain. As others have described elsewhere, these conditions signal the porous boundaries between scientific research and care.

across three major research areas: literature and document analysis, semi-structured in-depth interviews; and, participant observation of research study activities, conferences, workshops, and meetings.

Literature and Document Analysis: Literature reviewed for this study includes two major groupings 1) peer reviewed articles published in science journals; and 2) non-scientific documentary materials. Peer-reviewed scientific literature was identified through joint keyword searches including "autism" and "environment" in PubMed and other large literature databases and in reference to themes that emerge as salient over the course of the study. Reviews were selected from this initial search to identify key themes and actors of interest in the field. Articles by scientists involved in the discourse on autism and the environment (including MARBLES and EARLI Network Principal Investigators, scientists with the Center for Disease Control and Prevention [CDC], and members of the Interagency Autism Coordinating Committee [IACC] and those included in reports issued by the Institutes of Medicine [IOM]) were also reviewed. 'Non-scientific' materials included advocacy organization and research study newsletters and reports, news articles and editorials, conference proceedings, public awareness campaign documents, policy documents, websites and online resources. Document analysis helped identify the elements in the wider autism "situation" (Clarke 2005) (i.e., actors, groups, technologies, locations, historical events, and discourses, critical to understanding stakeholder perceptions). These analyses included comparisons across different literatures to identify specific domains of concern and differences of interpretation in the discourse on gene-environment interaction research and autism. These analyses played a

key role in orienting my observations around MARBLES and EARLI as exemplars of prospective studies of autism risk.

Interviews: With CHR approval, semi-structured, in-depth interviews were conducted with stakeholders involved in research, risk communication, and interpretation of environmental factors and autism. Key representatives of the groups outlined below were identified through document analysis, snowball and "theoretical sampling" (Charmaz 2006). Qualitative interviews used open-ended questions to elicit more candid responses from interviewees (Charmaz 2006), and were adapted to reflect themes of interest following initial informational interviews (2007-2008).[19] Interviews lasted approximately 90 minutes with scientists and advocates, and anywhere from one to four hours with mothers of children with autism. Below I provide a brief overview of the groupings that made up interviewees for this dissertation.

Scientists: Scientists in government, academic, and clinical settings were interviewed. Initial interviews focused on the Principal Investigators (PIs) involved in the EARLI Network and MARBLES study. Others included scientists associated with other research studies and scientific programs, as well as those projects that specifically addressed environmental factors or changing agendas related to autism science. Interviewees were also recruited from the CDC, the Children's Centers for Environmental Health, The National Institute of Environmental Health Science (NIEHS), and the MIND (Medical Investigation of Neurodevelopmental Disorders) Institute. Staff members of the MARBLES study were also interviewed.

Autism Advocacy Representatives: Select representatives of national autism advocacy organizations were also interviewed for this study. Individuals were recruited

[19] Interview guides for each group are included as appendices.

from advocacy organizations including *Autism Speaks*. Many autism studies (including the EARLI and MARBLES) have scientific advisory boards that include representatives from each of these national groups.

Mothers of Children with Autism: Parents have unique knowledge of autism and have historically been at the forefront of changing public understandings and federal policy for autism and other complex diseases (Silverman 2004, 2011; Tabor and Lappé 2011). They are also critical participants in research studies on autism, as the legal guardians of minors with autism and as research participants themselves. Mothers participating in MARBLES studies were specifically recruited for my research identified through advertisements in study clinics, information fliers, and through snowball sampling methods.

Participant Observation: Participant observation was undertaken at regional, national and international conferences, workshops, and meetings. These include "Medical Approaches in Autism: Clinical Implications of Environmental Toxicology for Children's Neurodevelopment in Autism" (San Francisco, February 2008), "The 7th Annual Developmental Disabilities: Update for Health Professionals" (San Francisco, March 2008), the International Meeting For Autism Research (IMFAR) (London, May 2008; Chicago, May 2009; Philadelphia, May 2010), "Ethics of Communicating Scientific Findings of Autism Risk" (Philadelphia, October 2009), "Making Healthy Babies, Raising Healthy Children: Living Well in a Toxic World" (Berkeley, November 2009), and a smaller, invited event also titled "Ethics of Communicating Scientific Findings of Autism" (Seattle, November 2010). I also followed media coverage of autism scientific

findings and policy changes, and listened to radio broadcasts addressing debates in diagnosis and autism care (KQED 2012).

In addition, ethnographic observations were undertaken during MARBLES home and clinic visits. The first wave of observations took place from March through August of 2010. Observations at home visits were conducted with the mothers I interviewed, and coordinated with MARBLES study staff. For each, I met MARBLES staff at the participant's home and shadowed the staff as they conducted evaluations and data collection. Each of the observations lasted anywhere from thirty minutes to two hours, and consisted of various developmental assessments and data collection processes (conducted by MARBLES staff) that are elaborated in Chapter Three. These observations also provided a longitudinal element to my relationships with mothers, their children and other family members (see also Beck and Niewöhner 2006 on longitudinal designs in STS). My in-depth interviews with mothers and observations of their participation in MARBLES together provided a first hand account of participating in autism research, relationships with study staff, and research procedures.

Data Analysis

All interviews were audio recorded (as permitted) and transcribed verbatim. Field notes were taken following all interviews and during participant observation. Data, including interview transcripts, field notes, and documents were analyzed using the principles of grounded theory (Glaser and Strauss 1967; Strauss 1987; Strauss and Corbin 1998; Charmaz 2006) and situational analysis (Clarke 2005). The method of grounded theory includes a process for sampling, a systematic method for making comparisons, and

the use of a coding system, to ensure objective development of concepts and theories (Charmaz 2006; Strauss 1987).

Situational analysis, developed Clarke (2005) extends the principles of grounded theory to include documentary materials and discourse analysis more ambitiously. Situational analysis has been explicitly useful in studies of controversy (Clarke and Star 2007) as it involves strategies for "mapping" individual actors, collective groups, discourses and debates, political and economic elements, technologies, key events, and cultural and visual elements in order to recognize, compare, and contrast the multiple perspectives and elements affecting a situation (Clarke 2005:xxix). These strategies are ideal analytical tools for multi-sited research of complex topics because analysis is ongoing throughout the research. Techniques enable the researcher to identify sampling needs for range of variation and to identify specific issues of importance in the data.

Dissertation Overview

In Chapter Two, "Constructing the Environment in Autism Science," I trace the emergence of gene-environment interaction research on autism. I argue that, through building alliances across lay and expert communities, parent concerns about the rising number of autism cases in the United States garnered both political and scientific support for research on the role of environmental factors. These facilitated what I deem "networks of concern." These included parents, policy makers, scientists and program officers across an expanded number of disciplinary fields and social domains. The chapter describes how recent shifts in understandings of autism genetics and these (sometimes uneasy) alliances extended specific questions about the environment that were closely aligned with vaccine concerns into a broader research agenda focused on the

interactions between environmental factors and genetics. This produced autism as a field of study commensurate with other chronic complex diseases, enabling the recruitment of scientists from fields such as cancer epidemiology and birth defects research into the fields of autism science. This provided the impetus, and forms of expertise, for longitudinal studies focused on gene-environment interactions during critical developmental windows, including pregnancy and early childhood development. Finally, this chapter considers how questions taken up by studies like EARLI and MARBLES resituate autism risk both temporally and spatially.

In Chapter Three, "Building Resources and Taking Care," I detail how prospective epidemiologic research on autism becomes meaningful to participants and scientists as both an investment in future understandings of autism, and as a form of support for participating families. In these ways, this model of autism research provides an infrastructure for building scientifically grounded relationships between nonhuman actants and autism as a disease category, and an opportunity for human relationships that offer care and understanding within conditions of uncertainty that surround autism.[20] I argue that what is produced through these studies is much more than knowledge about autism, it is a network of relationships that includes new ethical dimensions of mutual care and support, as well as resources for future questions about autism's connections with the environment, genetics and time. Care, I contend, thus becomes a central component of these studies; forms of care enable ongoing commitments both by families and researchers, as well as becoming a resource for the studies themselves. This chapter also considers mothers' participation in research as a form of affective labor, and the

[20] As I describe in Chapter Three, these actants include toxins, drugs, genes, immune markers, brain images and behavior, among others.

implications of this work for science and family life.

In Chapter Four, "Diagnosis and Transformation," I describe mothers' experiences of their children's autism diagnosis. In doing so, I trace diagnosis as both a label and an affective experience for mothers. I argue that the process of autism diagnosis recasts childhood behaviors as symptoms, and reorients mothers' identities as uniquely qualified advocates for their children. My analysis draws connections between the social and scientific experiences of autism diagnosis, and their consequences for mothers' individual and collective identities. I describe how diagnosis becomes an obligatory passage point (Callon 1986; Latour 1987) in mothers' participation in the larger autism community, and as potential participants in autism research. This chapter builds on and contributes to the scholarship in the sociology of diagnosis by highlighting the temporal qualities of diagnosis and its unfolding meanings over time (Bury 1982; Williams 1984).

Chapter Five, titled "Finding Cause" follows mothers through their experiences as research subjects as they prepare to have another child. Here, I reflect on how causal explanations for autism and prevention practices are informed through mothers' understandings of their affected child's condition, their own actions, and their hopes for the future. I argue that mothers' experiences of autism risk and prospective gene-environment interaction research are situated within a larger social and scientific process I call "finding cause." This concept frames how participation in research becomes one of many strategies mothers take up in navigating autism and negotiating the meanings of many *possible* risks. I argue that their experiences are situated within a discourse of proliferating risk factors, which encourages them to critically consider their own bodies and actions and the bodies their children in order to establish *what* is risky and *when*.

In Chapter Six, "Concluding Thoughts and Implications for the Field," I offer an overview of key findings in this dissertation. In doing so, I consider how risk and illness are increasingly taken up as sites where uncertainty and responsibility are negotiated and stratified in society, and the potential consequences of autism GEI research for thinking about the relationships between bodies, histories and potential futures. In this final chapter, I address the limitations of this project and the implications of my findings for sociology, medical sociology and science and technology studies. I also present several areas for future research based on my findings to date.

CHAPTER 2:
CONSTRUCTING THE ENVIRONMENT IN AUTISM SCIENCE

I feel like we're still dealing with a mystery wrapped in a riddle here… which gives me the luxury of having a position that's kind of like "Well, I'm not sure." I say that a lot.
(Chronic Disease Epidemiologist).

We were talking about the chapter on [autism] risk factors… and somebody else pointed out "I don't think that's even a reasonable question anymore – whether *there are – it's* what are *the environmental influences." And, wow, that means we've come a long way*
(NIEHS Funding Officer).

In this chapter I argue that autism science related to the environment has shifted in two ways in recent years. These shifts are changing how autism and autism risk are located and acted upon by scientists and policy makers. The first shift I describe is from a dominant focus on genetics to an emphasis on the salience of gene-environment interactions in the etiology of autism. The second shift is from a focus on the impact of specific environmental factors – most prominently vaccines – to the environment as a broad category encompassing *everything but genetics*. I argue that together these shifts have extended autism into new and more expansive domains, situating autism risk simultaneously within and beyond the body. In detailing these shifts in thinking and practices related to causal understandings of autism, this chapter sets the stage for the analysis of interactions among autism science, research practices and family experiences detailed in later chapters. Here, I describe the events and alliances that facilitated increased research on gene-environment interactions and autism. In particular, I consider

what ideas and practices related to autism and the environment reflect about changing complex disease science, stakeholder interactions, and family experiences of autism.[21]

The first shift I describe is from a dominant focus on autism genetics to a research agenda emphasizing gene-environment interactions. This shift involved changing understandings of autism from genetically caused to a condition that has multiple causes (Herbert et al. 2006; Happé, Ronald and Plomin 2006). This shift in causal emphasis is connected to changes in the social and scientific classification of autism (see Singh 2010; Eyal et al. 2010), changing technological and scientific approaches in the study of complex disease etiology, and a history of parent involvement in autism science (Orsini 2009, Singh 2010, Silverman 2011).[22] As I detail below, the turn toward autism genetics that began in the 1960s originally offered a causal paradigm that focused on the inborn nature of the disorder as an alternative to the widely held theory that "cold mothering" caused autism (Bettelheim 1967). Since the 1990s however, heritability estimates established during early genetics studies (Folstein and Rutter 1977) have been revisited and new theories developed to suggest that autism is much more biologically complex than originally thought (Happé et al. 2008; Newschaffer et al. 2007; Hertz-Picciotto et al. 2006).[23] While autism genetics continue to dominate research funding related to the etiology of the condition, changing understandings of autism as a disease category, coupled with the politics of knowledge production that I detail in this chapter, produced the conditions of possibility for studies on the *interactions* between genes and

[21] The two shifts described in this chapter are by no means totalizing. While these shifts have influenced the character of research on autism and the environment, these areas of science and their consequences remain in formation, with many possibly futures (and additional pasts) not detailed here.
[22] Autism self-advocates have also influenced autism science, most prominently in calling for researchers to recognize neuro-diversity and the continuum of human experience that autism reflects.
[23] The relationships between autism genetics research and social and diagnostic change, have been well documented elsewhere (see Silverman 2011; Eyal et al. 2010; Singh 2010).

environmental factors. This has become a site of intensifying focus in autism science that is reshaping understandings of autism as a disease category and social experience.

The second shift I describe focuses on the politics of knowledge production related to the environment within autism science. I illustrate the shift from a focus on *specific* environmental concerns, mainly the connection between vaccines and autism, to questions about the possible impact of a *broad* range of environmental factors for the etiology of autism. This shift was facilitated by two simultaneous and interacting processes: rising public concerns about autism's increasing prevalence in the population, and significant parent advocacy efforts that sought out and established alliances with autism scientists and policy makers in the name of environmental causation (see Brown et al. 2004 on environmental causation and contested illnesses).[24] I detail how this combination of questions of cause and alliance building created the conditions of possibility (Foucault 1973) for a new approach to understanding autism, in part as a result of the public health crisis evoked by the notion of an autism epidemic.

Tracing this second shift, I explore how specific concerns about the link between vaccines and autism – largely launched by parents of children diagnosed with autism – became refocused into a broad agenda, extending *both* environmental *and* genetic research on autism. Funding from the National Institutes of Environmental Health Sciences (NIEHS) supported this new area of scientific research, in large part as a result of pressure placed on the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) by parent groups (Kirby 2005; Lawler 2008). This led to the recruitment of scientists from outside autism research. The resulting initiatives had

[24] These advocacy efforts are described in detail in David Kirby's (2005) "Evidence of Harm. Mercury in Vaccines and the Autism Epidemic: a Medical Controversy."

the effect of folding concerns about vaccines into a broad research agenda focused on a range of environmental factors *and* their interactions with genetics. The result was a reorientation of questions of cause that encompassed parent concerns about expertise and jurisdiction over child wellbeing under the broad banner of gene-environment interactions.[25]

These simultaneous shifts from a dominant focus on genetics research to attempts to explore gene-environment interactions, and from questions about specific environmental factors to research on a broad range of possible environmental contributions, have accompanied – and in turn come to effect – changes in the organization, practices and priorities of autism science. This matters, I argue, because it reflects a qualitative change in the "problem" of autism from one located most exclusively *within* bodies and traceable through the language of heritability, to one that is always, already multiple, simultaneously *within, between* and *beyond* individual bodies and critically informed by *timing*. This reframes the possible "solutions" related to autism to include expanding domains of expertise and areas of risk considered scientifically meaningful for the condition.[26] This change has ushered in new relationships among research participants, advocates and scientists (see also Epstein 1995, 1996). It has also reoriented how answers to questions surrounding the disorder are produced. This is significant because expanding research on the etiology of autism into the environment offers the potential for responses that include broad public policies as well as personal

[25] Far from ameliorating concerns about vaccines and autism, gene-environment interaction research reflects just one site where questions of autism's cause are being constructed. For further details on the impacts of vaccine controversies on autism research see Wadman 2011 on the formation of the *Autism Science Foundation*. In many ways, my interviews with mothers, scientists and advocates positioned the prospective cohort studies I discuss later in this dissertation as strategically agnostic on many of these questions.

[26] How these areas of risk are produced and taken up by mother participants in autism research forms the basis for Chapter Five.

prevention strategies (Shostak 2003; Brown et al. 2004). As Shostak has argued elsewhere (2010:243), "by constituting new categories of people at risk, molecular epidemiological research creates new opportunities for biomedical surveillance and intervention, self-monitoring, and regimens of behavior change."

Below, I describe the dynamics behind these changing approaches in the study of autism etiology, charting how specific questions of cause were extended into support for the study of environmental factors broadly construed. I then detail how efforts to extend the environment required the recruitment of scientists from other complex research disease fields, producing a new area of research on autism. This sets the stage for new approaches in the study of autism that situate the environment as *internal as well as external*, with ongoing consequences for autism researchers and for family experiences of the condition. The chapter concludes with an overview of prospective cohort studies, an exemplar of these directions in autism research. My ethnographic observations of one such study, the "Markers of Risk in Babies – Learning Early Signs" (MARBLES) study, inform the remaining chapters of the dissertation.

The Productive Potential of Uncertainty

Changing Understandings of Cause

Social and scientific understandings of autism have changed dramatically since Leo Kanner's initial explanation of autism in 1943, which dwelled largely in the jurisdictional domain of psychiatry. Despite Kanner's (1943) assertion of the condition's inborn nature, autism's cause was predominately understood at that time as "a syndrome of ego damage resulting from unconscious parental rejection" (Silverman and Brosco 2007:393). This interpretation was epitomized by the "refrigerator mother" hypothesis

popularized in Bruno Bettelheim's (1967) book *The Empty Fortress: Infantile Autism and the Birth of the Self.* The theory suggested that it was a mother's inappropriate, cold and distant parenting that forced children into their own world, causing the symptoms understood as autism (Orsini 2009; Nadesan 2005). Bettelheim's theory and related treatment generated parental stigma associated with the diagnosis, especially for mothers. Despite being debunked, this theory had lasting effects, and also served as a catalyst for parent advocacy and shifting understandings of autism, that continue to this day (Clairborne Park 1967; Eyal et al. 2010; Silverman 2011).

During the 1960s, autism began to be interpreted as a neurological disease of biological origin. Largely due to the work of scientist Bernard Rimland (1964), himself the parent of an autistic child, and other parent and self-advocacy efforts (see Silverman and Brosco 2007; Eyal et al. 2010; Silverman 2011), this framework began to shift research efforts to explore autism's cause from family psychology and psychiatry to the life sciences. During this period, new frameworks also began to provide increased insight into the etiology of autism from genetic perspectives. In 1977, the first study indicating a high concordance of autism among monozygotic twins was published (Folstein and Rutter 1977), followed by supporting studies that indicated strong genetic components of autism (see Rutter 2000; Muhle, Trentacoste, Rapin 2004). These studies collectively characterized autism as the most heritable psychiatric condition, with estimates as high as ninety percent (Hallmayer et al. 2011). These original twin study estimates generated considerable fiscal support and enthusiasm for genetics research (Rutter 2000), supporting advances in genetics, including extensive investigations using traditional methods of behavioral genetic analysis (including family, twin and adoption studies),

quantitative trait loci (QTL), and biometric model fitting.

The Possibilities and Limitations of Genetics

Autism genetics research has played an important role in complex understandings of autism etiology within the scientific community today. Scientists I interviewed remarked that in many ways, the advances and limitations of autism genetics research created the opportunity for research exploring the role of environmental factors and gene-environment interactions. To date, identified genes or gene combinations (defined mutations, genetic syndromes and *de novo* CNV) account for only approximately 10-20% of autism cases (Abrahams and Geschwind 2008). In the wake of these limitations (Weiss et al. 2009), scientists have argued that, rather than reflecting a single disease, autism provides a common label for what are likely "hundreds or thousands" (Collins 2009) of distinct diseases (Szatmari 1999), each with their own distinct etiologies. In this way, the challenge of locating a gene (or genes) "for autism" became attributed to the complex phenotypic and multi-causal etiology of the condition (see Singh 2010; Engel and Daniels 2011). This has prompted new research strategies focusing on rare mutations, genome wide association studies, and exome sequencing (among others) (Abrahams and Geschwind 2008), and studies exploring the role of environmental risk factors as well.

Several researchers I interviewed explained how the limitations of genetics created a space for environmental research on autism etiology. One epidemiologist explained that, "the genetic studies have uncovered a lot but they failed to really say, you know, 'Oh, this is the cause… we can explain most of autism by this gene or that gene.' That hasn't happened (Perinatal Epidemiologist)." Another noted, "[with] the difficulty in identifying genes… you've got to start thinking about why is it that we can't find genes?

And one of the reasons is that, you know, you've got environmental influences, I mean it could be gene-environment interaction" (Chronic Disease Epidemiologist). As these epidemiologists make clear, the inability of genetic research to fully explain the causes of autism, as well as growing appreciation for the complex nature of the condition, were viewed as opening up opportunities for research exploring "non-genetic" factors.

Recent findings (Hallmayer et al. 2011; Croen et al. 2011) complement the picture of autism as a multi-factorial disease, positioning questions about "the environment" centrally in their analyses. In the largest twin study to date, former heritability estimates for autism were updated to account for the role of environmental factors, including shared fetal environment (see Saztmari 2011). Hallmayer et al. (2011:1095) found that approximately 37% of autism concordance was attributable to heritability, while 55% was likely due to shared environmental factors. This finding generated considerable media attention and was heralded by some as signaling a potential paradigm shift in autism research.

In the past decade, efforts to extend questions of autism's cause into the domain of the environment have gained increasing attention (Lawler 2005; Daniels 2006; Landrigan, Lucca and Birnbaum 2012). This is a result of interacting forces that include the limitations of genetics as described above, as well as the formation of "networks of concern" that I describe below. Further, researchers draw on early associations between autism and environmental factors including pre- and/or postnatal exposure to valproic acid, thalidomide, and infections such as rubella as additional support for their research (Chess 1971; Daniels 2006). The director of a leading autism research institute describes the limits of these early clinical findings, and their bearing on the field:

> The problem with a lot of the work done in the '70s and '80s and on sort of the non-genetic aspects of autism or the non-behavioral aspects of autism [is that] the work was considered to be sort of on the fringe, partially because oftentimes it wasn't done technically all that well or it wasn't done in a context where patient recruitment was all that good (Neuroscientist).

Improving the reliability of future research has been a central focus of the field in recent years. Buoyed by increased funding and public support, research on the role of environmental factors in autism now promises to uncover links between exposure effects and biomarkers of susceptibility. Studies utilize new techniques including DNA microarray technology (Iannaccone 2001), for example, to investigate the interactions between the neurodevelopmental effects of exposure to chemical and microbial agents and individual biomarkers of susceptibility (Hertz-Picciotto et al. 2006).

This research promises information on the effects of environmental factors on autism (Szpir 2006). For example, a recent editorial reflects findings based on studies of autism and the environment to date, identifying ten targets for future research (see Landrigan, Lambertini and Birnbaum 2012). Landrigan and colleagues (2012) note that research has linked autistic behaviors with prenatal exposures to the organophosphate insecticide chlorpyrifos (Eskenazi et al. 2007) and with prenatal exposures to phthalates (Miodovnik et al. 2011). Other research has found associations between autism risk and some commonly used household pesticides (Hertz-Picciotto et al. 2008), previous immune compromise in mothers (Ashwood et al. 2006; Braunschweig et al. 2008), and SSRI use (Croen et al. 2011), fever (Zerbo et al. 2012) or diabetes (Krakowiak et al. 2012) during pregnancy.[27] Despite the substantial investment of time and money in basic research and the myriad findings detailed above, questions about autism's etiology

[27] The concentration of environmental research during pregnancy is discussed in more detail in the final section of this Chapter.

remain unsettled. This has led efforts to understand the causes of autism in multiple, sometimes competing and sometimes complementary, directions. This is in part because, as Nadesan (2005:2) has observed, "the medical and scientific literatures often assume autism is some *thing* or *things*… which will ultimately be unequivocally identified and known as a spatially centered genetic, neurological, or chemical abnormality through the efforts of scientists toiling in their laboratories." I contend that such toiling, in its efforts to produce answers, also signals shifts in how autism and autism risk are conceptualized and acted upon by scientists, policy makers and families. Below, I describe the social and political conditions that underscore these shifts.

Identifying the Environment as Causal

The growing interest in exploring the role of environmental factors in the etiology of autism follows efforts to understand the multiple causes likely at play in many other diseases including breast cancer, schizophrenia, and diabetes, among others (Shostak 2003). As I detail below, however, the increasingly complex understandings of what causes autism have not taken place in a vacuum. Rather, efforts to identify the role of environmental factors in autism etiology have been motivated in part by concerns about the condition's rising prevalence in the population. In this section, I detail researchers' perspectives on how this influences etiologic research. On the one hand, it drives attempts to identify modifiable risk factors for autism; on the other hand, it orients research in particular directions heavily influenced by "the prevalence question."[28]

[28] Across my interviews with epidemiologists, neuroscientists, geneticists and advocates, this terminology of "the prevalence question" was often used to characterize unsettled debates that have accompanied autism prevalence estimates. My interviewees pointed to the multiple ways that autism's prevalence orients research practices and funding priorities.

Prevalence and Possibility

Within the United States, diagnosed cases of autism spectrum disorder have risen from 1 in 2,000 in 1966 (Lotter 1966) to an estimated 1 in 88 today (CDC 2012). This exponential rise in prevalence has become hotly debated, raising questions about changing diagnostic criteria (Croen et al. 2002), increased awareness, and the impacts of environmental factors in the etiology of autism (Szpir 2006). Though by no means mutually exclusive, the weight given to each of these factors tends to reflect strongly and often passionately held positions on the cause of autism.

As a result of this dramatic increase, the idea of an "autism epidemic" has circulated within public discourse surrounding autism. This idea has fueled efforts by government, academic researchers, and advocacy groups to provide better, and earlier, surveillance of autism spectrum disorders as well as increasing funding to conduct more thorough research to discover what may lie behind these rising rates (IACC 2011). While the increase in prevalence remains an empirical question, abundant media attention, parent activism, and public health concerns are changing understandings of autism, including what researchers and publics alike identify possible causes of autism.

Following the Numbers

Stemming from the first large scale surveillance studies conducted by the CDC, scientists I interviewed described how the rise in autism cases became central in intensifying interest and funding for studies focused on environmental factors. As an epidemiologist explained,

> I mean, a lot of the upsurge in autism epidemiology came from the up-tick in administrative cases, no doubt… there were more kids being diagnosed and CDC – and nobody really – had an answer for how big this was or why. There's this view that, you know, some of this increase has got to be real, there's got to be

> something environmental. So we need to be thinking about it and doing something about trying to figure it out (Chronic Disease Epidemiologist).

As this scientist makes clear, the goal of more fully understanding the dramatic increase in autism prevalence garnered considerable political and monetary support for research on environmental factors. While still a fraction of the overall budget for autism funding in the United States (IACC 2009), this field has gained significant ground and explanatory potential over the past decade. Questions related to autism's prevalence are also redefining the ways we think about the environment in relation to autism. As another epidemiologist explained,

> Regardless of whether you believe there's an epidemic, part of the process that drives the list of what people want to look at first are things that are going up. Because if there is an epidemic we want to look at those… the problem is well, if there isn't an epidemic then we're using sort of a false premise to generate our priority list (Environmental Epidemiologist).

This research priority list has been a source of considerable debate within both the autism and autism scientific communities (see Landrigan et al. 2012 for targets of future research). The question of how to identify and appropriately analyze possible environmental factors has been the focus of numerous federal workshops since 2000, including *The Institute of Medicine Workshop on Autism and the Environment: Challenges and Opportunities for Research* (IOM 2011) and the *NIEHS Workshop on Autism and the Environment: New Ideas for Advancing the Science* (NIEHS 2011). These events and the topics they address further demonstrate the shift in autism etiologic research from a focus on heritability to questions about what environmental *and* genetic factors to study, when and how. In many ways, this shift in the *kinds* of questions being raised about autism dovetail with larger questions about the social conditions that underlie modern disease "epidemics" more broadly.

This question is central to Eyal and colleagues' (2011) *The Autism Matrix.* The book eloquently maps autism prevalence in relation to shifts in the classification systems and structures of expertise surrounding mental illness, including those resulting from the deinstitutionalization of mental retardation. The authors emphasize that their thesis does not challenge the existence of autism – a critique often launched at attempts to chart the social dynamics of autism prevalence rates. Rather, they propose that complex systems of classification, family advocacy, and expertise surrounding mental illness provided the conditions of possibility for the autism prevalence trends we see today.

Eyal and colleagues' analysis poses interesting questions about the forms of knowledge production facilitated by prevalence estimates. Several scientists I interviewed also reflected on this question. One researcher noted: "The problem is… people think the prevalence is a very simple thing. But it's really very complicated, because you've got the gorilla in the room, which is 'is the prevalence increase real?" (Chronic Disease Epidemiologist). Peter Bearman and colleagues' *Understanding Autism Project* has extensively examined this precise question, illustrating the complex social and biological sources of autism's rising prevalence rates in the United States population (Fountain et al. 2011; Shwed and Bearman 2010; Fountain, King and Bearman. 2010; Bearman 2009; Mazumdar et al. 2010; Liu et al. 2010; King et al. 2009; King and Bearman 2009). To date, a variety of explanations continue to be advanced as explanations for this rise (see also Rutter 2009). Some of the best known, and most polarizing controversy about growing rates of autism cases and their underlying causes has revolved around vaccines and autism.

The Vaccine Controversy

The highly publicized debate over post-natal exposure to thimerosal through childhood vaccination has played a central role in public discourse surrounding autism (see Singh, Hallmayer and Illyses 2008). Despite a series of research findings indicating no relationship between vaccines and autism (Parker et al. 2004), parent concerns about the risks of vaccination and their relationships to autism have persisted. Rather than focus on the public health effects of these concerns, here I consider the political and social momentum produced by this discourse and its relationship to the study of environmental factors more broadly. In particular, I point to this debate as a key event influencing contemporary research on autism and the environment.

Concerns about vaccination and autism were most notable following the Food and Drug Administration (FDA) announcement in 1997 that the levels of exposure of infants and children to thimerosal far exceeded federal safety guidelines for exposure to methylmercury (CDC 1999). While thimerosal contains ethylmercury not methylmercury, following their finding the FDA, along with the United States Public Health Service (USPHS) and the American Academy of Pediatrics (AAP), recommended that thimerosal be removed from vaccines to avoid any possibility of neurological effects such as those seen with mercury poisoning in small children (CDC 1999). This recommendation, along with the increased number of vaccinations recommended for children, and observations by parents connecting the onset of autism symptoms with vaccination schedules, fueled the hypothesis that vaccines containing thimerosal cause autism (Kaufman 2010).

Several years later, brainstorming sessions were initiated with parent groups and scientists as a result of these highly publicized concerns. As a funding officer at the National Institute of Environmental Health Science (NIEHS) explained to me:

> In [2000] there were already some questions being raised publicly, particularly about whether there may be an environmental component to autism... So I was sort of given a charge, one of the first activities I had was to put together a brainstorming session on autism and the environment. At that point in time, NIEHS really reported *zero* funding for autism research. Those are formal figures that NIH reports out every year and our official figure was zero for that point in time. So my coming to NIEHS just sort of coincided with kind of a dramatic increase in interest in autism and particularly in whether there were any environmental contributors. It's grown, so it occupies a significant portion of my time (NIEHS Program Officer).

When asked what she felt were the major influences on autism and the environment at that time, she replied: "Well, I think it's pretty clear that it was really driven at the time from the questions about vaccines."

The brainstorming sessions mentioned above mirrored other efforts to better assess and contain concerns about vaccines and autism at the turn of the twenty-first century. As a result of rising concerns among parents and the possibility of a public health crisis, the Institute of Medicine (IOM) Immunization Safety Review Committee (ISR) convened three separate panels investigating the link between vaccines and neurodevelopmental delay beginning in 2001. Distinct from the brainstorming sessions at NIEHS, the purpose of these panels was to weight the scientific evidence related to vaccine concerns in several areas. These resulted in three separate reports on *Measles-Mumps-Rubella Vaccine and Autism* (IOM 2001a), *Thimerosal-Containing Vaccines and Neurodevelopmental Delay* (IOM 2001b), and *Vaccines and Autism* (IOM 2004). In the 2004 report, the Committee ultimately concluded that, "the body of epidemiological evidence favors rejection of a causal relationship between thimerosal-containing vaccines

and autism" (IOM 2004:151), recommending continued "surveillance of ASD as the exposure to thimerosal declines" (Schechter and Grether 2008).

Following this recommendation, several publications (see Parker et al. 2004 for a review) indicated no decrease in rates of new diagnosis of autism despite the exclusion of "all but trace levels" of thimerosal from nearly all childhood vaccines (Schechter and Grether 2008). This study and others provided evidence rejecting the hypothesis that "exposure to thimerosal is a primary cause of autism" (Schechter and Grether 2008:19). Several years later, allegations were confirmed that British scientist Andrew Wakefield, famed for his 1998 study reporting a connection between the MMR-vaccine and autism, falsified data in the original study and in publications that followed (Deer 2009). Wakefield had his medical license revoked and the Lancet retracted the original MMR publication (Lancet 2010). This body of evidence, however, offered little closure for those still concerned about the role of vaccines in causing autism (see Senier 2008; Kaufman 2012; Silverman 2011).

The controversy over vaccines and autism reflects larger questions of expertise and legitimacy vis-à-vis contemporary science and medicine more generally (Epstein 2007; Kaufman 2010; Silverman 2011). Rather than merely a problem of scientific knowledge, the debate raises not only questions about trust in the public health system and vaccine program in particular, but also reflects broader shifts in trust of expert knowledge (Kaufman 2010). As Kaufman has illustrated (2010), parents are increasingly aware that scientific and medical understandings about cause are unsettled. As a result, some see expert opinions as neither confirming nor denying the *possible* risks of vaccines for *their* children. In this context, parents feel compelled to seek more information, and to

consider scientific evidence and medical recommendations in light their own concerns, forms of knowledge, and the possibility of putting their children at increased risk (Kaufman 2010). This combination of considerations and what Senier (2008) has called "worst case thinking" provide the basis for their decisions about whether or when to vaccinate. It also motivates advocacy efforts related to these concerns.

Current research examining gene-environment interactions is partially rooted in this unique set of events related to vaccines, including the political and social momentum they established. As I illustrate below, this momentum coalesced in the extension of specific concerns about vaccines into broader questions about the roles that environmental factors might play in causing autism. The funder quoted above noted the influence that attention gleaned from the vaccine controversy had on autism research:

> It was both fortunate and unfortunate. Unfortunate because I think what happened at least initially was that from the scientific side scientists tended to ... if you wanted to talk about environmental influences in autism they thought you were talking about vaccines, so it was synonymous. So if there were environmental influences, you know, you're talking about vaccines and, you know, there was never I think really any strong ... there were a lot of questions but there really hasn't been any strong data implicating it. So I think it provided, in one sense – or at least for some scientists – it provided an easy way to ignore environmental influences. Because they just thought, "Oh, you know, there's some fringe people talking about vaccines and we know that they're not really involved so we'll just keep doing our research along the same lines." So that was the unfortunate part.

However, she went on to explain,

> I think the fortunate part was that it did bring attention to autism and environmental influences. And that whole controversy, I think, grew up serendipitously around the time that there became a broader appreciation that there are environmental inputs into most human disorders. And gene-environment interplay was probably the rule not the exception. So there was more attention, but also more gradual recognition that we weren't *just* talking about vaccines. And it did make sense, even with something that seemed to be strongly inheritable like autism, that there would be a role for the environment. It kind of kept [the environment] front and center.

The effort to keep the environment 'front and center' while reorienting the specific focus on vaccines into a broader research agenda, required many actors and efforts. These included building what I call "networks of concern" that connected parent advocates focused on vaccines to scientific researchers and policy makers. One result of these networks has been the introduction of new etiologic approaches to the field of autism. These networks utilized the political and social momentum surrounding the vaccine controversy to garner funding for research addressing environmental causes of autism, while moving away from vaccine-specific studies. This required defining the environment in simultaneously more expansive and specific terms.

Extending and Defining the Environment

Building Networks of Concern

Definitions of what is meant by "the environment" in autism research vary across different stakeholders and research projects. Despite these local distinctions, my interviewees often defined the environment first and foremost by what it was *not*. When asked, many scientists and mothers defined the environment as "everything but genetics," producing a distinction between genetics and the environment that reinforced the primacy of genetics while simultaneously advancing environmental factors as critical to understanding autism. These efforts dovetail with both the changing production of knowledge surrounding autism genetics detailed above, as well as the political and social conditions set in motion by the autism-vaccine controversy.

This language also enables researchers and parents to retain the importance of genetics while producing research on environmental factors as worthy of increasing

scientific study.[29] Further, while genetics were never counter to parent concerns about vaccines, the discursive and material work of producing the environment as both *distinct from* and always *related to* genetics has allowed stakeholders to build on the political momentum established by the vaccine controversy while expanding "the environment" into a more expansive, and less politically controversial, category.[30]

Federal committees, workshops and symposia convened to address stakeholder concerns about autism across a number of areas, including etiology, have played a key part in generating both broad – as well as increasingly more vast yet specific – definitions of the environment in the wake of the autism-vaccine debates. The Interagency Autism Coordinating Committee (IACC), charged with developing and coordinating an annual Strategic Plan and budget for all U.S. federal autism research under the 2006 Combating Autism Act (CAA), has been a central actor in these efforts. In their 2006 report, the IACC defined the environment as "an array of non-genetic risk factors" including, but not

[29] I mean this as a quality of this language more broadly, rather than an explicit intention of those who use it, necessarily. This more subtle effect is enabled both actively and passively through the work of scientists, policy makers and advocates, as well as research participants, study staff and media (as I illustrate in the next Chapter). As a result, the notion of the environment as "everything but genetics" has come to reflect a scientific "fact" that circulates without explanation for its cultural situated-ness (Clarke 2005). This has in part allowed the category of "the environment" to gain currency socially and scientifically while remaining empirically flexible, with different claims being made about it and its relationships to autism by various actors. The extensive and often purposeful *work* of this kind of fact making is further articulated in the remainder of this chapter. These efforts included building alliances between funding agencies and advocates, recruiting new kinds of experts into autism science, and attending to differences in individual or group definitions of the environment through on-going discourse. While this discourse continues to be punctuated by disagreement on *what* kinds of environmental factors matter most and *when*, in many ways, it is the ongoing nature of these questions that enables the research studies I describe in Chapter Three.

[30] Leaders in the field have further articulated this either/and approach. For example, National Institute of Mental Health (NIMH) Director Tom Insel (NIMH 2012) provided justification for the continued importance of environmental research on autism following findings on new genes associated with the condition (Sanders et al. 2012; O'Roak et al. 2012; Neale et al. 2012). In the "Director's Blog" he summarizes these findings on spontaneous mutations, the methods used to identify them, and their relationship to potential environmental factors including fathers' age (Sanders et al. 2012). He ends by asking "is autism genetic or environmental? These studies suggest it can be both" arguing that both areas of science are needed because of the diversity of syndromes associated with autism – "indeed," he notes "we should probably speak of the 'autisms'." This idea of multiple autisms has proliferated in part as a result of the genetics findings noted above, as well as the increasingly molecularized tools and techniques used in studying autism (Rose 2007).

limited to, "endocrine disrupting chemicals or pesticides, pyrethroid pesticides… persistent halogenated compounds" and metals (Amaral et al. 2006:14). The IACC also explicitly recommended increased research addressing "interaction of environmental and genetic factors" that had been given "insufficient attention in the first iteration" of planned and coordinated research on autism (Amaral et al. 2006:13).

A more recent IACC Strategic Plan for Autism Spectrum Disorder Research (IACC 2009) reports that research on environmental risk factors is underway, including studies on a number of "environmental agents… that are known or suspected to influence early development of the brain and nervous system." The report also identifies that there is "considerable debate about whether potential environmental causes, genetic precursors, or interactions between genes and environmental factors should be the highest priority for research aimed at identifying the causes of ASD" (IACC 2009). In addition, it reflects the continued presence of vaccine concerns within environmental research and their effects on debates over research priorities. For example, a call to design studies that "assess environmental exposure during the most relevant exposure windows, pregnancy and early development" is nested between paragraphs discussing the debated importance of research on vaccines and autism. While the authors emphasize that numerous epidemiological studies have found no relation between autism and vaccines containing thimerosal, the report acknowledges continued concern about a possible relationship between vaccines and autism, noting that "public comment to the Committee reflected opposing views on vaccines as a potential environmental cause" (IACC 2009). These debates, and the tensions between public opinion and policy recommendations, continue to shape discourse and practice related to autism and the environment.

Conversion Work

Researchers explained to me that the political momentum initiated by the idea of an autism-vaccine link was productive in building new approaches to the study of autism etiology, including initiating community-participatory research at the NIEHS, which incorporated parents and other stakeholders into research decision-making about autism. These efforts were met with push back early in the process, but nevertheless became central in advancing environmental research agendas that better reflected public concerns.[31] These models were initiated in part as a response to public pressures generated by the autism-vaccine controversy and the growing sense that autism was a public health crisis poorly managed by leading scientists and policy makers. An NIEHS funding officer described the early challenges of community-based participatory research:

> Well, it feels a bit like mission work at times. The Institute has a really strong and rich tradition of community-based participatory research and all the principles that go along with that. It's changing but say, ten years ago [in 2000] that was an unusual position for an NIH Institute. They were a little bit behind in terms of recognizing the importance of not only responding to public concerns but really having relevant public stakeholders be part of every part of the research process. So, you know, I'm on – I think – pretty firm ground. I have tried to kind of push the idea that advocates are not our enemy. They [scientists] have a broad spectrum of opinions as well but, at least initially, that sometimes feels like you're swimming against the tide. Because there still can be remnants of more of an old-fashioned approach of 'We are scientists and we know what we know and our only role is to…' It's not *bi-directional*, it's *unidirectional*. 'We'll do our research and I guess maybe we'll tell you what we found at the end.' There really wasn't a widely recognized role for other stakeholders in really shaping that research agenda. So… I work at an institute that really was at the forefront of an alternative way of thinking: that there's a lot of value to bringing in stakeholders early on in the process.

[31] These participatory models were also used in the formation of federal committees like the IACC and in research projects, where stakeholders often sit on study community advisory boards.

The dynamics described above – the initial pushback against advocate involvement and shifting scientific norms – mirror expert/lay relationships across the history of HIV/AIDS (Epstein 1996), breast cancer (Klawiter 2008; Brown et al. 2003), asthma (Brown et al. 2004), and health disparities (Epstein 2007). However, in the example of environmental research on autism, these dynamics also reflect something unique. Through placing stakeholders with various perspectives at the same table, questions about vaccines *in particular* became part of a more general network of concern emphasizing the environment as a broad category relevant to autism and in need of scientific investment. The NIEHS program officer went on to describe the relationship between community-based participatory research and extending the meanings of the environment.

> Then [bringing stakeholders on early in the process] kind of made it easy. I didn't have to focus on vaccines so much as just sort of respecting and understanding the different points of view. I think our Institute's been pretty unique because the advocates for the most part have recognized that we're a friendly place, that their opinions are valued and they try stuff. And that's been helpful. So part of it is just sort of advocating for them to have a seat at the table. And then, on the other hand, sort of advocating for the best science. Because that's what NIEHS wants to be recognized for as sort of supporting sound science, wherever that may take you. So it's a bit like a balancing act. *It's research because we don't know the answers.* And sometimes people think they already know, whether it's scientists or advocates. We don't know.

Here, she articulates both the challenges of stakeholder inclusion in research decision-making, as well as the consequences this had for autism research priorities at the NIEHS. Advocating for the "best science," however, also required enlisting scientists to conduct it and advancing new research paradigms that better reflected community concerns.

With the help of funding from autism advocacy groups such as *Autism Speaks* (Autism Speaks 2012) and federal agencies, parent concerns and advocacy facilitated a new program of research, but one that was not easily established. Many autism

researchers had built their careers in autism genetics and were either not methodologically equipped, or were frankly uninterested, in shifting course to study potential environmental causes of the condition. Recruiting scientists from other fields to study autism in new and different ways became an answer to this problem. The NIEHS program officer quoted above describes one of the reasons for this approach:

> And so in the beginning at least… an easier tack was to try to encourage the scientists who would be normally our grantees. So they would be from the field of environmental health science. Try to get them involved in autism research and that wasn't something they were doing normally. But it was an easier sell that direction than trying to go to the autism researchers and convince them to look for environmental influences.

Bringing outside researchers into the field of autism to study the environment then produced new approaches informed by parent concerns and questions. Several researchers I interviewed who were recruited from other fields described their own "conversion" stories to me. They detailed how they became interested in autism, and the relationship between their former and current research. A now prominent autism epidemiologist explained the relationship between her early training and her approach to studying autism:

> So when I started as an epidemiologist, I was starting to look more at pregnancy outcomes but had always been interested in neurodevelopment. And then I had a wonderful opportunity in 2000. I was contacted by a group that was starting a center on neurodevelopment [that] specifically focused on autism and the environmental factors that might be associated with autism. And, you know, at first I said, 'Well, you know, I'm not really the right person to help out because I don't know anything about autism.' But the people who were getting the center going said, 'You know, the problem is there's *nobody* who knows very much about autism and that's exactly why we need you.' And, so I sat down and I started reading and, you know, it was very interesting because within a week I could see that nobody had done the kind of epidemiology that is so common in so many other areas. Breast cancer – there's been many, many studies looking at environmental factors in breast cancer. Even, you know, low birth weight, going back to my own roots. But nobody had done anything like that in autism. And, I literally read *every* paper I could find. So, that kind of convinced me that, yes, I

> did have something to offer, even though I needed to learn more about autism… I could contribute using my skill. (Environmental Epidemiologist).

As others have illustrated (Frickel et al. 2011), studying the understudied offers even prominent scientists new advantages. For this epidemiologist, it meant an opportunity to apply her experience studying breast cancer and pregnancy outcomes to a field where few investigators were asking basic epidemiologic questions. This type of recruitment of scientists from other disease fields, a common experience across the scientists I interviewed, facilitated research that borrowed from epidemiologic approaches on cancer and birth defects studies, facilitating new approaches to studies of autism etiology.

This recruitment of scientists from other disease fields, alongside efforts to bring advocates into research conversations and decision-making, provided opportunities to approach autism in ways that had not previously been pursued. A genetic epidemiologist articulates how the social conditions surrounding autism research, compared to her research on schizophrenia and Alzheimer's disease, made it easier to conduct the large scale epidemiologic studies necessary to study gene-environment interactions. She explains:

> With autism, in some sense we're in a better place in epidemiology than we are with lots of other disorders because it's something that we can see early on in life. And it's a disorder that has a lot of people in the lay world interested and certainly a lot of parents very, very concerned about. So that actually means that there are a lot of people willing to cooperate with us and to support research studies and to be actively involved in them. So that's actually a great thing compared to something like schizophrenia [her previous research focus] where typically folks have, um – have not always severed but certainly strained ties with their family members. It tended to be a hidden-away disease so it's not that well supported or even thought about in the lay world. It's often associated with crime and negative things where people would rather not be involved in. So that's sort of – social pressure makes a big difference in how easy it is to get things like population-based epidemiologic studies done [on autism], because all of the kind of work that we do takes a huge amount of cooperation with local agencies and also cooperation, obviously, with the families who would participate.

As the quote above makes clear, families willing to participate in research are rich resources for understanding autism and in studies of gene-environment interactions. As the sections above illustrate, efforts to promote the study of environmental causes of autism have been heavily influenced by the history of autism research and the involvement of those concerned with specific environmental factors, most notably vaccines. In this way, parental concerns, the reactions of the autism scientists, and changing understandings of autism, together enabled new approaches to research on the relation between autism and the environment. The limitations of earlier research, the reopening of the questions of cause, and the expansion of ideas of the environment from vaccines to a broader research agenda, together made it possible to recruit scientists from other fields to pursue new directions in autism science. These factors have facilitated approaches including studies of gene-environment interactions in autism. The next section focuses on the spatial and temporal elements of risk embodied in one exemplar of this research area.

(Re)Locating the Environment in Bodies and Time

Windows of Vulnerability and Prospective Longitudinal Research

One result of the shifts described above has been the initiation of large-scale epidemiologic studies exploring potential genetic and environmental risk factors for autism during pregnancy and early childhood (as described in Chapter One). Scientists characterize prospective birth cohorts (such as MARBLES and EARLI) as "powerful engines" for the discovery of environmental risk factors, gene-environment interactions and gene-environment-timing research (see Stoltenberg et al. 2010; Landrigan et al.

2012). In a recent editorial (Landrigan et al. 2012), the authors characterized support for this area of research as the result of mounting scientific evidence. They state, "exploration of the environmental causes of autism and other NDDs [neurodevelopmental disorders] has been catalyzed by growing recognition of the exquisite sensitivity of the developing human brain to toxic chemicals" (Grandjean and Landrigan 2006 in Landrigan et al. 2012). They go on to point out the importance of timing for this research, noting that, "susceptibility is greatest during unique 'windows of vulnerability' that open only in embryonic and fetal life and have no later counterpart" (Miodovnik 2011 in Landrigan et al. 2012). This focus on windows of vulnerability during embryonic and fetal life reflects a shift in the timing and location of risk within discourse and scientific work related to autism.[32]

These studies extend questions of cause outward – into the environment – while simultaneously positioning the effects of those factors within bodies (see also Murphy 2006). In particular, by identifying environmental risks as consequential during fetal development, it is mothers' bodies that become *biologically* bound to autism risk. The locating of risks both beyond individuals and simultaneously *within* women's bodies, provides opportunities for science premised on the principles of maternal and fetal health,

[32] A link to The Endocrine Disruption Exchange (TEDX) under the original MARBLES website "Resources" tab provides a poignant example of this shift. The TEDX "Critical Windows of Development" website is a visual and interactive tool that illustrates the effects of endocrine disruptors including Bisphenol A, Dioxin and Phthalates (among others) during windows of fetal development. By indicating "on" or "off" on the website's toolbar, visitors to the site can see the effects of selected chemicals during distinct periods of fetal development. Choosing a particular chemical from the toolbar reveals color changes (from blue bars to red) on the developmental timeline. Specific time points, indicated with triangles of varying size, reflect the strength of scientific associations between the chemical(s) and their effects. Hovering your pointer over these triangles reveals a synopsis of existing scientific findings related to that effect. While this link is no longer provided on the MARBLES website, it was one of the only links available on the study website during the majority of my observations of the study. (see http://www.criticalwindows.com/go_display.php).

as well as new potential zones of responsibility for women.[33] In addition, while these studies may provide opportunities for future biological understandings of autism, I detail in the next chapter how the extended contact between scientists and families necessitated by this design becomes productive of changing relationships between science and care, as well. In these ways, this exemplar of autism gene-environment interaction research reflects a 'style of thought' (Fleck 1935) enabled by the social, political and scientific conditions detailed above, and a rich site for sociological research.

Conclusion

This chapter has described two shifts in autism science and their relationships to the emergence of gene-environment interaction research. The first shift traced the promises and limitations of autism genetics and their bearing on advances in environmental research. The second shift considered how attention to *specific* environmental factors – most notably vaccines – provided the political and financial support for research on environmental factors broadly construed. This was further facilitated through the recruitment of scientists from other disease fields into autism research, producing new approaches to the study of autism etiology. Through detailing the emergence of gene-environment interaction research on autism, I have argued that parent concerns about the rising number of autism cases in the United States garnered both political and scientific support for research on the role of environmental factors in causing autism. Through building alliances across lay and expert communities, these efforts and the limitations of autism genetics facilitated what I have deemed "networks of concern."

[33] I describe mothers' relationships to these responsibilities in Chapter Five.

Networks of concern include parents, policy makers, scientists and program officers across an expanded number of social domains and disciplinary fields. Accompanied by the limitations of autism genetics, these (sometimes uneasy) alliances did the work of extending *specific* concerns about the environment closely aligned with vaccines into a broad research agenda focused on the interactions between environmental factors and genetics. This produced autism as a field of study commensurate with other chronic complex diseases, enabling the recruitment of scientists from fields such as cancer epidemiology and birth defects research, and thereby changing the directions of autism epidemiologic research.

As I detailed in this chapter, one particular result of these changes has been efforts to prospectively study environmental and genetic risk factors during pregnancy and early childhood development. These studies present an exemplar of research on gene-environment interactions. As such, they provide an important window into the ways that risk and responsibility are employed in explanations of autism. Through focusing on gene-environment interactions during critical windows of vulnerability, these studies shape questions of cause as mediated *within and through* women's bodies. These studies therefore refocus etiologic understandings of autism in the relationships between bodies, histories and potential futures. In doing so, this research situates the possibility of prevention in the lifestyle choices and personal exposures of *mothers* as well as children, and in the biological legacy of distant relatives as well as close kin. The result is a sense of autism risk as both *exterior and embodied*, shifting understandings and experiences of autism, and the responsibility of negotiating its possible causes.[34]

[34] These studies and others exploring the relationships between environmental factors and autism are, in many ways, further examples of the Networks of Concern I describe in this chapter. As such, their

Gene-environment interaction research, while attempting to fill voids in existing knowledge about autism, simultaneously opens up new questions about the spatial and temporal qualities of risk. These studies also bring to bear politics of participation, anticipation, and hope, subjects that have been critical in the history of autism science (Orsini 2009; Silverman 2011). As I detail in the next chapter, these prolonged engagements provide the opportunity for multiple relationships to come into being – between researchers and participating families, as well as between environmental factors and genetics – while at the same time standardizing others (i.e., the womb as environment and autism as biological) (Star 1995).

infrastructures and the social, cultural and affective forms of capital that enable and are produced through them may well be another meaningful dimension of this concept.

CHAPTER 3:
BUILDING RESOURCES AND TAKING CARE

> *You know, this whole idea about epidemiology as discovery science versus having it be hypothesis driven and…is that a good thing or a bad thing? I mean I'm pretty convinced, that at least for autism, we have to do it. We have to be responsible about what comes out the other end, which is the tricky part… or a tricky part.*
> (EARLI Principal Investigator).[35]

> *When I found out that I was pregnant with my last daughter, I actually e-mailed the MIND Institute out of the blue and just said, "Listen, I'm willing to give my body to science, I'm pregnant with another child. Study anything you want about me." I didn't know about the study at the time. I was just like, "I'm pregnant, you can track what I eat, what I drink, what I clean with, what we do, everything."*
> (Elizabeth, mother of three-year-old daughter diagnosed with autism).

When I began this project, I considered the more than three years of participation required by MARBLES and EARLI to be a significant commitment to research. Then I started interviewing mothers. I sat with them as they rocked their newborn children, helped as they picked up toys and books from around the house, talked with them as they breastfed, and waited while they answered calls, put their children down for naps, drew baths, or coordinated rides to and from school, therapy sessions and doctors appointments. I sat with these women at their kitchen tables, on their couches, and in their backyards. I pored over albums of their children's old medical records, developmental assessments, and IEP (Individual Education Plan) paperwork with them, looked through photo albums, and traced their lives backward through time.[36] Gradually,

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[35] There are four Principal Investigators for EARLI (one for each site of the study). Throughout this dissertation, I indicate them all by their shared title so as not to distinguish them individually from one another.

[36] In Chapter Four I detail how mothers' reflections on their children's early behaviors and bodies are influenced by later autism diagnosis. Mothers often showed me photos of their children to indicate early signs of autism they felt they'd missed. During one of my interviews, Sarah took out her cell phone. Flipping through old photos, she pulled up one of her son at one year old, "See his eyes here," she said,

I came to realize that, for many of the families I engaged, research participation had been woven into the fabric of their everyday lives.

Study appointments were incorporated into family schedules packed full of school and work meetings, legal hearings, afterschool activities, and children's ABA (Applied Behavioral Analysis) sessions. Project staff worked diligently to fit themselves into these often-narrow spaces (as many autism families are very, very busy). Staff would drive from participant home to participant home six and sometimes seven days a week, coordinating sample collection, labeling and storage throughout each mothers' pregnancy, attending their deliveries, and scheduling appointments every three, six, nine, twelve, twenty-four and thirty-six months; gathering each sample, at each time point, for each family. This often meant long hours for study staff: they often worked from early morning to night and were sometimes on call for full days on end. This elaborate choreography – coordinating appointments, driving times, sample collection and family schedules – was part of the work of conducting a prospective epidemiologic study (see Thompson 2005 on ontological choreography).[37]

Through my interviews with scientists and participants, and during my ethnographic observations, I recognized this choreography as both thoughtful, in its

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pointing to the photo. "It looks like he's looking at the camera but if you look closely, he's not… and that was a sign of his autism. I just didn't know" (Sarah, mother of four year old son diagnosed with autism).

[37] Through conducting the majority of data collection in participant homes, research staff made it easier for families to go about their daily lives with as minimal interruption as possible. Staff capitalized on home settings for the collection of multiple types of data, from developmental assessments, child hair samples and head circumferences, surveys of cleaning products and electronics, to blood draws and dust samples. In many ways participants' homes became extensions of both the clinic and the laboratory (see also Altman et al. 2008). During one home visit I attended, Emily, a Junior Analyst for the study, ran up to the bedroom to vacuum for dust samples while a registered nurse conducted a blood draw downstairs in the living room. During the hour or so session, a friend of the participating family's brought over a new bed for the study participants' older child, assembling it while the family's nanny prepared lunch and the participating mother breastfed comfortably on the couch. Such everyday multitasking was characteristic of the families and the study staff. Mothers often had an older child in ABA or other therapies in the other room while they were present for their younger children's assessments. In these ways, home visits became more practical for both the researchers and participating families.

respect and accommodation to family needs and schedules, and also strategic. For principal investigators, this approach to studying the causes of autism had been deliberated at length. They had considered the contours of their study design, deciding on everything from research sites, recruitment and data collection, to storage, analysis and dissemination, with a keen eye on the past and future of the field – including its relationships with autism families – and the promises and limitations of the studies themselves.

For study staff, smoothly coordinating appointments required knowing participants, their schedules and availability, what assessments were needed, how long they took, and the equipment necessary before and after each appointment. This allowed them to efficiently collect data, and swiftly organize and classify specimens into color-coordinated glass tubes, labeled plastic bags, and into coolers for transport back to the designated laboratories. For families, participation required making themselves available for appointments every few months, filling out questionnaires, keeping ongoing diaries during pregnancy, and collecting breast milk, soiled diapers and first haircuts after their new babies were born. This was, of course, what everyone had signed up for. But it was also something more.

There was something both ordinary and rather extraordinary about each research visit I attended. During the appointments, staff exchanged smiles with participants as they maneuvered between assessments, inquiring about other children in the family, new schools, or parents' jobs. They asked questions that extended beyond the study, checking in to see whether children had received services from the Regional Center, how mothers felt their sons or daughters were doing, and what – if anything – the staff or study could

do to help. Many times while I was coordinating interview appointments with study staff, they would mention that the mother I would be interviewing was one of their "favorites." "She's so great," they would say, "she's been in the study since the beginning – you'll love her."[38] This affection, and a sense of profound respect for families, was palpable during my study observations, and extended beyond individual relationships.

Interestingly, affection was also echoed in my conversations with Principal Investigators (PIs) and in my review of study documents and visual cultures.[39] Alongside the technical duties of conducting "good science," PIs detailed how their study decisions also reflected the needs of participating families. In this way, I argue that prospective pregnancy studies act as a conduit, channeling individual experiences, exposures and DNA into aggregate information about autism. At the same time, this research provides emotional and practical support to families in the form of developmental assessments parents could use during Individualized Education Plan (IEP) meetings or doctors visits, referrals to services and other studies, and access to experts who would answer their questions. In short, the study was more than just a finely tuned research experience; it was a reservoir and a resource, an infrastructure and a form of care.[40]

[38] When asked during an interview about what being a "favorite" mom meant, a Junior Analyst for MARBLES remarked that it was usually the participants' warmth, commitment to their family, and candor with staff. She felt that being welcomed into these women's lives was really what connected her to the work. The "favorite moms" facilitate that feeling of connection for staff, and remind them why they work so hard.

[39] Below, I describe the visual cultures of EARLI and MARBLES through analyzing study websites, newsletters and promotional videos.

[40] As a form of care, these studies also become a way of *caring for.* With this distinction I am signaling how these studies provide resources for mothers, while mothers also participate in them as a way of caring for their own and others' families.

Science, Infrastructure and Forms of Care

In this chapter, I describe the scientific, material and affective dimensions of the autism research I studied. In doing so, I have two goals. First, extending from the history and controversies discussed in the last chapter, I detail the decisions and relationships that underscore the scientific infrastructure (Murphy 2012; Star 2010) of these particular cohort studies. In particular, I describe the institutions where which these studies are situated. I also detail the extensive work of principal investigators and study staff in coordinating and conducting these studies, and the relationships between these efforts and the meanings of research for the various actors involved. In articulating these dimensions of MARBLES in particular, I focus on how practices of care and caring become prominent features of this study.

Second, in thinking about the relationships between infrastructures of science and forms of care, I build on scholarship that extends feminist articulations of largely unacknowledged, feminized forms of economic productivity (Waldby and Cooper 2010; Hochschild 1983) to describe mothers' participation in autism research as a form of labor.[41] Following Cooper (2010), I argue that participation in prospective research contributes to a larger biomedical economy surrounding autism. I consider how affect motivates and supports this economy (see Ahmed 2004; Adams, Murphy and Clarke 2009), and how participation, in turn, becomes productive of shifting relationships

[41] Related to their work on tissue economies, Catherine Waldby and Melinda Cooper (2010) argue that female bodily productivity related to stem cell industries be considered a form of labor, which they distinguish from reproductive work as "regenerative labour" (2010:3). This recognizes the embodied productivity of the tissue donor as a form of labor, rather than positioning it in purely altruistic terms (Waldby and Cooper 2010: 9). Here, I am thinking with their term "regenerative labour" and their extension of feminist theories focused on women's labor within biomedical contexts. I am interested in considering how embodied labor in the MARBLES study is productive of both scientific knowledge, and forms of family care (see also Silverman 2011 on love and autism; Boris and Salazar Parreñas 2010 on intimate labor; Ahmed 2004 on affective economies; and Adams, Murphy and Clarke 2009 for a synthesis of literatures on affect and temporality).

between not only women, their bodies and biomedical knowledge, but autism families, scientists, and study staff as well.[42]

Through these two analyses, I show how research becomes meaningful to participants and scientists as both an investment and a form of support, as an infrastructure for building scientifically grounded relationships between nonhuman actants and autism as a disease category, and as an opportunity to build human relationships that offer care and understanding.[43] In connecting the private and the biomedical within my analysis, I mirror the conditions I observed during my research. What is produced from these interactions is much more than knowledge about autism's causes, it is a network of relationships that includes new ethical dimensions of mutual care and support. Care thus becomes a central component of these studies and a currency of exchange (Tabor N.d.) that enables ongoing commitment on the part of both families and researchers. I argue that, as a result, care provides a core component of these research studies, and is therefore foundational to the study of gene-environment interactions and autism.[44]

The data presented in this chapter are drawn from media and public accounts of the EARLI and MARBLES studies, interviews with principal investigators across the two projects, and observations and interviews with mothers participating in the MARBLES

[42] I transition to work here, rather than labor to signal sociological traditions focused on the sociology of work (see Clarke forthcoming).
[43] Actants include toxins, drugs, genes, immune markers, brain images and behavior, among others.
[44] Here my analysis is in conversation with Chloe Silverman's (2011:4) work on the history of autism science. Silverman uses love as an analytic tool to make visible the "emotional labor of science" taking place through parent and professional interactions. I use the term care (rather than love) to illustrate the intersections of prospective research, family relationships and prevention. This is an orientation most commonly associated with clinical settings, but one that is essential to the relationships among the scientists, staff and participants I studied. Here, care then gestures toward the practices of imagining, designing and implementing prospective epidemiologic research, and the affective dimensions that are produced through participation.

study. In providing accounts of both studies, I seek to convey that the work of producing care through scientific practice, and caring for families through participation in science, is broader than a single site. Indeed, it provides a critical framework for the prospective and longitudinal character of these research endeavors, which themselves form the basis of the distinctive GEI approaches to autism.[45]

I contend that, in many ways, it is the prolonged nature of MARBLES and EARLI that ushers in the possibility of support and exchanges of knowledge that move beyond the biological and hopeful to include both material *and affective* dimensions of care. In both studies a wide array of samples and assessments are collected over the course of many years. It is this extended time period and its ongoing intensity that invites mutual entrée: for researchers, into families' lives, and for participants, into the long process of research. Such sustained commitments also invite mutual responsibility: for researchers, to provide information on child developmental assessments and connections to early services if deemed necessary, and for participants to a whole host of possible care practices for their children whose effects remain largely uncertain.[46] These conditions signal the highly porous boundaries between scientific research and care (see also Mol 2010; Petryna 2009; and Whitmarsh 2008).

In the sections that follow, I detail the relationships between the UC-Davis M.I.N.D. Institute and the MARBLES study. I describe the specific design and data collection practices of MARBLES, illustrating its relationship to other research within the MIND Institute. I then detail the decision-making processes and considerations that led to

[45] The studies differ from other biological research on autism, including bio-repositories such as the Autism Genetic Research Exchange (AGRE) (Silverman 2011; Tabor and Lappé 2011; Singh 2010) particularly because of the breadth of samples provided by families and their involvement in the study over time.
[46] I discuss these practices in Chapter 5 in relation to mothers' understandings and experiences of autism's causes.

establishing EARLI. The contours of the both MARBLES and EARLI are illustrated here to demonstrate the connections between established scientific infrastructures and new questions about how to proceed when beginning a longitudinal investigation related to autism. I rely on media resources related to EARLI to illustrate some of the affective dimensions these decisions produce for study staff and participants. Finally, I detail how participants in MARBLES characterize their research participation. This analysis illustrates both the concrete and affective benefits that sustain mothers' ongoing commitments to the study. In conclusion, I consider what these findings reflect about the relationships among science, uncertainty, family and care.

Research Networks, Ethos and Infrastructure

The MIND Institute

The UC Davis MIND Institute (Medical Investigation of Neurodevelopmental Disorders Institute) is home to more than 40 research studies, 250 staff, and seventeen academic departments (MIND 2012). The Institute is funded by federal research grants awarded to investigators by the National Institutes of Health (NIH), private grants, and donations, and currently reports an annual budget of over $30 million. It is located in a state of the art building designed to facilitate interdisciplinary collaboration among basic scientists, developmental pediatricians, pediatric geneticists, child neurologists, child/adolescent psychiatrists, and child psychologists who work at MIND. The Institute is described as a "collaborative international research center, committed to the awareness, understanding, prevention, care, and cure of neurodevelopmental disorders" (MIND 2011). It has grown exponentially since its beginnings.

Modeling Science and Care

The Institute's beginnings signal its unique research and clinical model and an ethos of care and connection between family experiences and scientific endeavors. Frustrated by the lack of coordination among autism services and scientific research, the idea of the MIND Institute was initiated in 1997 by the father of a son diagnosed with autism. Joined by four other fathers in the Sacramento area, these men created a vision for a space that would facilitate communication and coordination of science and services related to autism and other neurodevelopmental disorders. These five fathers and their families met with researchers and service providers to garner support for their vision of an Institute that emphasized collaboration, transparency and interdisciplinary approaches to science on the causes, treatments and cures for autism (MIND Institute Director of Research; Anders 2003). The connection between clinical services and biological sciences were paramount to the founding parents. The Research Director of the MIND Institute recounted the parents' motivation and vision for the Institute:

> The parents, all who have children with profound autism, were frustrated in the late 1990s by the fact that very little was offered in the way of treatment or cures for their children. They were also frustrated that there seemed to be very little coordination between clinicians who well understood the phenomenology of autism and basic scientists who could try and understand the biological problems that might lead to the phenomena of autism, the behavioral impairments of autism. Based on that frustration they came up with a vision for an institute that would explicitly try to bring together clinicians and a clinic where families with children with autism could be seen, diagnosed and treated and at the same time, in the same facility, basic scientists who could start exploring the behavioral and biological causes for the problems in autism.

He went to explain the relationship between this vision and the academic center's home institution, UC-Davis:

> They brought that vision to UC-Davis, which at the time had virtually no research being done on neurodevelopmental disorders because UC-Davis was in a situation of programmatic development, particularly in the neurosciences and then translational or biomedical research. All of the administration here was actually very open to the idea of partnering with the parents.

Finally, he detailed how the parents' philosophy for the Institute continues to impact the approach they take to research on autism, especially their focus on the relationship between environmental factors and autism based on parents' experiences and questions about the condition:

> The parents actually came up with the name MIND Institute, which stands for medical investigation of neurodevelopmental disorders. They have the notion not only of the daily interaction between clinicians and basic scientists but they also have the view that the MIND Institute should take a very holistic approach towards autism, not think of it purely as a psychological disorder or behavioral disorder but as a medical disorder. Both of those principles have actually really guided me in trying to think of how to implement the vision. As one example of that we have been from the very beginning very open to the idea of studying environmental factors that might be contributing to the etiology of autism… The parents really guided...really set forth the vision of what the MIND Institute should be and I hope has become. I've really taken very seriously their vision. They are still actually involved and continue to give us guidance and suggestions about how we should make the MIND Institute better and more effective. Of course, now since the founding there have been dozens and dozens of other families who have gotten involved in providing us with advice about how to move forward (MIND Institute Research Director).

The Institute continues to pride itself as a model of parent-university-community partnership (Anders et al. 2003), highlighting the importance of the integration of "service delivery, supporting research and interdisciplinary education" throughout the Institutes' studies, clinical and community programs (Anders 2012).[47] Facilitating more fluid exchange among patient and carer experiences, clinical and biological sciences, and community services, also had the effect of connecting basic scientists to the families' whose lives they might someday impact. The Director noted the influence this model had

[47] American Academy of Child and Adolescent Psychiatry Website (accessed January 30, 2012): http://www.aacap.org/cs/root/developmentor/the_mind_institute_at_the_university_of_california_davis

on his own research, signaling the connections between scientists, clinicians and families are shaping research on autism for some scientists:

> On a personal level, prior to getting involved in the autism world a lot of my work was on parts of the brain like the hippocampus that are involved in clinical syndromes like Alzheimer's disease or epilepsy. I was really never all that interested in pursuing those clinical aspects. I was more interested in the basic science understanding of how the brain works. But for whatever reason, I've gotten personally more captivated by the stories that these families told, by how compelling they were, by the idea that with profound autism it really is a lost life although the life goes on full course. Since meeting the parents really my whole research career has changed. And I now consider myself to be fully invested in research on autism and committed to trying to accomplish some of the goals that they set out for us. (MIND Institute Research Director).

The Director's experience reflects the affective dimensions of autism science, echoing Silverman's (2011) astute analysis of the earlier scientific history of the condition. In these ways, the history of the MIND Institute signals both an extension of the relationships that have shaped autism science from its beginnings, and a new direction in their focus. Through intensifying scientific investments in questions related to the environment, the MIND Institute has helped reframe the scientific agenda related to autism and the environment (the emergence of which is detailed in Chapter Two), providing the basis for prospective epidemiologic investigations exploring the relationships between genetic and environmental factors in exploring the causes of autism.

The MIND Institute now hosts research and clinical programs that focus on autism, ADHD, chromosome 22q11.2 deletion syndrome, Down syndrome, fragile X syndrome and Tourette syndrome (MIND 2011). In expanding to focus on conditions beyond autism, the center also mirrors a shift in research related to the condition more generally. As Singh (2010) has noted, autism is being connected genetically with

conditions such as schizophrenia and attention deficit and hyperactivity disorder (ADHD). This pulls research efforts focused on autism's underlying biology in more expansive directions, connecting to myriad psychiatric and neurodevelopmental conditions. The impacts of these studies have also grown in their influence and prominence in the field, with many researchers and the Institute itself becoming nationally and internationally recognized. Findings have been presented at local, national and international conferences, with numerous results published in top ranking academic journals and news media often reporting on Institute studies.

Consistent with its mission, the Institute goes to great lengths to communicate research progress, findings and new questions to study participants and the larger community. Information dissemination programs including the "Minds Behind the MIND" lecture series and a "Distinguished Lecture Series" are free, advertised on the MIND website, and open to the public. Video recordings are later provided on the website as well. The catalog of presentations reflects the range of topics specifically oriented to the public. This public face of research is reflected in media about the Institute as well, portraying scientists and families as friends, colleagues and comrades supporting one another through their shared commitment to the disorder.

These studies and outreach efforts at the MIND Institute reflect a vast network that scientists employed and parents accessed through participation in MARBLES. While not every participant I spoke to utilized this network extensively, each mentioned the benefits of being connected with the MIND Institute, drawing on the recognition of the Institute and its experts, as well as the additional resources provided through access to the Institute's clinical and research programs. While the MIND Institute is part of UC-Davis,

research studies also exist outside of the Institute, within the University of California more broadly or through surrounding collaborative sites including Kaiser Permanente and other organizations, providing other mechanisms of connection for research participants.[48]

The parent-university-community partnership model of the Institute and its intellectual and clinical infrastructure provides a kind of connective tissue for participants' experiences as study subjects. These programs and the relationships between them also reflect researchers' locations as Investigators within the larger networks. As I detail in the last section of this chapter, mothers I spoke to conveyed a sense of being plugged into a larger network that provided benefits extending beyond their specific research study they initially participated in. Many of my interviewees were concurrently or formerly participants in other UC-Davis or MIND Institute studies, in addition to MARBLES. Next I describe MARBLES to illustrate its relationships to the MIND Institute as a scientific infrastructure and an ethos for conducting autism etiologic research.

[48] The contours of the MIND Institute, including its beginnings, expanding research focus, and relationships to the autism community, State and Nation, can also be seen as extensions of the Networks of Concern I detailed in Chapter Two. In many ways, the forms of capital and biocaptial that support the infrastructure I describe in this chapter are central components of *how* science becomes a form of care and caring for. The relationships between the specificities of scientific practice and participation described in this chapter, and the conditions of possibility detailed in Chapter Two, therefore provide further examples of the connections between science, uncertainty and care. In this way, the feedback loops among advocacy efforts, scientific practices (large and small) and family experiences, may very well extend networks of concern beyond the establishment of research agendas, into the very practices of these agendas and their relationships to changing understandings and experiences of autism. These layers reflect the macro, meso and micro dimensions of anticipating autism, revealing how much *work* truly goes into this orientation across domains of policy setting, scientific practice and family life.

Relations Between: MARBLES and CHARGE

The MARBLES study (described in detail in Chapter One) grew out of the Childhood Autism Risks from Genetics and the Environment (CHARGE) study. While scientists explained that the idea for MARBLES circulated widely among epidemiologists as an ideal study design for considering autism risk factors, it was the connection between CHARGE and the MIND Institute that provided initial institutional support for MARBLES. The first study of its kind, CHARGE was launched in 2003 and sought to enroll "1,000 to 2,000 children with differing patterns of development." The goal of the landmark study was to explore the environmental and genetic causes of autism through employing a case control design. Several researchers I talked with described this as a seminal study in the field of autism epidemiology. CHARGE was also unique as it offered an explicit commitment to concerns about understanding autism's causality that fully embraced questions about the role of the environment.

The case control study enrolled three groups of children: "children with autism, children with developmental delay who do not have autism and children from the general population" with the goal "to better understand the causes and contributing factors for autism or developmental delay" (CHARGE 2012). The study, originating from the UC-Davis Center for Children's Environmental Health (CCEH), offered one the largest epidemiologic studies focused on gene-environment interactions and environmental contributions to autism. As such, CHARGE also offered a unique participant population from which to draw families who had a child diagnosed with autism and were considering having another child.

MARBLES was designed to recruit expectant mothers from the CHARGE case population and to recruit additional participants from the surrounding community. This approach gave principal investigators the opportunity to explore the broader implications of findings generated from CHARGE data through focusing on a more specific population. Early on, MARBLES focused specifically on questions related to immunologic aberrations found in children with autism within the CHARGE case population (e.g., Ashwood et al. 2006). The MARBLES study design and population allowed researchers to consider through prospective longitudinal data collection whether these findings related to autism, when they started, how and why. A Principal Investigator of both CHARGE and MARBLES explained the advantages of the prospective design of the MARBLES study:

> So it makes sense that there could be these immunologic aberrations but how can we know which came first, the chicken or the egg? That's where the MARBLES study came from. It's a way of stepping back in time and it's very complementary to the CHARGE Study. So basically, all the findings we were starting to get, these biological findings [from CHARGE]… we got them and we said, "Gee, when did that start?" You know, is this part of the cause or is it just part of the outcome, or it could be neither.

The close connections between CHARGE and MARBLES from both scientific and recruitment perspectives, and the large network of studies and clinics illustrated in the map of the MIND Institute, provide a snapshot of the intimate connections among what may have otherwise been distinct research areas outside of the MIND Institute. The unique model of connecting studies to one another and to the questions affecting families lives – including what causes autism, when and how – was the model envisioned by the Institute's founding families.

Such models of research are by no means new (see Silverman 2011; Tabor and Lappé 2011; Singh 2010 for examples in autism). As I have detailed in this section, however, the unique beginnings of the MIND Institute, and its ethos of interdisciplinary collaboration, family support and community education, provided the infrastructure for studies like CHARGE and MARBLES. These studies ushered in new research questions related to environmental risk factors and autism, further extending the networks of concern I detailed in Chapter Two, and building an infrastructure for these sciences and *simultaneously* forms of care. The mission of the MIND Institute and the connections between science and family experiences set forth by its founders, became palpable in the intimate exchanges and experiences of the research participation I observed. These affective dimensions also extended beyond the MARBLES study to characterize other prospective cohort studies, including the Early Autism Risk Longitudinal Investigation (EARLI).[49]

Research as Investment and Infrastructure: From Ideas to Studies

For many of the scientists I spoke to, imagining, articulating, initiating, and conducting research studies reflected investments in knowing autism better through building resources that created enhanced opportunities over time.[50] These included investments in exploring existing questions about autism's biological basis, efforts to

[49] Universities have long been fertile sites for scientific knowledge production, and are representative of bioeconomies (Waldby 2009) in their own right. As such, this analysis offers just one example of broader economies of science built on circulations of uncertainty, hope, bodies and biologies.

[50] Across MARBLES and EARLI, this was accomplished through incorporating studies into existing research infrastructures, extending existing infrastructures into new domains. For MARBLES these were UC-Davis, the MIND Institute, and the Center for Children's Environmental Health (CCEH), where existing studies provided a pool of potential participants, should they become pregnant again, and word-of-mouth helped garner participants within the surrounding community. For EARLI, the study was built from Autism Centers of Excellence (ACE) and thriving University and research clinics. Each site had its own protocol for recruiting participants and used existing systems to facilitate more fluid recruitment and retention of families.

establish broader research agendas, and opportunities to build biological databases that would allow emerging questions about the condition to be answered far into the future.

As with many large-scale research studies, scientists I spoke to discussed how the ideas for MARBLES and EARLI stemmed from conversations, conferences and workshops organized years before they ever submitted successful grants. I detailed in Chapter Two how growing political and social momentum surrounding questions about the relationship between potential environmental risk factors and autism provided the conditions of possibility for *multiple* kinds of research on the environment, including the studies I focus on here. However, garnering funding for prospective studies meant years of concerted efforts on the part of PIs. Gaining funding for these elaborate, expensive, multiple year studies reflected scientists' ability to strategically build on existing research infrastructures and smaller pilot grants. This meant that PIs had to position themselves and their forms of expertise as meaningful in addressing continued questions about the causes of autism.[51] In these ways, grantsmanship, research experience, and established scientific and administrative infrastructures, all provided the foundations for prospective studies. This was especially the case for EARLI, which involved the funding and establishment of four separate coordinating sites across the United States (EARLI 2012). One of the Principal Investigators of EARLI, recalled the origins of the study idea and its initial limitations:

> The idea's been kicked around for a while. I mean Autism Speaks did a workshop, years before. Several years before MARBLES or EARLI started we

[51] I detail in Chapter Two the structural and funding conditions that underscored these opportunities. Even given these mechanisms, it was not always easy for environmental and genetic epidemiologists to garner funding given the much smaller budgets of the NIEHS (as compared with other institutes). Many sought pilot grants through advocacy funding organizations, such as Autism Speaks (see for examples, Autism Speaks Environmental Factors in Autism Initiative 2012). Some scientists felt this was potentially problematic because of the political nature of the advocacy organization (see Weintraub 2011).

> had a conference. I organized a conference in Baltimore where we brought together Irva [Hertz-Picciotto] and Judy [Van de Water], and all these people... a variety of people - Ezra Susser - who's now doing prenatal studies too. You know, we all came together and we talked about 'is this a good idea to do a pregnancy cohort study and enriched risks?'[52] We talked about all the issues and, you know, again a lot of these people had been thinking about it, you know, it's come up. It's sort of a no-brainer and so we tried to hash it out a little bit. So that sort of laid down, I think, the design principles certainly for EARLI, I don't know whether it did the same thing for MARBLES or not. So the idea's been around a while. I mean the reason why it took a little longer, [is that] it's always easier to do retrospective studies. So, that's why all the retrospective studies go first.

As this quote describes, the design principles for the prospective studies were laid out years before the first grants were written and awarded. Here, the Principal Investigator also points out an important aspect of the trajectory of epidemiologic research, that prospective research must often follow retrospective studies. This dynamic of epidemiologic knowledge production speaks to the tempo and timing of autism epidemiology and risk factor studies. It also reflects the scientific, social and political conditions required for the development of prospective investigations such as EARLI and MARBLES from ideas to material research endeavors.

The scientist quoted above goes on to explain the tensions implicit in designing EARLI as a rich resource and meaningful data repository, rather than highlighting specific analytic goals for the first funding cycle. The quote below makes clear that these two priorities – building a rich resource and generating meaningful early findings – are intimately intertwined, but often in tension with one another when designing prospective cohort studies for complex conditions. This detailed account reflects the careful promissory work (Novas 2006) of balancing study design decisions and later results:

> You know, the amazing thing about getting EARLI funded is we really do not have a pre-specified list of environmental factors, which is, you know, sort of

[52] "Enriched risks" here reflects an epidemiologic term characterizing the cohort of families with higher risk of having a subsequent child diagnosed with autism or a developmental disability.

> procrastination of the inevitable. But we really, we wrote the grant saying that we wanted to develop the robust capability to look at many different things. If you were to read the grant application you would see that, you know, classes of exposures are just mentioned as *potentials*. Because we had the luxury of the fact that we made the decision early on when we were developing the project… we had a strategic decision from the grantsmanship perspective of 'should we claim that we can get something done in five years?' And we decided not to, which was a big discussion because, you know, it's a gamble because a lot of times things like that are hard to support, harder to get supported. So we didn't. And so, because of that, it was liberating. And then we said, "You know, well, look, we want to build this cohort, we want to collect these samples, we want to ask these questions. Here are the kinds of things we're going to look at. But, you know, the landscape's going to change over these five years and it's really in the second five-year cycle that we're going to have to do the hard work of prioritizing our analytic aims" (EARLI Principal Investigator).

This Principal Investigator went on to detail the process of prioritizing what they called "exemplary specific aims." The quote below points to the importance of the expertise and experience of the Co-Investigators and the resources of their existing sites, as well as the limits of the sample population for producing meaningful results within the first five years of the grant cycle:

> We included a class of things that were called "exemplary specific aims." Because we did feel that we had to do *something*. We couldn't just say we were going to enroll them. Well, now, I would have been happy saying, "let's just enroll." But we really felt that we needed to do something, that we had to come up with *some* things. So what factored into the list of the things that made exemplary specific aims? Was it things that we think are most likely driving... you know, [that] are "real" autism risk factors? Well, I can tell you it was not, you know, 'priority one, two, three...' it was the things that we had experience in, we have to show a track record. It was things that we thought we could do something with. You know, to spend some resources on the analysis and not have it be silly to do it. Because, at that point [five years into the study] we're going to have very few kids to follow up at 36-months. Anything that really is supposed to be, you know, based on a contrast of cases/non-cases, we're not going to be anywhere near power to do any of that. So it was things that we thought we might learn something about.

This quote illustrates the continuities between existing infrastructures of science and autism knowledge production. For EARLI, priorities are established with regard to

existing forms of expertise and the limitations of both data and analysis imaged in the future. These become central in generating early research priorities for autism GEI research. The Principal Investigator quoted above went on to detail the five exemplary specific aims that were included in their initial grant application for EARLI. These included exogenous exposures such as PBDEs, gene-environment interactions related to particular classes of drugs, DNA analyses, and endogenous biomarkers such as immune markers. However, he also pointed out that one central goal of the study was to produce a rich resource that would allow scientists to develop meaningful research questions and analyses as time went on:

> Again...I signed a consent so I'm being honest, this is more grantsmanship than priority science. I wanted to come up with a set of things highlighting the different things that we could do with the study because that's really where the *value* is. This idea that we're going to build this rich resource and then, you know, as we *know more* we hopefully, we'll be able to follow those *evidence-based leads* and make a contribution that way. So we want to show the range… So, we took form the different centers things that people had experiences in that kind of highlighted the potential of the cohort. But are those...are those five things going to be the first five? I mean maybe there'll be some inertia established because we've done the pilot work but maybe not. There could be, you know, leads in other areas and that'll focus our bigger analyses in a different direction. And I'm comfortable [with that]. And that's a very controversial thing. You know, this whole idea about epidemiology is discovery science versus having it be hypothesis driven. And is that a good thing or a bad thing? I mean I'm pretty convinced that at least for autism we have to do it. We have to be responsible about what comes out the other end. Which is the tricky part. Or *a* tricky part. (EARLI Principal Investigator, emphasis added).

This quote reflects the careful scientific work of establishing a prospective pregnancy study while recognizing the risks and possibilities inherent in this prolonged approach. This dynamic places questions of cause as constantly moving targets that must be arrived at through careful consideration of data within the limits of the study. This simultaneous attention to early research processes and later outcomes helps to produce an infrastructure

for knowledge production that relies on the *accumulation* of data in order to generate central questions about the relationships between autism and risk. This process and the tensions inherent in building cohorts as resources over long periods of time are also reflected in researchers' decisions about participants' experiences during the study.

Intersections of Life and Research Design

During my conversations with PIs, in addition to recounting the processes involved in establishing MARBLES and EARLI, they also reflected on their decisions related to recruitment, participant retention and sample collection. There was an ever-present awareness of time, the value of collecting data prospectively, and the obligations of doing so responsibly. Another Principal Investigator of the EARLI Network reflected on the benefits and concerns involved in prospective research:

> It's really an ideal design because you're...you've got prospective data collection. You know, you're there when things are happening. You can take samples during pregnancy and ask people what's going on right then and there. Rather than this retrospective kind of, you know, data collection that we do most of the time, which is problematic. [Prospective data collection] is very intensive and it takes a lot out of everybody I think [chuckle], you know, the participants and the researchers, to get all this information. It's a burden but I think, if we do it right, there'll be something in it for the families who participate. You know, they'll get something out of it as well as giving a huge amount to the research.

Here we see the value placed on building understandings of autism in real time, sample-by-sample, pregnancy-by-pregnancy, birth-by-birth and evaluation-by-evaluation. These efforts provide the potential for future knowledge of autism. The ongoing and time intensive nature of this study design required that researchers be aware of the tolls participation might take on families. Playing a key role in families' lives through providing resources not otherwise available, including the prospect that more could be known about autism in the future, became both an investment in good science *and* in

caring for individual families within the study. These dual investments in good science and care for families are produced – or at very least *intensified* – by the prospective nature of the research design.

In sharp contrast with retrospective studies and hypothesis driven research, the opportunities of prospective studies are partially situated in their emergent qualities. Prospective research is both immediate and fast paced, slow and prolonged. It requires day-to-day activities of coordinating staff, recruiting and enrolling families, conducting informed consent procedures, scheduling study appointments, and collecting and storing data. In the long term, data are accumulated, stored, shipped and analyzed. This work produces findings that will be published and grant applications that will be written, promising opportunities for future knowledge based on the quality and efficacy of efforts in the present. Importantly, the balance of collecting data in real time, and producing enough information to generate new knowledge about autism in the future, required investments on the part of PIs, study staff and funders in both the possibilities of the science and in families themselves. Investigators I spoke to were very aware of these dual commitments of the study and the opportunities and challenges each posed for study Investigators. The Principal Investigator quoted above went on to illustrate this point as she explained what she hoped might develop from EARLI:

> I'm hoping that we will really discover things that haven't been discovered before, that we'll really learn something and we'll have *large enough numbers* to really look at a lot of the suggested factors that have come up in smaller studies and be able to do a much more controlled analyses, you know, more rigorous kinds of analyses of the data. And I think also, aside from the research findings and the sort of the risk factor causal thing, it's going to teach us a lot. We're going to be sort of going through this process with a lot of these families and I think, you know, that's going to be pretty profound. And there's going to be a lot of issues that come up that, um, hopefully will help guide service provision and health education efforts and… counseling and whatnot. You know, it's a little bit hard…

> just how to best serve and provide resources for these families, for the older kid, for the new baby, for the pregnant woman, for the family. A lot of that which I think will be really fascinating and helpful because there's a lot of fear and anxiety and a lot of unknowns, you know. Just by sort of *going through this process with these participants* we're going to hear about a lot of stuff within a research structure so we can hopefully capture some of this and relay it into something that'll be helpful. I mean that's what I'm hoping.

Her hopes for EARLI reflect the possibilities for autism science, as well as family care. When asked whether there were systems built into the study to account for families' experiences and service needs, she replied:

> There are going to be certain things that emerge [during the study period]. You know, there's going to be these new babies, for example. If there are some developmental concerns, you know, we're going to capture them from the research point of view. But we have to connect these families to resources and get them engaged in early intervention and all that. So we have a process for doing that, sort of a structure for doing that. But at each site it's probably going to look at little differently. I think there's going to be a lot of issues that we can't anticipate. We're just going to have to kind of deal with when them when they arise. Like, "Oh." Like, you know, "What do we do now?" But it's very much part of our consciousness that these are real people with real things. And we're going to be looking at their babies and some of them are going to end up having some developmental concerns and we've got to deal with it clinically.

As her response details, researchers were aware of the need to build in resources for families whose children showed signs of developmental delay. In addition, they knew that parents' participation might be motivated in part by their concern about their new children's development, their interest in catching signs of autism early, and in gaining assistance in navigating the complex logistics of coordinating resources and services for autism. Doing something to ameliorate the anxieties produced by these realities therefore became an important element of conducting prospective longitudinal studies that could effectively generate knowledge about the causes of autism, while not over burdening families who agreed to participate.

The sections above make clear that, as the first large-scale U.S. studies to

prospectively follow mothers through their pregnancies and after their children are born, both MARBLES and EARLI provide unique opportunities for both science *and* care. The prolonged engagements between researchers and participants become a central component of these studies, built into the very fabric of their design. These facilitate access to participants' biological samples, surveys and developmental information, and intimate knowledge of their lived experiences with autism. The result is not only the possibility of generating more reliable knowledge about autism as a disease category, but also opportunities for care. These are reflected in the commitments of scientists and study staff, as documented above. As I describe below, these commitments are further evidenced in the visual cultures of EARLI and in mothers' work as participants in MARBLES.

Prolonged Connections and Caring for Families

In their first Study Newsletter, "the EARLI Edition," staff members from several EARLI Network sites detail the connections they felt to families involved in the study. One researcher stated, "It's pretty amazing to be able to follow a family through this study. It lends a very intimate window into a family's life" (EARLI Newsletter 2011). This is in part because, like in the MARBLES study, EARLI Network staff members interact with participants throughout their pregnancies and during early child development. They analyze mothers' in-depth pregnancy diaries, collect samples during each trimester, and are often there in the delivery room because of the time sensitive nature of collecting placenta and umbilical cord blood (EARLI Newsletter 2011). Following the delivery, staff might be some of the first non-family members to check in on families.

Staff follow-up with mothers and their children every three months for the first year of the child's life to collect samples, and conduct behavioral assessments beginning when the child is six months of age. While required appointments become less frequent over the last two years of the study (every six months, then once per year), copies of each assessment are provided to families throughout. These become a valued resource for families, especially if developmental delays are suspected. If delays are identified, study staff assist families in accessing early developmental services or enrolling their children in early intervention studies, aspects of care that I describe in more detail in the sections below.

The connections between families and staff form an important foundation for participants' ongoing commitment to the study. These relationships begin during, and sometimes before, a mothers' pregnancy and are sustained during some of the most formative years of her child's early development. The first three years of a child's life have become increasingly concentrated sites of attention when it comes to autism. As I describe in Chapter Five, mothers participating in MARBLES described being attentive to early signs of autism throughout the study period. These ranged from observations and feelings about their experiences during pregnancy, to their newborn children's behaviors and similarities between them and their older siblings who had been diagnosed with autism.

Images of Care

The visual cultures of EARLI and MARBLES further demonstrate how relationships with study staff and principal investigators become part of these modes of surveillance, as well as care, for participants. For example, in advertisements and public

relations materials Principal Investigators are pictured, smiling warmly with their arms around the shoulders of parent participants. In other photos, they hold participating children in their arms, playing with them on grassy lawns (EARLI Newsletter 2011). In these depictions, the Principal Investigator is easily mistaken for the parent of the children pictured. The children are laughing, smiling, playing and scientists appear relaxed, comfortable and affectionate. The genuine feeling of these photos isn't surprising, as many investigators I spoke to voiced strong commitments to the autism community and personal connections with the experiences of parents in the studies.

In other photos, the Principal Investigator is pictured patiently explaining aspects of the study to families and listening intently to families' questions (EARLI Newsletter 2011). While such depictions do not represent all families' experiences, these images reflect not only the idea of the research, but many of the practices I observed as well. In promotional videos and testimonials for EARLI, parents discussed feeling relieved when they found out about the study, describing the sense of reassurance they experienced as participants (EARLI Video 2012).[53] Mothers and fathers in these videos position themselves as resources for studies, and research as a resource for them as well. One participant states that families "are the ones who can provide the answers. They are living through things that research can contribute to" (EARLI Video 2012). Another video displays a mother who states passionately:

> Being able to participate in something for the betterment of your child, or even if it's not your child, if it's somebody else's, for these children, for this disorder. To be able to sit there and say you did something, and to educate yourself in the process – I mean that's awesome. I think that's what every parent wants, a little bit of clarity and just someone to hold your hand through something (Mother Participant, EARLI Video 2012).

[53] EARLI Network Website (Accessed January 30, 2012): http://www.earlistudy.org/.

This testimonial reflects the benefits to families of participating in prospective studies, as well as the benefits they felt the research might yield for others. This sense that participation is both a commitment you make as the parent of a child diagnosed with autism and an opportunity to gain support, was echoed across study materials related to MARBLES and EARLI, and during my study observations.

Across study materials, the feeling communicated about the research is one of connection: between the science and the daily lives of autism families, between the myriad samples collected and answers about what causes autism, and between the studies' promises and ameliorating parents' uncertainties about autism. These images illustrate the dual priorities of the study that Principal Investigators detailed above.

Participation as Care: Mothers' Work

For the mothers I interviewed and observed, participation in MARBLES offered both an investment in knowing autism better, as well as a form of care for their own and others' families. In these ways, I see mothers' participation in prospective autism research as a form of "taking care." I distinguish this work practice from caretaking because of its preemptive qualities. Through investing time and energy in research, mothers aimed to create better conditions for the future, rather than to solely ameliorate the effects of an established diagnosis. This adds an additional dimension to the analysis of autism parenting as a vocation offered by Eyal et al. (2010). The authors' work reflects how parent activism has been foundational to the changing relations of expertise that surround autism (see Eyal et al. 2010). They describe how parent activism inverted histories of blame wrongly attributed to parents (and mothers in particular) through positioning themselves as co-therapists and essential partners in autism care (Eyal et al. 2010). In my

analysis, mothers' participation in prospective autism research becomes a form of "taking care" because it embodies both material benefits, should their new children develop autism, and a commitment to the *potential* benefits of their efforts for future families.

Through their participation, families gleaned material and affective resources including concrete benefits like behavioral assessments, developmental evaluations and letters they could use to support their child's classroom needs during Individual Education Plan (IEP) meetings. But there was also a sense of reassurance that mothers recounted as a result of having "another set of eyes" assessing their child and validating their experiences. In addition to investing in the production of knowledge of autism for future families, mothers I talked to described tapping into important networks their research participation made possible.

The credibility of the MIND Institute and the access it provided to clinical experts were central in some mothers' decisions to participate in MARBLES. The reputation of the Institute, along with the recognition of its experts, provided resources that became valuable benefits of participation. Eleanor described how the reputation of UC-Davis and the MIND Institute circulated widely among parent groups, especially as a resource when requesting services from the school district:

> When we came [to the Sacramento area] one of the things that people told us was "You should try to get plugged in with UC-Davis." You know, the MIND folks because they do studies. For one thing, if you enroll your son in a study with them and they do evaluations that can help you when you're fighting with the [school] district [for services] if they say your kid doesn't need whatever. Because you know how it is when you're dealing with the districts and the regional centers. If [the district] finds something wrong then they're obligated to pay to remediate it, and so they have a tendency not to find stuff.[54]

She went on to say,

[54] Eleanor is talking about developmental and Individual Education Plan assessments conducted by the California statewide regional center system and the school district, respectively.

> So if you want to have outside evaluations, which we do… if you have the MIND Institute's name on it, well, that carries a little more weight than just 'Joe Blow guy in the community,' you know. Because they're well respected, they've published, they're not quacks. And so it was a… it's way, you know, to get him in to get evaluated.

Eleanor describes the value of the clinical assessments provided by the MIND Institute and their translation into services for children diagnosed with autism. These are positioned in relation to state services, which are cast as less reliable resources in her experience. Here, the MIND Institute becomes a resource for care through providing reputable developmental assessments during research participation.

Alongside the material benefits of obtaining developmental assessments, mothers' participation in MARBLES was also reflected their investments in their knowledge of, and support for, their child and their larger family. This took place on different registers – from social and emotional support, to access to clinical trials and experimental interventions. These are each aspects of a larger reinforcement of biomedical research participation as a potential site for care (Petryna 2009; Whitmarsh 2008). Mothers' participation in MARBLES and other autism research also signals an investment in future autism families, and in knowledge about autism as a biomedical category and experience that can be known better through biomedical research. Elizabeth describes these dual motivations for participating in MARBLES in particular:

> I'm obviously always interested in helping where I can. If I can save another child from having to go through the struggles that [my daughter] experiences, and the frustration that she experiences, I will do it. And if I can do something to help my family in that particular case, like have a child watched for the first three years of their life and go through studies and know that she was okay and that everything developmentally was okay, I would do it. Because I wanted to know if there was a point when things shifted, I want to know where that is. I want to know what happened and when and where and why and how... I wanted to know. So for that one it was very selfish, I got that out of it.

Maria echoed Elizabeth's commitment to finding answers about autism through investing in research. Maria explains her feelings about the research:

> I just think, I mean research is so important, it's the key to answers. And, with autism being one of the most confusing diagnosis that offers almost *no* answers from how did they get it, is there a cure, what kind of treatment should you use, what can you expect? You don't know anything… All these things that parents with typically developing children don't even think about. I think... it shouldn't be like this. And I feel like I'm taking one for the team. Like, "Okay, this is it, this is my life." But if it doesn't have to be this way, if someone is willing and able to find an answer so that the future will be able to handle all of this better or easier then *I* want to make that happen, *I want to help make that happen*. And that's why I look for all the studies that I can do.

Maria's participation in research is situated here in relation to both the potential and promise of research, and her personal experience following her son's diagnosis. When asked whether there was anything that drew her to MARBLES in particular, however, Maria answered definitively: "The developmental evaluations that would be given as a participant." She went on to describe the importance of participating in the study in order to catch developmental delays as early as possible for her younger son:

> I've wanted to make sure that if we were going to have another baby I want as many eyes on him as possible. And if he is going to develop autism I want it to be caught even earlier than [my other son] and get going *immediately*. Because I've seen the difference between my [older son] being diagnosed at 2 and someone being diagnosed at 13 or even in between. There is a huge difference. And I figured the study says they'll be developmental evaluations at 6 months, 9 months, 12, 2 years and 3 years. I'm like, "That is great. I need that. Otherwise I'm going to have to pay." Or that [my insurance company] is not going to want to pay for it, or do it, or refer me somewhere where it can get done.

Maria frames the opportunity to have her son evaluated early and often in terms of both his development and their finances, pointing to an important relationship between research participation and care (see also Cooper and Waldby forthcoming). As a social worker, she mentioned seeing the advantages of having a child diagnosed early, rather

than later in life. Personally, with her older son already diagnosed with autism, she felt these benefits of research participation as significant for her child's health and her family's wellbeing. Here, the study offered the opportunity of knowing earlier, and by extension, the promise of better care for her son. For Maria and others, these themes punctuated their descriptions of participating in MARBLES.

Others reflected their commitment to finding research that aligned with their specific concerns about what caused autism, and that would provide them peace of mind, especially surrounding an unanticipated pregnancy. Elizabeth notes:

> When I found out that I was pregnant with [my third daughter] I was first shocked and then second, shocked. And then when I got over my shock I became extremely frightened because, you know, that knowledge that there are in my opinion strong environmental factors that went into [my first daughter] developing autism. I just wanted to be sure that I was avoiding whatever those things were, that I was trying to live clean enough that, hopefully, it wouldn't trigger whatever the genetic component was.

For Elizabeth, participating in MARBLES provided a resource and scientific experts that she saw as aligned with her concerns about the causes of autism. This network also provided support as she faced a pregnancy she had not planned.[55]

In addition to the sense of reassurance and the ongoing evaluations of their new child's development, mothers described MARBLES as offering them support in navigating research and service opportunities for their children if or when developmental delays were detected within the study. Maria detailed the instrumental role of the

[55] For many of the mothers I interviewed, their pregnancies were unplanned. Elizabeth, for example, had been told she would be unable to have another child due to health complications. She described in further detail in our interview the sense of concern and joy that came with the news that she was pregnant. For others, they carefully thought through when and whether to conceive; often delaying plans to have another child until their children were older and the severity of their diagnoses more evident. Still others became pregnant just on the cusp of their older child's diagnosis. As I detail in the next chapter, the process of obtaining a diagnosis often took participants months or years and is not usually given before age three. As a result, many had already become pregnant when they received their child's autism diagnosis.

MARBLES staff when they recognized early signs of developmental delay in her younger son:

> When I got into MARBLES the rest just kind of lined up from MARBLES, the infant-sibling, from the infant-sibling the one that my baby's in, the intervention. It's like prevention of ASD, [an] intervention study where he has therapy once a week.

In other instances, staff helped families gain access to services through the regional centers, and checked in with mothers during follow-up study appointments to assess the quality and efficacy of the therapies their children were receiving (Fieldnotes January 21, 2010). This example and the quotes above illustrate the forms of both material care and emotional support mothers' and their families gleaned by participating in MARBLES.

As I have illustrated in this section, the ongoing nature of data collection in MARBLES offers a resource many of the mothers I spoke to thought of as a benefit to their families and to their own sense of wellbeing. Mothers were not only interested in the evaluations offered by MARBLES but the attention provided to them by experts during these pivotal developmental periods of their children's lives. In these ways, participation provided mothers' with peace of mind and a sense of support as they navigated their pregnancies and the early years of their new children's development. The ongoing nature of the evaluations conducted by trained staff and their ability to document children's needs, provided a resource and a way of taking care in anticipation of autism. Participation therefore provided mothers access to networks of both affective support and material resources that helped them care for themselves and their families. In these ways participation not only signals an investment in answering questions about autism for future families, but commitments to their families as well.

Conclusion

In this chapter, I have illustrated how forms of care become central to the infrastructures of prospective cohort studies focused on pregnancy and early childhood. I have detailed the unique infrastructure of the MIND Institutive and its relationships to the frustrations and hopes of parents of children with severe autism. I detailed the connections between this unique model and the MARBLES study, as well as the relationships between MARBLES and EARLI. I also pointed to the unique ways in which prospective research focused on autism risks is positioned to follow the experiences of families during important and meaningful points in their lives.

In tracing these dynamics of autism research, I considered the complex relationships between scientific infrastructures and forms of care. These simultaneously position research participation as both a means of producing knowledge about autism in the aggregate, and an opportunity for reassurance and resources that offer affective and material forms of support for participant families. These relationships between science and care are produced by the commitments of scientists, study staff and participants alike.

As a result of Principal Investigators' awareness of the opportunities and obligations of this design, I argued that forms of care are built into this very design of these studies. These come in the form of developmental evaluations, answers to parents' questions about autism, their children's behaviors, and possible risk factors, and reassurance that services or research opportunities would be made available should early delays be detected. The material and affective dimensions of participation are then reflected in the accounts of participants' themselves. Through detailing mothers' reflections on their reasons for participating, I connect the personal and the technical in

this analysis, pointing to the porous boundaries between scientific research and care that are especially salient in long-term research commitments.

Through making research participation complementary to family needs and concerns, Principal Investigators provided participating families resources and points of contact with a large apparatus of coordinated information and accumulating knowledge about autism. Thus, through complementing systems of autism care and family needs, MARBLES and EARLI are able to provide participants with ongoing reassurance, while also recruiting cohorts and collecting samples that are considered investments in knowledge production in the future. Scientists also pointed out how the design of the study provided both practical clues to research questions, and research practices that supported families' needs. These forms of support were made visible in mothers' accounts of their participation in MARBLES. Families were both partners in and resources for research.

As I've attempted to illustrate in this chapter, the unknown and uncertain elements of autism – when it begins, why and what should be done about it – serve as motivations for participants and researchers alike. While the samples and data collected throughout the study are anonymously stored and await future analysis, the personal engagement of study staff with parents on an ongoing basis, and the commitments of the Principal Investigators, provide the intimate ties that produce this science as a form of care. Mothers engage the studies as a resource for their families, while researchers and principal investigators recognize these as benefits of participation and specifically structure the studies to provide more than just future answers to families current questions about autism's cause. This analysis contributes to sociological research on

women's labor and care work (Hochschild 1983), extending feminist articulations of largely unacknowledged, feminized forms of economic productivity (Waldby and Cooper 2010) to include women's work as participants in the autism knowledge economy. This form of affective work is largely initiated through processes of diagnosis, which I describe in the next Chapter.

CHAPTER 4:
DIAGNOSIS AND TRANSFORMATION

> *Diagnoses do not exist ontologically. They are concepts which bind the biological, the technological, the social, the political and the lived* (Jutel 2009:278).

Transforming Autism Diagnosis

At the 2009 *International Meeting for Autism Research* (IMFAR) I settle into a stiff, neatly upholstered seat in the Grand Ballroom of the Chicago Hilton. A colleague of mine and I have made our way to the middle of a row of seats not far from the podium. We are here to listen to the keynote presenter. As I position my computer on my lap, I notice how closely spaced our seats are and realize that the room can seat nearly 1000 people. Though not all of the seats are filled, it is clear that the organizers have arranged for as many people as possible to attend.

Looking around, I can't help but think that this annual meeting makes autism seem rather glamorous – like autism science is an exclusive club that more and more people want to join.[56] Even the hotel feels like it has been dressed to the nines for the occasion, with its vaulted ceilings and vintage details throughout, the lobby floors buffed and polished. As a participant observer for several years at IMFAR meetings, I also have the sense that the topics and sessions are at an interesting crossroads this year. I think back on the 2008 plenary session in London, where the hall was also large, the meeting a smorgasbord of the latest findings in autism science and care. This year the participants seem younger, the events and sessions more expansive. There is a sense of liveliness, a

[56] Singh (2010) has illustrated that this sentiment is shared by many of the original researchers in the field, who have mixed feelings about the influx of funding and its effects on the field.

sort of youthful excitement that infuses the space.[57] While there will continue to be sessions on autism genetics, clinical assessment and behavioral interventions, the following year will see more educational and scientific sessions specifically devoted to autism epidemiology, autism and the environment, and risk communication (IMFAR 2010). However, as someone who has been following the changing locations of "the environment" in autism science, the 2009 keynote presentation provides an important reminder of what continues to organize this growing field: the diagnosis itself.

The keynote presenter, Dr. Catherine Lord, is introduced and takes the podium. Her reputation certainly precedes her. Dr. Lord is an expert in autism diagnostics and their changing features over the past 30 years. In 1984, together with Michael Rutter, she developed the Autism Diagnostic Interview (ADI) and the Autism Diagnostic Observation Schedule (ADOS). Intended to complement one another, these tools remain the gold standard in autism diagnostic instruments to this day (Silverman 2011). Since then, Dr. Lord has continued to impact the field. She sits on the American Psychiatric Association (APA) Neurodevelopmental Disorders Work Group for the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5).

The title slide of her keynote illuminates her from behind: "What Would a 'Better' Diagnosis of ASDs Look Like?" As she proceeds with her presentation, she describes proposed changes to autism diagnostic criteria in the fifth addition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). These include the elimination of Asperger Syndrome (see Singh 2011), changes to core diagnostic criteria,

[57] This youthful excitement is most certainly gendered. It feels as though many of the younger scientists are women, their hair pulled into low ponytails and their pencil skirts, blazers and suits a sea of grey and black punctuated by a vibrant blouse and bright white smiles. Like the staff I've met from the MARBLES study, they seem earnest, genuine and very committed.

and better accounting for autism severity over time (Lord 2009). As she concludes her presentation, I realize that the proposed changes to autism diagnosis will require significant social, scientific, bureaucratic and individual changes in how autism is identified, what falls under the conditions' purview, and who can receive services. While the presentation was the first I'd heard of these changes, it would not be the last.

In January 2012 the *New York Times* reported on the potential effects of changes to autism diagnostic criteria. The article (Carey 2012) notes that a new analysis suggested that proposed changes in the definition of autism in the DSM-5 "would sharply reduce the skyrocketing rate at which the disorder is diagnosed and might make it harder for many people who would no longer meet the criteria to get health, educational and social services." The ensuing controversy, documented in reactions by members of the Working Group, over 642 reader comments posted in response to the article (Carey 2012) and several follow up pieces (see Harmon 2012), indicate how consequential the diagnosis has become for individuals' identities (see Singh 2011) and for gaining access to services.

* * *

The vignette above and its reverberations in the public discourse illustrate the shifting clinical and social meanings of autism and their central role in organizing experiences of autism for scientists, clinicians and families alike. The setting captured in my account of the 2009 IMFAR keynote presentation also reflects where information about changing understandings of autism is often first communicated, and the often-distant relations between these venues and families' lives. This setting is far from pediatricians' offices, playgroups, behavioral therapy sessions, and homes where autism

resides. It also eclipses the effects of the process of diagnosis and its consequences for carers. These are the themes that I attend to in this chapter.

Below I highlight mothers' experiences of their children's diagnosis to trace how this process transforms mothers' relationships to their children, to motherhood, and to experiences of care. In attending to mothers' accounts of diagnosis, I show how autism is made meaningful over time, through their on-going assessments of difference and their experiences of services, therapies and treatments. My analysis engages the sociology of diagnosis, the concept of "looping" (Hacking 1995, 2006, 2007; see also Eyal et al. 2010), and the sociology of disease (Timmermans and Haas 2008) to situate how the meanings of autism for mothers become cemented through both social and biological processes.

Mothers' Experiences of Autism Diagnosis

This chapter offers an analysis of mothers' experiences of their children's autism diagnosis. I argue that the experience of autism diagnosis presents an extended period of transformation for mothers, reorienting their relationships to their children, to themselves, and to their ideas of autism. Important to the larger dissertation, this transformation also signals the enrollment of mothers into larger autism communities, situating them both biomedically and personally as potential participants in autism research. I demonstrate how this transformation happens over time, beginning before diagnosis and extending long afterward. The transformative character of mothers' experiences of diagnosis is negotiated (Strauss 1978) through interactions with various forms of information and experience that both lead to, and are arranged as a result of, autism diagnosis.

The diagnostic transformation mothers experience has three primary features. First, autism diagnosis as process reorients mothers' understandings from difference as natural to difference as a potential symptom, reframing their child's behavior and development through the lens of diagnostic criteria. Second, autism diagnosis reorients mothers' priorities by positioning the condition as central in their lives. This often requires practical reorganization of priorities, time and what they see as their responsibilities as parents. Finally, the consequences of diagnosis recast mothers as not only carers but as managers of their child's condition, in many instances simultaneously isolating and empowering them as uniquely equipped advocates for their child. This position requires a delicate balance of acceptance and vigilance with regard to autism and possibility.

These three features are temporally and affectively messy, often occurring simultaneously or in haphazard succession. Consequently, diagnosis not only reorganizes mothers' perceptions, priorities and responsibilities, but also their sense of time, "progress," and the meanings of these in their lives. Diagnosis recasts children's past behaviors as symptoms, doctor's visits as turning points, and treatment outcomes as reflections on the potential causes of the condition. Importantly, autism diagnosis provides a label that reflects intersections of the social and biological for mothers. As I detail below, an autism diagnosis often provides both a sought after answer to mothers' questions about their child's development, and access to a complicated and demanding system of services and support. However, it also confers uncertainty, complexity and – in

many cases – a profound sense of duty to navigate structures of science and care that may offer more questions than answers about how best to proceed.[58]

Importantly, mothers' experiences of their children's autism in turn informed the meanings of the diagnosis. Here, I am engaging Hacking's (1995, 2006, 2007) work on making up people and his concept of the looping effect. These refer to the ways that scientific classification may "bring into being a new kind of person, conceived of and experienced as a way *to be a person*" and how that classification then interacts with the people thus classified (Hacking 2007:286). Hacking's work points to the interactions between classification, people, institutions, knowledge and experts as five distinct components of "the looping effects of human kinds." Here, I consider how these are negotiated *through diagnosis* and over time, therefore putting the concept of looping in conversation with the sociology of diagnosis (see Jutel and Nettleton 2011 for a review) and work on the sociology of disease (Timmermans and Haas 2008).

To illustrate the key features of diagnosis and their effects I detailed above, I engage two main dimensions of diagnosis as a sociological phenomenon: diagnosis as process and the consequences of diagnosis (Baxter 1978; Brown 1995; Jutel 2009; Jutel 2011; Jutel and Nettleton 2011). These frameworks provide tools for exploring the power of diagnosis in organizing illness (Brown 1995), and in delineating new experiences for those it implicates. I illustrate these framings by detailing mothers' accounts of their child's diagnosis, from the first signs that something might be "wrong," through initial treatments and therapeutic interventions. These interventions provide social and biological clues to mothers about the underlying nature of autism. They also serve as

[58] Janet Shim (personal communication) has thoughtfully pointed out that the experiences of diagnosis reflected in this chapter may also enroll mothers in the very Networks of Concern detailed on a more macro-level in Chapter Two.

"feedback loops" (Brown 1990) that change the meanings of autism from a label to a meaningful resource and reference point for mothers.[59] This trajectory also reflects the experience of diagnosis over and through time (Bury 1982; Williams 1984).

Diagnosis as Process and its Consequences

Work on the sociology of diagnosis raises two important points for this chapter. First, diagnosis organizes what we come to know as illness (Brown 1995; Jutel 2009), and second, diagnosis can be both process and consequence (Bowker and Star 1999; Olson 2011; Schaepe 2011; Singh 2011; Turndle 2011). These two features of diagnosis make it an important element of the structural, affective and embodied dimensions of mothers' experiences of children's autism diagnosis. These points on diagnosis are drawn from work that dates back more than three decades (Baxter 1978; Brown 1995), recently reinvigorated in the sociological literature (Jutel and Nettleton 2011; Jutel 2009; Jutel 2011; Brown 2011). The first explicit call for a sociology of diagnosis by medical sociologist Phil Brown (1995) provided a framework for understanding diagnosis as a social process informed by social power structures, individual experiences and their interactions (1995:34). Brown (1995:39) described diagnosis as "the set of interactions which leads to the definition of the category and to its imposition in particular cases." Diagnosis as a process, "brings conditions forward as 'always-already-there objects in the world' via a convincing display of objective evidence: 'a discovery of what was present but previously unseen'" (Brown 1990:295 in Jutel 2009). In this way, diagnosis works as a powerful framework that organizes disparate experiences into identified illness

[59] Chapter Five, "Finding Cause," takes up the implications of these feedback loops for mothers' experiences of autism risk as they prepare to have another child.

categories (Jutel 2011). The consequences of diagnosis, however, are multiple (Mol 2002) and often reflect the cultural, structural and embodied experiences for those diagnosed and their supporters, carers and kin.

The power of diagnosis as process and its consequences are reflected in how autism reorients mothers' relationships to their children, to themselves and to their ideas about the future. Mothers' experiences of diagnosis also reflect the intertwining of diagnostic category, social experience and biology, pulling threads from the changing understandings of autism's causes into the meanings of the diagnosis itself and vice versa (see Hacking 2006 on autism and genetics). This is possible in part because autism as a diagnosis reflects a combination of observable symptoms, but is noted for its heterogeneity and the limited understanding of its underlying biology. As a result, the unique symptoms of each individual thus diagnosed often become salient markers *of autism*. In this way, emotional, behavioral and physiological manifestations become reflections of autism's roots and important clues in mothers' identification of the condition (see Timmermans and Haas 2008). These unique constellations of symptoms become integral in how mothers' interact with their particular children's autism, helping them to define the condition in more specific terms than the broad diagnosis. In turn, these individual distinctions help orient mothers' attention and actions with regard to particular treatment options and forms of support.

Diagnosis as Transformation

Two key processes lead to and through diagnosis in the accounts I trace below. The first is "recognizing difference." Here mothers come to identify in their child's

behaviors as meaningful differences in need of expert evaluation, often later recasting these behaviors as risk factors or symptoms. These are often identified through comparisons with other children, siblings or because of dramatic changes in a child's own demeanor or wellbeing. The second process is "check lists and clinical encounters." Here mothers discussed their experiences of evaluating their child through the use of developmental checklists and appointments with pediatricians and other experts. In many cases, checklists and clinical encounters preceded the process of recognizing difference, demonstrating the temporal messiness and varied pathways that led mothers to their children's diagnosis. Whether mothers initiated these appointments because of their own or others' concerns, or pediatricians raised questions about children's behaviors or delays for the first time, for the mothers I spoke to, the experience of diagnosis often entailed extensive evaluations, second and third opinions and sometimes years navigating different forms of expertise. Through these interactions, the meanings of autism were negotiated over time. The section below details the early phases of this process.

Recognizing Difference

> *Gradually we just sort of noticed that Alex was not the same as his sister.*
> (Eleanor, mother of eight-year-old son diagnosed with autism).

Recognizing difference is a foundational feature of mothers' experiences of their children's autism diagnosis. This process includes identifying initial clues that something was not quite "right." Initial clues took many forms, from drastic shifts in their child's development or character to more subtle concerns about their behaviors or physical wellbeing. As mothers learned about autism – usually following diagnosis, but sometimes

beforehand – many came to identify their children's behaviors as symptoms or initial indications of autism. This is important because it reflects two kinds of work accomplished during the process of diagnosis. First, as a lens onto the past, diagnosis transforms differences into symptoms; second, it retroactively reorganizes experience, enrolling mothers as observers of their children, at least in part, through medical terms.[60] For almost all mothers, this shift took place over time, and was aided by increasing indications that their children were different in ways that reflected a need for expert advice.

Mothers' observations and others' opinions led them to see their children's differences as not only unique, but indicative of a possible diagnosis. Mothers described several ways they came to see their child's behaviors and needs as *clinically* relevant, usually leading to clinical encounters that then led to their children's diagnosis. For many, family members or friends raised concerns about the children's behavior. Elizabeth noted that her sister's concerns caused her to question her daughter Alana's behavior: "My sister had five kids at the time and she said, 'I've got five kids. None of my kids have behaved like that. I don't know that that means that it's not normal, but I'd go to the doctor.'" Elizabeth's sister's concerns focus on two important features of recognizing difference: First is the comparison across children, reflecting an idea of normalcy that excludes particular behaviors, casting them as potential symptoms (see

[60] This second feature is often noted in epidemiology as "recall bias." However, rather than positioning mothers' accounts of diagnosis as the subject of scrutiny, here I consider how the processes of diagnosis co-constructs these accounts and the important ways that these feedback loops (Brown 1995) inform the meanings of autism.

Leiter 2007). Second, we see the primacy of physicians as the authorities in determining appropriate levels of concern related to childhood behavior.[61]

As mothers reflected on their experiences of recognizing difference, they described signs their children exhibited. Maria realized: "Diego's not the same anymore, something's different," noting a stark difference in his interactions and speech that seemed to develop suddenly. Others noticed signs of difference or delay early in their children's development. Jennifer described the first clues that something was different about her son, Oliver:

> I couldn't place into words how... the cry that he had. After having the other two kids it was *different*. With the cries in the other two kids, I knew that they were okay. I could bear it. There was just something very chilling and very, um, *desperate* in his cry that was almost painful to hear. And I didn't know how to handle it.

A pediatrician herself, Jennifer went on to describe how her familiarity with early childhood development focused her attention more critically on Oliver's behavior. She remembers being told to wait and see, and always finding a reason to reassure herself that Oliver was okay, despite her concerns and her own clinical training. She recalls:

> I think I always knew something was wrong with Oliver. He was about 2 weeks old when I noticed that he didn't look at me. And then everyone kind of said, you know, 'Let's wait, let's wait.' So Oliver then eventually did look at me and I thought, 'Okay.' But he would do a lot of these staring spells and so then I was afraid he had seizures. He would just kind of stare and it would take me a little while to get his attention. And Oliver always seemed a little… delayed, you know, at two months he didn't smile. But then, at about two and a half months he started smiling. And so it was just kind of like, 'Okay, we just waited, waited.' But all these things kind of nagged at me. But then we always kind of brushed it off because we always thought, 'Oh, maybe he's just a little delayed.' And some kids are a little delayed and then they catch up. And he did things that made me

[61] While pediatricians are most centrally implicated in this second observation, the vignette that opened this chapter points out the primacy of psychiatrists in organizing the dimensions of childhood health and wellbeing in the contemporary United States. Importantly, Eyal and colleagues (2010) trace the changing character of autism diagnosis and expertise since the 1950s, drawing many other forms of expertise into understandings of autism, classification and family experiences.

> suspicious… he would turn the light switch on and off, he would line up toys. But then I thought, he hugged me, he looked at me. He would sometimes move the cars as if he was playing with them. So I was finding reasons why those other signs were not signs of autism. And I read up on it and I tried to remember what I remembered during training of an autistic child. And they were the ones who were flapping their hands, rocking back and forth and totally non-verbal and cerebrally affected.

Jennifer's description provides an example of the monitoring, assessing and comparing that the process of recognizing difference entails. Following her son's diagnosis, some of his behavior became indicative of autism, while other seemingly 'normal' signs of development offset these as such. This balancing act of negotiating *which* differences warranted attention *when* is echoed in Jenny's experience. Jenny described her son, Adam, as exhibiting what she considered subtle signs of autism: "He was very borderline even back then. Like he wasn't completely ignoring us and he wasn't completely… I mean he didn't have too many of the stereotypical behaviors that would have really been a red flag, just kind of subtle things." Both Jennifer and Jenny's experiences speak to the changing meanings of difference following diagnosis and their effects on mothers' experiences of autism.

It was common that mothers I interviewed didn't associate their children's delays or differences as *symptoms* until after diagnosis. Anne describes her son Joey's development, and what led to his diagnosis: "He met all the milestones, but just barely. Like he had five words at a year and he had two-word sentences at 2 years old. He had all that, but just barely, the minimum requirements. But the big thing [was] he wasn't answering questions when he was 3. And then it took us six months to get him diagnosed." Similarly, Eleanor described her son Alex's behaviors before his diagnosis, explaining things she now saw as indicative of autism: "You know, he didn't seem to

respond to his name, and I remember that he wasn't walking at that point, he was still crawling. So I guess it was somewhere between 6 and 8 months." Eleanor and her family arranged for Alex to be evaluated by their family practitioner, who assured her that he was fine but a bit behind in his language development. Still uneasy, she decided to have a behavioral therapist come to their home to assist Alex with his speech. She described her conversation with the therapist: "It was like her very first visit with Alex and she just looked right at me and said, 'Have you taken him to a developmental pediatrician?' And I was like, 'No, why would I do that? They told me he was fine.' And she's like, 'Oh, I don't think he's fine. You need to take him in to be seen… he might have autism'."

These examples demonstrate the processes through which differences became matters of concern, and how matters of concern became clinically relevant. Across each of these examples, recognizing difference was not something most mothers learned in a moment. Rather, this was gleaned through their own ongoing observations, others' comments, and clinical encounters. These experiences, in many instances, began the process of shifting mothers' perceptions and experiences of difference toward the possibility of diagnosis, recasting their child's behavior and development as symptoms. In the quotes above, mothers described how their concerns accumulated over time and through interactions with others, reflecting something significant about their child's health and wellbeing. This often led them to seek additional information, utilizing developmental checklists or assessments by pediatricians to gauge the severity of their concerns.

Checklists and Clinical Encounters

Developmental checklists have become a common feature of modern parenthood. Professional and parental organizations including *American Association of Pediatrics* (AAP 2011), *First Signs* (First Signs 2011) and *Autism Speaks* urge parents to track their child's behavior and growth against easy-to-download checklists that indicate developmental milestones. Many of these organizations, including the *Centers for Disease Control and Prevention* (CDC 2011), explicitly detail "early warning signs" and "red flags" for autism on their websites and within public health campaigns. In this section, I demonstrate how these tools serve as references for mothers as they begin their journey beyond initial concerns and, in the case of all of the mothers I spoke to, toward an autism diagnosis.

Jenny reflected the consequences of finding an online checklist and filling it out with her son's pediatrician. She notes how a list of red flags for autism changed her thinking about her son's behavior: "So I just printed that stuff out. I found a few that just basically said, 'These are red flags of autism,' you know, and I'd say, you know, 'My son is exhibiting, you know, 75% of these.'" Others used developmental checklists more regularly to learn what to expect from scheduled visits with their pediatrician. Maria explains the important role the checklist played leading up to Diego's diagnosis. Her description also provides an important example of how gender influences the meanings of recognizing differences, checklists and diagnosis:

> I scheduled his 2-year checkup. At Kaiser they always give you the little checklist, 'Does your child do this? Yes or no.' And 'Do you do that?' I remember using those as a guide every appointment that I had from the time he was born until then to kind of see like, 'Oh, he should be doing that.' I'm like, 'Oh, good, he does that'… And that was the first time I had so many no's. And I was really scared going into the appointment. I had never had a checklist that was

> so... incomplete. The checklist was hard to see, hard to see all the no's. And even at that point, I don't know, I thought, 'Well, he's a boy, everybody says boys are behind, everybody says every child develops differently.' *Never* had I thought my son would be diagnosed with something. And [the doctor] asked, 'Do you have any questions, concerns?' And I was like 'Yeah, my child stopped talking and I don't know what's going on.' He started asking questions like, 'Well, what do you mean he stopped talking?' And I gave him kind of a... just the brief [version], "He's more withdrawn... I don't know if he lost his hearing." And I remember [the doctor] asking some questions and then he said, 'Excuse me, I need to pull something up on the computer. I have some questions to ask and it's coming from something called the M-CHAT.[62]' He didn't tell me what the M-CHAT was. And he said, you know, 'Does your child this? Does your child that?' And it was yes or no, that was it. And after those, the series of questions, I remember I was sitting at the chair, my husband was holding my son. He [the doctor] looked at me and he said, 'I think your son has autism.' And not even fully understanding what that meant, my heart broke.

Maria's experience demonstrates the power of checklists to suddenly transform mothers' understandings of their children from healthy to potentially unwell.

Maria and Jenny's accounts indicate how diagnosis is often brought to bear vis-à-vis such mundane technologies as 'yes or no' questionnaires and routine lists. While Jenny detailed her earlier suspicions that her son might have autism, for Maria the translation from checklist to diagnosis was abrupt and shocking. In these ways, checklists, whether administered at home or in the clinic, became powerful tools of evaluation and important resources during mothers' experiences of diagnosis. What these tools set in motion in terms of follow-up appointments, developmental assessments and educational evaluations, often shifted the course of mothers' thinking about themselves, their children, and their actions related to autism, as I detail next.

Mothering After Diagnosis

So everything just took a different perspective. What I want out of life, what I was happy about in life, was just different. I just wanted my kids to grow up, be self-sufficient

[62] The M-CHAT™ is the "Modified Checklist for Autism in Toddlers," a screening tool used to assess risk for an autism diagnosis in children age 16-30 months (MCHAT 2011).

and happy. Yeah, what I wanted out of life was very different. (Jennifer, mother of six-year-old son diagnosed with autism).

Here I portray three key features of mothering after an autism diagnosis. The first is "moving through diagnosis." This section traces the affective and pragmatic transition autism diagnosis often entailed for the mothers I spoke with. The experience of diagnosis often intensified mothers' sense of responsibility. At the same time, mothers described how existing opinions and information about autism placed their own actions in conflict with others' expectations. Next is a description of the experience of "seeking services." Once a diagnosis is made, the next series of tasks for mothers is to gain access to services, to confront and negotiate the complex structural conditions mediating access. Mothers' experiences of navigating services then often mobilized them to become, not only carers for their affected children, but also managers of their child's illness. I describe this in the section on "becoming advocates," which details mothers' often simultaneously isolating and empowering experiences of becoming experts in their child's condition. This section also details the changing relationships and responsibilities involved. Last, in the section "balancing autism," I describe how mothers' experiences are informed through diagnosis and its consequences, posing different challenges over time.

Moving Through Diagnosis

Following their children's diagnoses, or occasionally before clinical confirmation, mothers I spoke with described a period of emotional transition when coming to terms with the meaning of autism diagnosis related to them by a physician. Many saw diagnosis as an answer to questions they had, while also an indication of profound changes in their lives. Elizabeth described her experience immediately following Alana's diagnosis: "So there's a sense of loss but… I pushed that down for a long time because I felt like I

couldn't do anything because I had that loss. And I probably couldn't have, if I had allowed myself to really feel what ended up down the line hitting me." Others expressed a different experience, immediately seeking information about autism through books, online resources and by talking to other parents. Mothers described managing new information about their children's diagnoses and the implications these had on their expectations for their children's futures. Jennifer explains: "I feel like I can't stop being worried about his future, you know. What's going to happen? And it sounds horrible, one day I just want one moment where my mind is totally empty of that and I can just like sit and just veg, you know? That's my dream day." Like Jennifer, many of the mothers I spoke with discussed how the experience of their child's diagnosis demanded difficult emotional transitions, changed their personal relationships, and often left them feeling isolated. These affective dimensions took place at different times following diagnosis, extending the experiences of diagnosis far beyond the diagnostic encounter itself.

While Jenny had been concerned with what she identified as her son's autism symptoms, she later realized that she hoped all along that she would be wrong: "I think kind of the whole time we were going through that process, I don't think I had really processed it in my head, you know. Like I don't think it was sinking in, I think there was like an 'Oh...' I think maybe probably at that point I was still kind of hoping they were going to tell me I was wrong." Her experience is an example of how diagnosis can at once be a turning point and simultaneously an incomplete transition for mothers.

While the experience of diagnosis entailed different consequences, the limited answers mothers' received about autism's causes and treatments left many feeling personally responsible for something over which they had little control. Elizabeth

explains how her initial feeling about having children and her responsibilities as a mother changed dramatically after her daughter's diagnosis:

> I always felt fairly competent, that I would be able to navigate the world of childhood. I mean I could read books, there are experts that I liked, and we had taken a parenting class, and I just... I felt like I had a pretty good basic understanding. And I knew that there would be things that challenged me but, I kind of knew. And this was like a kick in my butt, I had no clue. And the worst part was, *nobody else did either*. I was responsible for trying to figure out how to cure autism. You know, trying to figure out how to do something that you can't actually do.

Eleanor reflected on her experience following Alex's diagnosis, and her frustration with others' assumptions about autism:

> So we were terrified. We were thinking of all kinds of backup plans... I mean it's like if you're told your kid has cancer and that's what you have to do. You do it, you know. People thought we were crazy. I mean people... my colleagues, people who were doctors were like, 'You know, it's like Down's syndrome, there's not anything, you just have to *adjust*. Your problem is you have an adjustment.' Can you imagine such a thing? People with MDs telling you that your problem is you need to adjust your expectations for your kid?

Most mothers I spoke with shared Eleanor's experience of being told at one point or another that their child's condition would not improve and that their problem was not autism, but with their reactions to it. Mothers' often had questions about autism that no one could definitively answer. These experiences often left them feeling both isolated and personally responsible for assessing and advocating for their child's needs (see Olson 2011). For all of the mothers I spoke to, diagnosis was only the first event in a prolonged saga of gaining information and services for their child.

Seeking Services

Here I briefly examine the structural and interpersonal dynamics of seeking services in order to illustrate mothers' transition into advocates for their children.

Mothers I spoke with reflected on how existing systems surrounding autism care required them to be vigilant in securing necessary resources and services for their children. This often required significant changes on the part of families' decisions about where to live, how to allocate resources and raise their children. These are some of the more concrete – often fiscal as well as emotional – consequences of diagnosis.

While autism as a neurodevelopment disorder is currently considered medically incurable, forms of behavioral, occupational and other therapies have proven efficacious in improving autism symptoms (Ospina et al. 2008). Mothers were intimately aware of this tension between the possibility of ameliorating symptoms and 'curing' the condition. They knew that while an autism diagnosis usually qualifies families for Applied Behavioral Analysis (ABA) and some amount of speech or occupational therapy, each individual diagnosed with autism is unique. As a spectrum disorder, an individual with autism can have varying challenges related to socialization, communication and restricted, repetitive behaviors. This means that assessments are required by state agencies and schools in order to determine the specific services for which a child qualifies. While medical social workers are sometimes provided for families following an autism diagnosis, many mothers I interviewed felt independently responsible for securing the best possible biomedical and behavioral services and treatment options for their children. This sense of responsibility reflects how the structural conditions and organizations of autism diagnosis and services produce particular consequences for carers.

Mothers often faced difficult choices about which treatments or therapies might be most efficacious for their child's particular combination of symptoms. They described

various ways that they became aware of and pursued different forms of therapy and treatment. Many relied on pediatricians' referrals, books they had purchased, websites and other parents as initial resources. In order to secure these services, however, they described everything from moving to different counties, states and countries to taking on extensive debt to afford additional services not paid for by the state. These decisions reflect the lengths to which mothers went – with their families, allies and partners – to facilitate the best possible environments of care for their affected children.

Anne reflected on the cost paid out of pocket for their son's services before moving in order receive state support: "When we moved to Sacramento we were $87,000 in debt because of the things that we had done for Joey… We had done practically everything." Others also expressed financial challenges receiving coverage for services. Eleanor recounted the sentiment her first doctor communicated to her:

> She basically said, 'Listen, I understand you're mad about the insurance company not wanting to pay for therapy and that kind of stuff. But, you know, you just have to look at it from the standpoint of this kid's never going to hold down a job or pay taxes. And so there's just not really any point in spending a bunch of money giving these kids therapy because, even if it helps a little bit it's not going to help enough to pay for itself, you know. We're never going to get that money back. It's just money down a rat hole basically.'

While few mothers experienced such blatant affronts, the strategic, emotional and financial challenges of garnering services for their children often required mothers to significantly shift their priorities to center more fully in procuring forms of care related to their child's autism diagnosis. In this way, the meanings of diagnosis and its influence on mothers were elaborated through their navigation of the structural conditions surrounding autism care. This influenced them as much – if not more than – the initial diagnostic experience itself. As one consequence of diagnosis, this experience contributed to their transition from carers to managers of their children's symptoms and advocates on their

behalf. This pivotal experience is a foundational element of the transformation some mothers went through as a result of their children's diagnosis.

Becoming Advocates

As detailed above, finding services and choosing treatments for their children comprised a significant element of mothers' experience of autism following diagnosis. For some of the mothers, this experience transitioned them from carers to advocates. Specifically, once they secured services covered by the state or insurance providers, mothers often complemented these with biomedical options that address physiological and behavioral symptoms associated with autism (see Silverman 2011). These were often pursued because they addressed symptoms not treated by other therapies. Many biomedical options, including specific diets or supplements, addressed children's physical symptoms, or appealed to mothers' analyses of what caused their children's autism.

The breadth of options, and the complex processes necessary to research, secure and pay for services, meant that mothers as carers often had to become experts in the unique details of their child's autism, the range of available treatments, and how they might be accessed. Mothers and their families, partners and supporters, had to simultaneously manage their expectations of therapies and interventions and their children's care. This compelled them to closely follow treatments and interventions, assess their individual child's reaction, and communicate promptly with service providers about the efficacy or limits of treatments. While this was often done as a collaborative process with pediatricians, behavioral analysts, and teachers, mothers often described

themselves as feeling solely responsible for advocating for their child across each of these domains.

For example, during a one-day symposium titled "Making Healthy Babies, Raising Healthy Children: Living Well in a Toxic World" in Berkeley, California, a presenter illustrated a detailed online data-analysis program for parents of children with autism. The woman presenting the program was the mother of a son with severe autism who held a PhD in computer science. She had developed the system after years of trial and error with her own son's autism and frustrations communicating her efforts to his doctors. The online program provided an organized data management system for parents of children with autism. Using the system, they could enter each food and medication their children ingested, when and how much, and to document that intake alongside their other symptoms. These symptoms were provided in a drop down menu, or could be entered manually into the program (as they were often quite unique). Examples from the menu included categories for children's number of hours and quality of sleep, behaviors, and moods, types of food, and common medications.

The program was advertised as a way for parents to more easily discern the efficacy of each treatment they tried for their children. Since dietary, medical and behavioral interventions often overlapped, it would allow them to more identify the relationships between interventions and their outcomes, and to track them over time. A special feature also allowed parents to chart their children's symptoms over days, week, months or years and by intervention type. While parents (or other carers) had to enter each piece of information themselves, the program came with the option of a physician subscription (for an additional fee). If their physician subscribed, parents could

communicate their efforts at home to doctors and behavioralists using the system (Fieldnotes November 21, 2009).

The detailed program recounted above illustrates the common, yet extensive, efforts parents – and especially mothers – often navigate in order to establish what autism means for their children. These are often pursued in light of both their personal experiences (such as those detailed above) and the structural challenges of the systems themselves (no standard dietary guidelines or medical recommendation exists for autism). Maria, a trained social worker, expressed her reaction following Diego's autism diagnosis:

> I at that time got into social worker mode. I'm like, 'Okay, here's my number one client and he needs services. I don't really know what services he needs or what's available or how much do they cost or where do I get them.' And at that point I just started... I went back to that book I had bought [about autism] and listed different services and the regional center was the starting point. After that evaluation I got going with it. [At] Kaiser there was a - February, March, April - there was a two-month wait before they could evaluate him. So in those two months I was able to get him evaluated by the regional center and start looking into referrals while I waited for Kaiser. At the time it was almost like, 'Well, I'm still going to do the Kaiser evaluation just in case this other one was wrong.' But it required a lot of phone calls, *a lot* of phone calls. The regional center kind of says, 'Well, this is what he's going to need.' [There are] a lot of visits to your home. The psychologist, people certified in ABA, speech pathologists. I can't even remember the amount of people that came to my home just to do even more assessments. Um, and ones that said, 'Oh, yes, he needs speech therapy, occupational therapy, ABA therapy, feeding therapy and these are the providers that we have. Some you have a choice and you will have to call them and pick one.'

Maria's experience of jockeying between providers, garnering recommendations and referrals, and negotiating with her family's insurance provider was not unique, and further positions "do-it-yourself" systems as the norm in autism parenting. Elizabeth described her experiences of trial and error, fighting for services and trying different treatments:

> I didn't know what had happened, so there was this sense of loss of power almost. But then I had this incredible optimism, which pulled me through, and I thought, 'You know what, she's so young.' Everyone kept saying, 'She's so young. You're going to have...you're going to have great outcomes because the younger you start programs and services, the better you're going to be.' So I fought. I fought for the best programs and services I could get. We moved here *specifically* to get closer to services… We had done diets, we had done supplements, we had done the ABA, speech therapy, music therapy, occupational therapy.

Elizabeth and Maria's descriptions of trying everything they could is further articulated in the next chapter. Here, their detailed accounts of securing services and forms of support makes clear the distinctions that exist within systems of autism care, distinctions that vary by nation, state and county. Importantly, the experiences following diagnosis conveyed above reflect how individual efforts influenced the timing, cost and quality of care that children received. These components of autism care reflect the uneven ways that diagnosis is experienced, bringing to light the social and structural determinants that construct advocacy as an essential means of caring for children following diagnosis (see Shim 2010 on stratified biomedicalization and Eyal et al. 2010 on autism parenting as vocation).

Balancing Autism

In this section, I describe the balancing of vigilance and acceptance mothers sought to achieve in their experiences of autism. Specifically, they described trying to strike what they saw as a delicate balance between the vigilance, described above, and acceptance of their children's autism diagnosis. Elizabeth's account continued:

> I had fought with every department I could figure out to fight with to get her what she needed if they wouldn't do it on their own. I have been this tireless advocate and every day I hoped I'd wake up and it was gone. And [then] realizing that, while it may some day go, chances are it wasn't going to. And then that's when it struck me that I'm going to have to find a way to fight this like I can beat it and

> accept it like I can't. That's what autism is, you fight it like you have a chance, and you accept your child regardless. And that's a really hard place to be.

Eleanor described similar experiences of trying anything possible, advocating for her son, and hoping for the best: "So we just felt like we had to go balls to the wall, everything we could get. Because at the end of the day, if things don't go the way you want, you want to be able to say, 'We did the best we could.' And that has been, you know, kind of our motivating force."

Mothers' experiences of securing the best possible services and treatment options following diagnosis played a significant part in shifting their experiences of caring for their children as a result of diagnosis. In becoming advocates for their children's medical and psychological needs, mothers described the challenges of balancing dogged determinism and hope with acceptance. This balance included questions about whether and when they should change course, hold back or shift their priorities. These questions were constantly being revisited, in part because of the fluctuation characteristic of many autism symptoms. Jennifer explains the experience of living between vigilance and acceptance:

> I'm always in constant limbo. I'm always feeling like I'm grateful that he's made this progress because I know families of kids who don't. But I'm always constantly aware of what typical kids are. So, even though you feel like you should be happy with what progress he's made, you don't want to give up on your son. You don't want to write the final chapter to what his potential is before he's ever reached it. So you're kind of always reaching for the stars, and then you're always kind of afraid because you see how far ahead the other typical kids are. And they are really, really ahead. And it hurts when I look at him. And I go, 'Oh, he's 7,' but he functions more like a five-year-old socially, and on a good day. And on a bad day he functions less than [his sister], and she's 2. But he has a harder time coping. And so it is hard to watch that fluctuation and seeing your child totally disintegrate in front of your eyes on a bad day or a bad moment. And so I think I'm always feeling like I'm going back and forth. 'Oh, I'm really happy and grateful he's doing really well' and 'Oh, my God, I can't believe we're back to this point.'

Mothers I spoke to also expressed difficulty deciding when to make changes related to their affected child's care, especially as they got older. Eleanor explained her personal experience deciding when to shift the amount of attention she allocated to her son:

> Alex is going to be eight in October. And so at what point do you say, 'Okay, we've done what we could and now it's time. Maybe Alex's situation is not as perfect as it could be in terms of services he's getting but it makes more sense for the rest of the family.' You know, and where is that line? And so that's something we still struggle with.

Elizabeth shared similar feelings about autism and her experience of accepting her daughter Alana, which had changed with time:

> It's funny because over time, you know, I don't wake up in the morning and think, 'Oh, you know, I hope Alana's not autistic today, I hope we don't have autism today.' I really can't even imagine it anymore. Like *she's Alana and that's just how it is*. So I think my challenge has been how do I give her the best quality of life? How do I make the most of her life? How can I help her be comfortable and happy and feel like she's part a team? You know, it switched from being about my comfort level to being about hers.

As Elizabeth's quote details, balancing autism reflects how autism diagnosis as a process and its consequences transform mothers' and families' experiences over time. The important changes in mothers' relationships to their children and to the diagnosis often came with time and were deeply affected by their social situations (see Shakespeare 2006). In this way, autism diagnosis becomes differently meaningful in relation not only to the specific symptoms of the condition, but also to the structural, organizational and social situations that surround these. Together, these features shape the experience of being the mother of a child affected by autism and the delicate balancing of vigilance and acceptance that entails.

Conclusion

This chapter has analyzed how the processes and consequences of diagnosis begin before and continue long after the diagnostic encounter for mothers of children with autism. I have detailed how diagnosis reorganizes mothers' experiences of difference, recasting their children's behaviors as symptoms. Through checklists and clinical encounters, autism diagnosis becomes a meaningful point of reference that informs mothers' ongoing navigation of their children's experiences, as well as their own. After diagnosis, through negotiating the affective, structural, medical and biological dimensions of living with autism, mothers become not only carers for their children but managers of their symptoms and advocates on their behalf. This often entails the management of new relationships with not only their children and themselves, but with the possibilities and limitations of science and medicine. In these ways, the transformation reflected in mothers' experiences of diagnosis also demonstrates the enrollment of mothers' into larger autism communities, situating them as potential participants in autism research.

In analyzing mothers' experiences of their children's autism diagnosis, my analysis draws connections between the social and scientific experiences of autism diagnosis, and their consequences for mothers' identities as uniquely qualified advocates and carers for their children. Diagnosis here becomes an obligatory passage point (Callon 1986; Latour 1987) in mothers' participation in the larger autism community, and especially as potential participants in autism research. This chapter builds on and contributes to sociology of diagnosis by highlighting the temporal qualities of diagnosis and its unfolding meanings for mothers *over time* (Bury 1982; Williams 1984). Further,

by engaging Hacking's (2007) work on looping and the sociology of disease (Timmermans and Haas 2008), my analysis reflects how mothers' experiences of autism diagnosis are informed by their children's distinct symptoms, the constellation of which is unique for each individual. Through focusing on mothers' experiences of diagnosis in particular, this chapter contributes additional analyses of carers' experiences of illness (Jutel and Nettleton 2011; Olson 2011), a theme that is further articulated in the next Chapter.

CHAPTER 5:
FINDING CAUSE

> *Unlike previous moments of modernity, the future of now is that which not only gives meaning to the past, but conjures new temporalized domains, versions of the present as sites of contingent and malleable action.* (Adams, Murphy and Clarke 2009:251).

I arrive at Hannah's house a few minutes before the MARBLES team. I've been here once before, for my first interview with Hannah a few months earlier. The house is quaint, with a small grassy lawn in the front and a narrow but inviting porch that welcomes visitors. To the left of the doorway are kids' toys, a plastic playhouse and several pairs of galoshes for adults and kids. In the driveway there is a new mini cooper and a minivan.[63] I open the screen door and knock. Hannah's older son David comes to the door, opens it and looks up at me briefly as I introduce myself. I ask if his mom is home. We make eye contact for a fleeting moment before he turns away, leaving the door hanging open as he yells toward the back of the house: "mom, someone is here." Before I can respond, he's made his way back to the table in the open area adjacent to the kitchen. As I peek in, he pulls himself up onto the chair and sits, his back toward me, concentrating on his workbook.

Hannah comes out with Arthur in her arms. The baby seems so much bigger than when I saw him last. His eyes are still a deep gray, his hair a tuft of blond bangs that floats just above his forehead. He doesn't smile, but looks content – quiet and slightly sleepy against his mother's chest. Hannah and I talk, catching up a bit. We talk about

[63] Hannah tells me during one of our conversations that she purchased the Mini Cooper as a birthday present for herself, one of the first major purchases the family had made since David was born.

Arthur, how big he's gotten, how old he is now, and about how her work is going and how David has been. David is homeschooled and working on his math workbook. I perch next to him, looking over his shoulder and ask about his favorite subject. He responds that it is math, his attention still trained intently on his workbook. Hannah places Arthur in his highchair, pouring some pieces of cereal onto the tray. Arthur reaches gingerly for the little pieces, grabbing some of them awkwardly and dropping a few as he eats.

As she sits down at the table, Hannah seems tired or tense. I can't quite tell which. I don't have many details about the study assessment I'll be observing today, and I don't know until Dana and Abigail arrive that Arthur has been showing some developmental delays. They have helped Hannah access early services from the State and will be assessing his development again today. As they come into the house, Hannah greets them with a smile. They catch up for several minutes, asking questions about how Arthur is doing and which therapies he's been receiving. Both Dana and Abigail smile and nod continually as they talk, infusing the conversation with an air of positivity that feels completely genuine.[64] As they prepare for the assessment, Hannah lifts Arthur from his highchair and sits him on her lap.

Dana organizes her materials for Arthur's assessment as Abigail stands behind her, observing the assessment from afar. At Dana's feet is a large Mary Poppins style bag, packed full of props – binders, toys, a washcloth, blocks, plastic rings, puzzles and a small red ball, among others. I have seen the assessment before and know that these

[64] During interviews and conversations with study staff, it is clear (as I describe in Chapter Three) that they are very committed to the participating families. Many field emails and phone calls from mothers during their off hours, and speak of needing their "baby fix" when they go too many days without an appointment with the families. They enjoy seeing the kids grow up, they've told me. And they feel especially connected to their role as analysts when they can help catch delays early and assist families with services (Fieldnotes January 2010, April 2012).

everyday objects will indicate whether Arthur is meeting the appropriate developmental milestones for his age. The assessment will be a series of small tests, one object will click, and the washcloth will cover another. The red ball will be bounced and Dana will smile and probe Arthur, drawing his attention ever so slightly then waiting for his response to the tests. She will indicate something in the binder. Every once in awhile Dana will turn back to check something with Abigail, "Yeah, that's okay" Abigail will confirm. "I heard him make an 'mm' sound earlier, you can check that box." While the tests will concentrate solely on Arthur, the majority of the questions asked during the evaluation will rely on Hannah to answer, "what sounds does he have? Any 'bah' sounds, what about 'duh' sounds?"

Before the process begins this time, Dana readies a few objects at the top of the bag and lifts one of the large binders onto the table. She opens it to the proper page and looks to Arthur, smiling, and then to Hannah. "Okay, ready?" Dana asks. Hannah smiles and leans around to see if Arthur is paying attention. She repositions him again so he is facing Dana and puts her hands down, steadying his legs on her lap. She nods, "We're ready."

* * *

Risk & Meaning in Uncertain Times

Scholars have argued that the increasing focus on risk in contemporary society has led to an "intensifying sense of uncertainty, complexity, ambivalence and disorder" (Lupton 1999:11-12). This has been characterized as one feature of the post-modern condition. However, rather than the "emptying-out of the established meaning of things and social relationships" (Lupton 1999:11), this chapter illustrates how meaning is

constructed within these conditions of uncertainty. Through my analysis of mothers' experiences navigating the possibilities of autism for future children, I consider how they situate risk through the concerted management of information, experiences and expectations. Through learning to live *with* and within these conditions of uncertainty, mothers establish relationships that matter quite significantly for their understandings of, and actions related to, autism. In this chapter, I argue that these relationships ground uncertainties in quite specific – though no less multiple – locations and times. Importantly, these understandings of risk and cause are continually reconsidered through the tacking back and forth between past, present and future.

Through documenting this process, this chapter describes mothers' experiences navigating the possibilities of autism as they prepare to have another child following diagnosis of a son or daughter with the condition. As indicated in the vignette above, navigating these possibilities is an ongoing process, which I call "finding cause." "Finding cause" documents how mothers make sense of autism as the outcome of vague and particular, complex and interacting, factors. These factors are manifest in past experiences, the bodies and behaviors of their children and other family members, and in the futures they imagine for their children and families. I discuss how these collective and interacting resources orient mothers' actions as they prepare to and then have a child following the diagnosis of a son or daughter with autism.

Below, I detail the connections, concerns and actions mothers articulated as meaningful as they prepare to have another child. I describe how memories of their past choices, their extended families and their affected child's development, symptoms and diagnosis, come to inform their experiences and choices during and following pregnancy.

This analysis explicitly considers how bodies, symptoms and interventions become central in constructions of autism's cause. Through doing so, I argue that scientific information and categories of risk are made meaningful (or not) to mothers of children with autism based on the relationships between both biological and social experiences. Through the process of "finding cause" autism becomes a classification system, illness experience, and social and affective orientation that is continually revisited in reference to these myriad and intersecting experiences.

This chapter begins with a review of work on anticipation (Adams et al. 2009). This is followed by a section addressing new logics of child development that charts increasing efforts to expand early screening and intervention for autism and their targeting of "at-risk" families. I then describe three features of the process of "finding cause:" "Drawing Connections Between Bodies: Locating Risk and Reassurance," "Managing the Unknown: Changing Landscapes of Responsibility," and "Looking Back, Moving Forward: Temporality and the Promise of Early Intervention." These are followed by a discussion that considers risk, responsibility and temporality in relation to scholarship on anticipation. This chapter builds on science, technology and medicine studies on anticipation (Adams et al. 2009), which I describe in detail below.

Anticipation and Abduction

> *Through anticipation, the future arrives as already formed in the present, as if the emergency has already happened* (Adams et al. 2009:249).

Adams, Murphy and Clarke (2009:246) argue that one of the "defining qualities of our current moment is its peculiar management of time, or what might be called a politics of temporality." They state,

> this instantiation of modernity offers both a promise of certainty (that the truth can be known for certain in a way that applies across time, into the future), coexistent with the acknowledgement of an ongoing deferral of truth as ever changing (as more sophisticated ways of knowing continually emerge) (247).

The authors call this state "anticipation." Characterized by its temporal and affective qualities, anticipation is "a regime of being in time, in which one inhabits time out of place as the future" (Adams et al. 2009:247) and "anticipation," as the authors articulate, has several dimensions: injunction, abduction, optimization, preparedness and possibility. Injunction is defined as "the moral imperative to characterize and inhabit states of uncertainty," abduction, the "requisite tacking back and forth between futures, pasts and presents, framing templates for producing the future," optimization as "the moral responsibility of citizens to secure 'the best possible futures'," preparedness as "living in 'preparation for' potential trauma," and possibility as "'ratcheting up' hopefulness, especially through technoscience" (Adams et al. 2009:247). As this dissertation has illustrated, all of these dimensions of anticipation are lively in the practices, politics, and experiences of prospective autism research.

In this chapter, I focus on how the concept of anticipation is particularly salient for thinking through the experiences of mothers participating in prospective autism gene-environment interaction research. I argue that the process of "finding cause" takes much of its form through practices of "abduction." Abduction is the concept that the authors "adopt and adapt to capture the processes of tacking back and forth between futures, pasts and presents, framing the life yet to come and the life that precedes the present as the

unavoidable template for producing the future" (Adams et al. 2009:251). This notion, of an 'unavoidable template for producing the future' reflects, in one sense, the experience mothers conveyed of living with autism. As I detailed in the last chapter, while the diagnosis of autism may provide a sense of knowing where there were once only unknowns, families I observed and mothers I spoke with relayed how this sense of reassurance quickly cascaded into a series of questions about the best possible courses of action following diagnosis. Many of these questions were unanswerable accept in the most basic forms: seek state support for services, enroll your child in Applied Behavioral Analysis (ABA), discuss an Individual Education Plan (IEP) with your school and wait. And even these most basic steps are extremely convoluted processes that usually only skim the surface of what most parents will navigate following a child's diagnosis with autism.

Below I pay particular attention to how the tacking back and forth between futures, pasts and presents orients mothers of children diagnosed with autism, who are pregnant with another child. In particular, I describe how it orients their understandings of autism's causes in reference to their existing child and the symptoms, treatments and opportunities for intervention they employ to manage the condition, as well as their memories and hopes for the future. The attention given to each of these time periods is situated within an increasing concentration of energy and information around childhood, which I describe next.

New Logics of Child Development

Early Intervention and Hope

Scientific findings have become a critical part of our everyday lives. From our daily routines to the choices we make for the future, science shapes anticipation, risk and calculation on a day-to-day basis. As a particularly powerful framework for understanding health and disease, science serves as a source of legitimacy when weighing various sources of information. As a result, for parents of children affected by an autism spectrum disorder, science is often an ever-present yet insufficient companion on their journeys from initial concerns to diagnosis, from diagnosis through service navigation and procurement, and from services and treatments to "progress" – in the many, myriad forms it may, or may not, take. While science may offer the hope of answers to the questions that parents have about what causes autism and what can alleviate their child's hardships, it often finds those answers only through incremental trial and error with educational, behavioral and biomedical strategies, leaving families with little guidance in their day to day experiences with the condition, and more questions than answers when considering a new pregnancy.

As described in Chapter Two, the field of autism science has shifted over the past decade to highlight the more molecular, interactive and vastly complex biological underpinnings of the condition. These shifts in emphasis and approach have developed alongside changing definitions of autism that changed the observable characteristics of the condition to include more (though now potentially fewer) symptoms within its diagnostic purview (see Carrey 2012). While findings have indicated specific SNPs (single nucleotide polymorphisms) and classes of environmental factors as associated with autism, there remains little scientific consensus about *what* causes autism and

when.[65] It is within this setting that early childhood development has emerged as a more concentrated site of attention in autism intervention science (see Ozonoff et al. 2011).

Working most closely with baby siblings of children diagnosed with autism (for reasons I describe in more detail below), clinical psychologists have recently converged on therapies that seem to ameliorate early developmental delays (see BSRC 2009, 2010 and 2011). Some have been efficacious in changing the course of what might otherwise develop into an autism spectrum disorder (Dawson et al. 2010; Dawson 2008). Related to these efforts, autism awareness campaigns have stressed the importance of early intervention, targeting themselves toward the detection of "warning signs" for autism (Zwaigenbaum 2010). Tools indicating the standardized child developmental milestones, and focusing on when parents should approach their pediatricians with concerns, can be found on the websites for *Autism Speaks*, *The Centers for Disease Control and Prevention*, and the *American Academy of Pediatrics*, *First Five* and many others (AAP 2011; CDC 2011; Autism Speaks 2011). These resources provide free checklists of developmental milestones and online quizzes for parents and physicians. Through their observations of and experiences with their children, parents in particular are encouraged to indicate whether their child is meeting the expected developmental milestones for their age, and to seek the opinion of their pediatrician should delays become apparent.

Pediatricians are also expected to be closely monitoring for autism spectrum disorders. In a 2009 article however, Zwaigenbaum and colleagues identified that

[65] Here, rather than indicating a lack of *knowledge* about autism's causes, I emphasis the lack of scientific *consensus* over specific risk factors, their timing and effects. I make this distinction to signal that information about autism is by no means lacking. The ways that this extensive and often competing information is discerned as *meaningful*, however, has become the source of public scrutiny and scientific debate. Here, I want to emphasize that it is within these conditions that mothers and others must negotiate the possibilities of autism and their relationships to those possibilities.

"unique challenges exist in applying current diagnostic guidelines for ASDs to children under the age of two" because "standard criteria of the *Diagnostic and Statistical Manual, Fourth Edition* and *International Classification of Disease, Tenth Edition*, gold-standard diagnostic tools, and even the best judgment of experienced clinicians have rarely been applied to this age group" (2009:1383). This has placed much of the responsibility on parents to find and use these resources in order to advocate for their children.

These diagnostic tools and their focus are part of a long history of childhood surveillance that has positioned many responsibilities for autism predominantly within the family (see Eyal et al. 2010 for an account of this history). These also follow increasing efforts to draw attention to earlier and earlier signs of *potential* illness, which have manifested in the molecularization of risk (Rose 2007), increasing scientific efforts to designate individuals or groups as uniquely susceptible (see Shostak 2003, 2010 and forthcoming), and the designation of pre- or *potentially*-ill persons (see Timmermans and Buchbinder 2010, 2012 on "patients in waiting"). These circumstances are made possible by an overarching cultural focus on prevention, which notably emphasizes biomedical interventions, and eclipses the potential for different kinds of questions and answers about life itself (see Clarke et al. 2010).

At Risk & Highly Motivated

While the resources and early interventions described above target the general population, these efforts may be most salient for (and are also most heavily scrutinized by) parents of children affected with an autism spectrum diagnosis. These families have, since the first descriptions of autism, been particularly implicated in changing

understandings of autism. Since early genetic studies, estimates of families' recurrence risk – or the chance of having another child with an autism spectrum disorder – have played a key role in generating knowledge about the biological basis of the condition. Recently, this recurrence risk was estimated to be between 10.9% and 30% (Constantino et al. 2010). These estimates are central in the scientific rationale for prospective autism studies that explore early development in baby siblings of those diagnosed with autism (Tager-Flusberg 2010) and for MARBLES and EARLI, which trace the possible environmental and genetic causes of this higher risk from before birth. What these estimates also signal, which is less often discussed in the scientific literature, are the complex social, scientific and emotional experiences of navigating the possibilities of autism risk for these families.

As discussed in Chapter One, the women enrolled in MARBLES are identified as an "enriched risk" cohort. This category has specific scientific and social meanings for researchers. Not only do these families have a higher risk of having another child with autism, but, as several scientists I spoke with indicated, they are also considered "highly motivated." This is because participants within this population are believed to have a more vested interest in the research due to their personal experiences with autism; each participant had navigated the process of autism diagnosis with an existing child, had selected among the myriad services available the behavioral, social, and occupational therapies their affected child would take part in, and decided to participate in the MARBLES study as they prepared to welcome a new child into the world. This, investigators shared with me, made the study population easier to recruit, more likely to be compliant with research protocols, and less likely to leave the study over the course of

the three-plus year commitment. As parents of children diagnosed with autism, many were also already well versed in research-participation.[66] As I detail in Chapter Three, this also made the study a valuable resource for families in a number of ways. Some of these are made clear in my analysis of mothers' experiences navigating autism risk, which I turn to next.

Locating Risk, Finding Cause

During my interviews, mothers' answers to questions about what caused their children's autism were often woven through detailed descriptions of diagnosis and the condition's progression, treatments they had tried, what worked and didn't work, their own upbringings and behaviors, and their uncertainties moving forward. While many explicitly used the language of "genes" and "environmental factors," their answers also indicated the more nuanced and deeply personal ways that ideas and experiences of risk entered into their daily lives. I describe their responses in order to elucidate the process of "finding cause." This concept reflects how experiences of autism risk became articulated through mothers' interactions with science, their affected child's symptoms, and their own memories and hopes for the future.

The following findings focus on how mothers interpreted, organized, and acted upon autism information in light of their own experiences with autism and in relation to time. This took place in various ways as women I interviewed had different views about autism's causes, distinct experiences of their own child's autism diagnosis and progression, and took different steps related to their younger children based on these experiences and beliefs. Despite the differences across interviewees, each of the mothers

[66] See methodology in Chapter One and limitations in the Chapter Six.

I spoke with actively constructed understandings, interpretations, and actions related to risk that drew on scientific information as it became relevant to their lives. This helped shape mothers' experiences of autism's possible causes in relation to both their affected children and their newborn children. In these ways, "finding cause" oriented mothers' actions toward their new child in relation to the ever-present possibility of diagnosis for their *next* child. Even when their younger children showed no signs of language delays, emotional or physical difficulties, behavioral problems or other developmental challenges, mothers often remained concerned about autism because their older children's diagnoses presented such a sudden and sustained shift in their lives.

While many of the women I spoke to expressed a sense of always looking for the next best option to help their affected children, they were also intimately aware that there was not likely to be a magic bullet or instant fix for this complex condition. While they had concerns about what caused their child's autism, and what might help, all were intimately aware – had experienced daily – that autism was less an answer than a complicated balancing act of possibilities depending on the salience of particular treatments or therapies for their specific child. In this way, autism was a question that always had more than one answer. Below, I illustrate three themes that convey mothers' experiences of this balancing act, and its relationships to understandings and experiences of autism risk for their new children. These themes are: "Drawing Connections Between Bodies: Locating Risk and Reassurance," "Managing the Unknown: Changing Landscapes of Responsibility," "Looking Back, Moving Forward: Temporality and the Promise of Early Intervention."

Drawing Connections Between Bodies: Locating Risk and Reassurance

> *And I have lived and continued to live with those unknowns and I just think that it's a horrible feeling.* (Maria, mother of five-year-old son diagnosed with autism).

For the mothers I interviewed, risk is an important and poignant way of framing their actions as they prepared to have another child following an autism diagnosis. This sense of risk, however, was never static. Rather, it shifted and changed throughout significant periods of time that women imbued with developmental importance, including pregnancy, early child development, and various developmental or personal milestones they encountered with their children.

Instead of being "in the clear" mothers' reflected a kind of moving-target mentality. If their child was born healthy, change might be right around the corner. If their well-baby check-ups and early developmental milestones were met with flying colors, parents might still make choices about the foods, supplements or forms of medical intervention their child received based on the possibility of autism. These decisions were made *just in case* their choices held the key to their children's future health (see Senier 2008). One mother's experience exemplified this form of thinking.

Elizabeth's daughter Alana is ten years old and, as she recalls, was developing typically until 16 months, when her language and behavior regressed significantly following a particularly high fever. After Alana recovered from the fever, her language and behavioral problems persisted, and Elizabeth sought expert advice about what was wrong. After almost a year, Alana was diagnosed with autism. That was six years ago. Since then, Elizabeth has had two other daughters, Denise and, two years ago, her youngest daughter Jenna.

Elizabeth discusses how her experience of Alana's regression influences her ideas about what causes autism and how best to ameliorate her affected daughter's symptoms. This also influences her decisions about how to prevent what she feels are possible risks to her newborn, Jenna. Elizabeth explains how what she describes as her "particular brand of sense of loss" influences her belief that environmental factors were the cause of Alana's autism:

> Over the years I just, that felt like something that was really true for my daughter… I've wondered some times how much I would have focused on that approach had she maybe been born with autism, maybe one of those children who like never really connected and, um... I mean I can only speculate on the sense of loss that that would have been compared to the sense of loss of actually having a child who was really connected and then not having that same child anymore. So I'm not really sure if that...if my particular brand of sense of loss, if that's spurred me to look more environmental. Whereas if she had been born that way I might have been more focused on the genetic.

She went on to explain:

> But I also knew that focusing on the genetic didn't yield any answers right now. They may be able to say, "Oh, yeah, well, she's got this and this and this genetic," which would be rare at this point, they just haven't found any real, you know, big thing. But that doesn't equal anything yet. They're still years away from, I think, making the step from "They have this particular genetic mutation" to "This is a treatment to help your daughter." And here it was a group saying, "Here are some environmental things that could be playing a role," and it just made sense to me to remove those anyway.

Elizabeth's active, thoughtful and calculated interpretation of her daughter's experience and its bearing on her actions and advocacy was one strategy parents utilized in finding cause.

Other mothers relayed a sense of ambivalence related to potential risks. Maria is a social worker and mother of five-year-old Diego and one year old Emilio. Here, she considers her decisions during her pregnancy with Diego and their relationship to her choices while pregnant with Emilio. She explains:

> With Emilio I'm like, "You know what, I'm not even going to go there. With Diego [her older, affected son] I cut out all caffeine, all of it. And with [Emilio], um, I was less strict…. I was like, "I did all that with Diego and he still has autism so if I dye my hair and get a pedicure and have some ... have a latte chances are he might still have autism or he might not." So… pregnancy-wise I was not as picky with what I ... with the care.

She went on to describe her sense that exclusively breastfeeding Diego for his first year may have caused his autism. In a description that reflects connections between women's choices, their bodies, scientific information and risk perceptions, Maria explains her approach to breastfeeding with Emilio. She states:

> I'm not stuck on the "I'm going to breastfeed for a year" because I just ... I don't know. And I have my fears where I was like, "Maybe I did it to Diego." Like maybe I ... I didn't have the best diet and maybe he didn't get what he needed even though they say they get everything and like I don't know. Or just how I was feeling, if I was feeling stressed or sad or whatever. In our culture they say that the baby can feel what you're feeling through nursing. I remember if I was ... if I had gotten scared, even a scare, my mom was like, "Oh, no, no, don't feed him right now, you need to wait." Or if I was emotional or sad like, "No, no, don't feed him right now." So all of that goes back ... like I was just thinking like, "God, how many times was I like crying and feeding him." Or maybe it was what I ate or didn't eat enough of. So with him [Emilio] I was like, so many babies are so healthy on formula that maybe that's better and I made that decision to just take him off, wean him.

This sense of not knowing reflects the multiple ways that scientific and medical information about pregnancy, child-development and genetic and environmental influences on disease are made meaningful through mothers' interpretations of their own actions, responsibilities, and choices related to autism. When I asked Maria's views on what causes autism, she explained, "We don't have the answers yet. We can't be black or white, and that's very much how they [doctors] are. So I had to kind of be in the middle."

The quotes above indicate how mothers constantly adjusted their thinking about autism and autism risk according to their interpretations of their own actions, their affected child's experience, and – as I discuss below – their new child's vulnerability.

They gauged this vulnerability not only by medical and scientific standards of healthy child development and in regard to their feelings about their past actions, but also with respect to their affected child's experiences.

Below I consider how drawing connections between their children's behaviors, bodies and experiences provided mothers with meaningful filters through which to consider autism risk. Through drawing connections between their older and younger children, women I spoke with interpreted and utilized the idea of autism risk as a flexible category that changed over time, helping them make choices related to their children. This was often thought of in relation, or in contrast, to how warranted they felt their concerns were about genetics or environmental factors for their children. These connections also served as filters through which mothers' evaluated how "at risk" their new child might be.

For example, when asked about what she felt caused her daughter's autism, Elizabeth evaluated the relevance of genetic explanations in relation to her and her husband's extended families. She explains:

> In my particular instance with Alana I feel like genetics were a lower portion of developing autism. I had come from a large family, they all have...I wouldn't say large families but good size families. I have a lot of nieces and nephews and we don't have any autism on my side at all. My husband's family, while not as large, they don't have anything on his side either. So from both of our sides there's nothing so it would be hard for me to feel strongly that it was genetic.

Later, Elizabeth went on to describe how the physical similarities between Alana and Jenna affect how she raises Jenna. She explains:

> Jenna and Alana [are] very similar… very similar personality traits, they look similar from their baby pictures, they both have the super hyper flexible joints in their hands. Like all these little things. [So] I'm like, 'Oh, yeah - they probably have enough similarities that if there was a genetic predisposition, I [think] Jenna would be a lot more likely [to have autism] than [my other daughter] would have

> been, because genetically they just seem more similar. I mean, right from the beginning I was like, 'I've been here before," so maybe that's one of the reasons I was determined that this time if I had any control it wasn't going to end up the same way. And I didn't know which factors were involved so I just tried to control every factor that I could.

In this case, Elizabeth's taking control over "every factor" was informed by the similarities she both saw and sensed between Alana and Jenna. Similarities that evoked a strong sense for her that Jenna and Alana shared a similar vulnerability to environmental factors – a connection that seemed to indicate Jenna's increased risk for autism. Elizabeth's description of her daughters also reflects the complexity of mothers' understandings of autism risk. While she stated that genetics were not likely to play a large role in Alana's condition, she reflects on the relationship between genetic susceptibility and environmental factors when comparing the two girls.

For other participants, rather than indicating higher risk, drawing connections provided them reassurance that the patterns they were witnessing in their child's development were normal, or at least not a cause for serious concern. Hannah, mother of five-year-old David, and six-month old Arthur, felt that the similarities between her son's development and her husband's childhood experiences provided reassurance that everything would be okay. Hannah describes during our interview how this affected her initial reaction to David's diagnosis:

> A lot of people use words like "devastating" and things like that and I didn't really feel that way. I think partly because my husband also hadn't spoken when he was a kid 'til he was about three and a half. So in that sense it wasn't that surprising.

In this case, the connection between her husband's childhood, his success as a adult, and her son's diagnosis, gave Hannah a sense that David would be okay. While these

embodied markers of risk, vulnerability or wellbeing reinforced parents' sense of their child, doubts and uncertainties persisted.

Managing the Unknown: Changing Landscapes of Responsibility

Scholars have described the sense of responsibility and stress felt by parents of children with autism, and research has shown that this is particularly true for mothers (Larson 2010; Sawyer et al. 2010). In this section, I consider how mothers' managed actions, objects, or exposures that they perceived as possible causes of autism. This strategy relates the ways that mothers used their interpretations of possible risk factors to guide their actions when doing everything from feeding themselves and their families to bathing, applying lotions, creams or ointments, and using home cleaning products.

Maria explains her thinking about vaccinating Emilio. She describes her uncertainty about immunizations in terms that reflect a similar concern about sensitive bodies and vulnerability as that expressed by Elizabeth above. Maria states:

> Is that [immunization] what causes it? Well, maybe some bodies can't handle the immunizations as they're given, like how they're given right now. Maybe they shouldn't be given the same dosage, the same sets to every single child because every child's different. And, just as we adjust medication that's prescribed to adults based on their weight or height or diagnosis, I mean… how can so many immunizations be given at a set standard just across the board, to every child not knowing what's going on in the body or in the mind? And that's the main reason why we haven't given them to Emilio... I don't know, he's too young. He just started having solids so even that I don't know, you know, can he handle foods, does he have any allergies? And my husband's like, "No, we're not giving him any shots." And I thought, "Well, we'll give him the shots but do the alternative vaccination schedule." And then I changed my mind with that. I had said, "Oh, I'll start him when he 's 6 months," he's now 7 months and, especially after that developmental evaluation. I said, "Oh, no, I'm not giving him anything now. I'm not risking it."

Maria's quote details her uncertainties about vaccinations for her son, but also weighs these uncertainties based on continual evaluations of her son's vulnerability. His age,

ability to eat solid foods, and his developmental wellbeing as based on the most recent MARBLES assessment, each provide Maria a sense of his ability to "handle" the immunizations. Her quote reveals the shifting ways that science and uncertainty are balanced for parents of children with an autism diagnosis based on their experiences over time.

Returning to Elizabeth, she discusses how her concern about the similarities between her two daughters has informed her approach to making family purchases- from the food they eat to the car seat that Jenna sits in. She walks me through her process of deciding to buy a car seat for her younger daughter Jenna. She explains matter-of-factly:

> If I was going to be buying [a car seat], I needed to find out which cars had the least amount of toxic off-gassing and I needed to find out which car seat had [the highest safety rating]... So I would compare the car seat that I found at healthycars.org with the safety ratings at Consumer Reports - and I would find out which one matched up the most with those things. You know, I became very, very active in making decisions about which things would happen and wouldn't happen.

The example of purchasing the car seat illustrates the kind of tacking back and forth that Elizabeth engages in order to make what she believes to be the most informed, and safest, decisions related to her children's environment. Determined to eliminate what she perceives as a possible risk factor for autism, toxic-off-gassing, she takes responsibility for researching, comparing, contrasting, and ultimately deciding on many more elements of her family's life than she did before Alana was diagnosed. While she continually emphasized that she didn't know what caused Alana's autism, she and others I interviewed described how they had a sense of responsibility to try anything they could, just in case.

Elizabeth went on to explain the burdens that this sense of responsibility and wanting to know creates in her life. In describing what it was like to research the possible connections between environmental chemicals and autism, she states:

> When I had information, [I had] too much information to sit back and be relaxed I guess. Because you know too much. I knew that there was Scotchguard in my carpet and, well, what was I going to do about that? And I knew... like when I researched everything from the chemicals in cribs and baby bedding and the stuff that's in mattresses and you know, I did extensive research for just hours and hours and then I was thinking, "Oh, great, now I'm exposed to my computer and who knows..." I know things like mercury and different chemicals are in it, it's like, you know, the electromagnetic radiation because we have a wireless home and… It becomes really overwhelming. And you don't know. I mean that's the thing. I could be worried about, you know, thousands of things and you really don't know which one or which ones or which combinations of things. I mean there are thousands and thousands of chemicals that we don't have any research on.

Elizabeth's sense of responsibility to learn what she could about her family's exposure had not always been a priority. She explained to me how her thinking had changed significantly since Alana's regression and diagnosis. Reflecting on her experience with autism, she described herself as having gone through a type of conversion, a sentiment shared by many other mothers I interviewed. She explains:

> I feel like I'm really a different person. I'm different politically, I'm different in every possible way because of this experience. It's like my soul just kind of shifted and, while I recognize where my soul used to occupy that space, it's not there anymore. Like I'm a different person and regardless if Alana were to wake up tomorrow and not have autism, this is who I am now and I would be aware of the other people who struggled with this and it would be my calling.

While others were not as vigilant about one particular arena of risk as Elizabeth, each of the mothers I interviewed described dramatic adjustments they made in their lives in relation to not only their child's autism, but also their own ideas about risk more generally.

Maria described being generally more "careful," a term that came up across all of the interviews. Being careful usually described different ways that mothers' approached their preparation and experience of a new pregnancy, how they raised their new children, but also their broader choices for themselves and their families. Maria explained:

> And I'm so much more careful. Everything this little guy eats is organic. Um, and I have organic. And I do that with Diego. Even the lotions, the baby shampoo, everything. The lotions and creams are all paraben-free, everything. I look, I read labels. His body wash, same thing, I order that online.

These quotes reflect the extensive efforts that mothers took to alter materials, exposures or conditions they felt could potentially harm their children, whether via their own bodies (in utero), or following their child's birth.

Dovetailing with Maria's experience, Elizabeth talks about how her parenting philosophy has changed since her daughter was diagnosed with autism, and how her ideas about responsibility have changed as well. She explains,

> With my other kids I had been very lax. It's like, oh, you know, kids are kids. We've been growing kids for a long time, they'll be fine. And after [the diagnosis], all of that kind of comfort that people had kids and they always were happy and healthy, all of that was just ripped away. And so I suddenly felt like it was my responsibility now to ensure certain things, whereas before I had been very lax and not feeling like that was my responsibility. Because I didn't realize somebody needed to be responsible for it.

This sense of responsibility, but also hope, is clear in the section below on "Looking Back and Moving Forward: Temporality and the Promise of Early Intervention."

Looking Back, Moving Forward: Temporality & the Promise of Early Intervention

Elizabeth explains how participating in the MARBLES study allows her some relief and reassurance that she's doing everything she can for the future. She states:

> I wondered a million times if I could go back would I have seen something? But I look at these pictures of her and I go, 'There was nothing, you know, there was nothing'. So to know. I mean that was my comfort, if they're assessing her, if

> there's anything out of the ordinary, I'll know it early. I don't know what the difference would be. But to just, even to be able to say, "See. See, on this date it was okay. I just need to know that I can breathe deeply today and say, "Okay, we made it this far." And then I can also breathe a sigh of relief and say, "Great. Today we're going that path.

The sense of uncertainty about autism's cause was evident in this and other ways that mothers talked about their motivation for participating in autism research. Here, each assessment offers a comforting element of knowing, even if just for that moment, what path they are going down. While, as Elizabeth acknowledges, these moments may only last until the next assessment, they also provide a sense that she is preparing for the future as well as she possibly can.

Various temporal aspects of risk perception have been described in detail elsewhere. I want to reflect on the ways that time enters into both the coping strategies of the mothers' I spoke to, as well as in their efforts to intervene at earlier and earlier points in their new child's lives. Elizabeth provides an example of how time is reflected in her own experiences with her daughter's autism:

> I feel like even now sometimes when we have rough days it's like, "Okay, how do I get through this?" Because you extrapolate. That's one of the things that got me through when Alana was young. She wasn't a great sleeper and she wanted to nurse like constantly and I kept saying, "Well, you know, by the time she's six months that won't be an issue" Okay, it's still an issue. "By the time she's a year, by the time she's two years." I remember thinking… You know, one of my coping mechanisms I guess is to say, "Well, if she's not sleeping now I don't know any 16-year-old [children] that are still sleeping in their parents' bed. So, okay, if I can just get through this to 16 I can do it. But it was hard. I mean those months, they went by in a very, very difficult blur but I just kept thinking every day, "Well, she's young, we've got time on our side. We're just going to keep doing this." And I think that just got me through. It was hard. I don't even know how else to phrase that. It was really difficult. It was emotionally challenging… I mean I had a lot of fear at first that my second daughter would have problems, that she would regress. And I think every month, even if you don't want to sometimes your mind keeps track of dates and times and I remember thinking, "Okay, she's this old. This is how old Alana was when this happened."

Here, temporality plays a different, but always important, role in Elizabeth's orientation to her experiences of autism. Time provides both a resource – as a signal of hope that interventions may be more effective – and also a constant reminder to pay close attention to her daughter's development. In these ways, autism and autism risk become constantly moving targets and a set of possibilities that conjure up the past and its potential place in the future.

Conclusion

> *Abduction moves reasoning temporally from data gathered about the past to simulations or probabilistic anticipations of the future that in turn demand action in the present* (Adams et al. 2009:255).

Rather than holding fast to a notion that one thing or another was the cause of their child's autism, the mothers I spoke with interpreted information about autism - whether gathered from pediatricians, other parents, scientists, or alternative sources - in relation to their personal experiences. Importantly, their perceptions were also affected by time. As they prepared for and then brought a new child into the world, mothers evaluated information about autism and autism's possible causes based on their relevance for *their* child and based on knowledge gleaned from their experiences with autism. These perceptions of autism risk were both steady and fluctuated over time. Ongoing assessments of their new child brought to bear their past experiences - with their affected children, pregnancies, larger family histories, or particular exposures – creating meaning and action that was oriented not only to the future, in terms of preventing autism for their newborn, but also back in time, solidifying through their vigilance or ambivalence that things could have, or maybe could never have been, otherwise.

This sense that something could have been otherwise is evoked in Jain's (2007) "Living in Prognosis." Jain describes these possible pasts as counterfactuals. Talking about cancer she notes how "trying to 'know what the past holds,' what alternatives and what necessities it contained, can become a near obsession," turning past behaviors or unidentified symptoms into "the material remnants of lost opportunities" (Jain 2007:84). For mothers participating in MARBLES, this tacking back and forth, of considering missed chances as opportunities for the future, also relies on science and the hopeful possibility of "knowing better" through knowing *earlier*. This allows the possibility of navigating the future based on the best information about the present. Importantly, through research participation, researchers become part of these ways of knowing and forms of support in mothers' negotiations of autism risks.

Adams et al. (2009) note that, "abduction is a means of determining courses of action in the face of ongoing contingency and ambiguity." Through abduction, "ideas about how to 'move forward' are generated by tacking back and forth between nitty-gritty specificities of available empirical information and more abstract ways of thinking about them" (255). In this way, as Clarke (in prep) has argued elsewhere, abduction is work that is often invisible when it comes to anticipation. For mothers of children diagnosed with an autism spectrum disorder, "finding cause" therefore reflects an experience of trial and error with advances and setbacks that fluctuate continually and inconsistently along the way. In this way, I see mothers of children with autism as their own version of the "moral pioneers" Rayna Rapp (1999) discusses in her work on amniocentesis. Faced with something they cannot know for certain, they look toward the

future in reference to the past, articulating ways that something could be otherwise, while also living in the best possible ways with autism, in the present.

CHAPTER SIX:
CONCLUDING THOUGHTS & CONTRIBUTIONS TO THE FIELD

This dissertation has described social and scientific dimensions of research exploring environmental and genetic causes of autism spectrum disorders. In particular, I have traced the emergence of autism gene-environment interaction (GEI) research (Chapter Two). I then drew upon on my interviews and extended ethnographic observations of an exemplary GEI prospective pregnancy study to illustrate its practices (Chapter Three), central social and medical systems (Chapter Four), and the subjective experiences (Chapter Five) of those involved. I have demonstrated how autism is increasingly positioned as a *possible future* that should be preemptively considered, acted upon and engaged in the *present*. I argue that this orientation and the processes it entails reflect spatial and temporal shifts in social and scientific understandings of autism as a disease category and lived experience. I call the overall process "anticipating autism."

Anticipating autism challenges the *when* as well as the *what and why* of autism, raising new questions about relationships between bodies, environments and time, and about the intersections of scientific practice and care. My analysis reveals that responsibilities for anticipating autism fall largely on women as mothers and potential mothers, profoundly reshaping their actions, bodies and lives. The processes involved in anticipating autism thus embody relations among contemporary categories of health and illness, genetics and environment, family and gender. In tracing these relations, this dissertation offers an example of how risk and illness are increasingly taken up as sites where uncertainty and responsibility are negotiated and also how they may be extensively

stratified. Next, I discuss the significance of this analysis for the fields of sociology, the sociology of health and illness, and science, technology and medicine studies.

Implications for the Field

This study draws upon and contributes to theoretical scholarship on biomedicalization (Clarke et al. 2010), biopolitics (Foucault 1973), and feminist science and technology studies (Haraway 1997; Thompson 2005). This study highlights the increasing complex forms of knowledge production surrounding disease (Chapter Two), their relationships to care (Chapter Three), and how they intersect with the intensifying technoscientization of everyday life (Clarke et al. 2010). This latter theme is evidenced in the surveillance of childhood behaviors through the uptake of diagnostic tools including developmental checklists (as illustrated in Chapter Four), and through the comparisons of bodies and embodied experiences that situate knowledge and actions related to autism risk (Chapter Five). Through exploring the institutional, technical and everyday ways that knowledge about autism is taken up, this dissertation reflects relations among parents, scientists and notions of cause as actors, as well as discourses produced over time and entangled with one another in meaningful ways (Myers 2008).

Specifically, these findings contribute to studies of expertise, the sociology of diagnosis and research on subjectivities and identities related to health and illness. In studying science as social practice, this dissertation also provides important insights into several key concepts and areas of scholarship in science, technology and medicine studies. These are the study of boundary objects and their relationship to complexity, the intersections of science, medicine and care, and issues in classification of disease. These contributions are illustrated below.

Networks of Concern: Expertise, Boundary Objects and Knowledge Production

In Chapter Two, "Constructing the Environment in Autism Science," I traced the emergence of gene-environment interaction research on autism. I argued that through building alliances across lay and expert communities, parent concerns about the rising number of autism cases in the United States garnered both political and scientific support for research on the contribution of environmental factors in causing autism. These alliances engendered what I have deemed "networks of concern" that include parents, policy makers, scientists and program officers across an expanded number of social domains and disciplinary fields. Accompanied by recent acknowledgment of current limitations of autism genetics, these (sometimes uneasy) alliances did the work of extending *specific* concerns about the environment closely aligned with vaccines as potential causes or triggers of autism, into a broad research agenda focused on the interactions between environmental factors and genetics. This in turn has produced autism as a field of study commensurate with other chronic complex diseases, enabling the recruitment of new scientists from fields such as cancer epidemiology and birth defects research, and thereby changing the directions of autism epidemiologic research.

The concept of "networks of concern" contributes to studies of expertise and extends scholarship on health social movements (Brown et al. 2003; Epstein 1996; Epstein 2008) by focusing on the effects of these movements on autism etiologic research (see Orsini 2009; Silverman 2011). Importantly, in these networks focused on autism, "the environment" – and perhaps now increasingly gene-environment interaction – operates as a boundary object (Star 1988; Star and Greisemer 1989; Bowker and Star 1999; Star 2012). That is, in terms of its interpretive flexibility, it's ability to organize diverse sets of work practices and actors, and act as an infrastructure (Star 2010), the

environment, is quite potent. The extension of the environment as a meaningful site of scientific inquiry therefore produces autism as a "problem" that can be addressed by a different set of experts – environmental and genetic epidemiologists – ushering in new forms of scientific practice and assemblages of expertise.

One particular result of these shifts has been efforts to prospectively study what particular environmental and genetic factors are associated with autism. These prolonged research engagements provide the opportunity for multiple relationships to come into being – between researchers and participating families, as well as between environmental factors and genetics – while at the same time standardizing others (i.e., the womb as environment and autism as biological) (Star 1995). Through focusing on gene-environment interactions during critical windows of vulnerability, including pregnancy and early childhood development, these studies shape questions of cause as always, already mediated *within and through* women's bodies. These characteristics are critical to the next several areas of literature to which this dissertation contributes.

Taking Care: Care Work, Infrastructure and Biolabor

Throughout this dissertation, it has been my goal to focus attention on how risk and responsibility shape and are configured through the intersections of science, family and biomedicine. I chose to study research on pregnancy and early childhood development because it offered a concentrated site where questions about relations between genetic and environmental factors were being considered. This site also reflects the social and scientific attention placed on mothers' negotiations of risk and uncertainty as increasingly consequential sites for constructions of autism. In paying particular attention to women's experiences, I sought to highlight the intersections of their

experiences and the practices of autism research.

In Chapter Three, "Building Resources and Taking Care," I detailed how prolonged engagement with questions of cause enabled through prospective cohort studies becomes productive of other relationships as well. In tracing decisions and practices that emerge within these studies, I detailed how prospective epidemiologic research on autism becomes meaningful to participants and scientists as both an *investment* generating an infrastructure for building scientifically grounded relationships between nonhuman actors and autism as a disease category, and as form of support generating opportunities for relations of care under the conditions of uncertainty surrounding autism.

This analysis contributes to sociological research on women's labor and care work (Hochschild 1983), extending feminist articulations of largely unacknowledged, feminized forms of economic productivity (Waldby and Cooper 2010) through describing mothers' participation in autism research focused on pregnancy and early childhood. In doing so, I articulate how mothers' participation becomes a way of contributing to the larger biomedical knowledge economy surrounding autism. It is also a form of affective work that is productive of shifting relationships between not only women, their bodies and biomedical knowledge, but also autism families, scientists, and study staff as well (see also Mitchell and Cooper 2010 on clinical labor). These relationships are facilitated by the decisions principal investigators make about study design and protocol. Such decisions simultaneously position "at-risk" populations as central to questions of autism's cause, while also producing forms of care as central to the research.

I argue that what results from these interactions is much more than knowledge

about autism's causes. It is a network of relationships that includes new ethical dimensions of mutual care and support, as well as resources for examining future questions about autism's connections with the environment, genetics and time. Care, I contend, thus becomes a central component of these studies. It is in part necessitated by the prolonged nature of the studies and also becomes an emergent quality of the study design. As such, care becomes a currency of exchange (Tabor and Lappé N.d.) that enables ongoing commitment on the part of families and researchers, as well as supporting the accumulation of biological and environmental samples for ongoing autism research. Here, my analysis contributes work on the logic of care (e.g., Mol 2008), and follows Puig de la Bellacasa's (2010) recommendation that we approach science and technology as "matters of care," paying attention to often neglected things. In my research, neglected things are relationships produced at the intersections of uncertainty and science, which are both foundational and transformational for families and for changing understandings of autism.

Diagnosis, Classification and Motherhood

In Chapter Four, I described mothers' experiences of their children's autism diagnosis. I trace diagnosis as both a label and an affective experience that recasts differences as symptoms and informs mothers' actions and identities. My analysis draws connections between the social and scientific experiences of autism diagnosis, and their consequences for mothers' identities as uniquely qualified advocates and carers for their children. Diagnosis here is an obligatory passage point (Callon 1986; Latour 1987) in mothers' participation in the larger autism community, especially as potential participants in autism research. This chapter builds on and contributes to the emergent sociology of

diagnosis by highlighting the temporal qualities of diagnosis and its unfolding meanings for mothers *over time* (Bury 1982; Williams 1984). I engage scholarship on diagnosis as a process and a consequence (Brown 1995; Jutel 2011).

Further, by engaging Hacking's (2007) concept of "the looping effect of human kinds" and the sociology of disease (Timmermans and Haas 2010), my analysis reflects how mothers' experiences of autism diagnosis are informed by their children's distinct symptoms, the constellation of which is unique for each individual diagnosed with autism. This poses the prospect of multiple kinds of belonging connected with diagnosis (see Singh 2010), a finding that has been documented in work on biosociality (Gibbons and Novas 2008) and charted in research following the molecularization of autism (Navon 2011) as well as other areas of social life (Rose 2007; Clarke et al. 2010). Through focusing on mothers' experiences of diagnosis in particular, this chapter contributes additional analyses of carers' experiences of illness (Jutel and Nettleton 2011; Olson 2011). Further, this analysis considers how diagnosis is situated within cultures of surveillance that become aligned with "good" motherhood in the contemporary era, a theme further articulated through the concept of "finding cause," discussed next.

Finding Cause: Surveillance, Risk and Subjectivity

Over the past several decades, questions about the causes of autism have captured the popular imagination and garnered increasing resources from government and private funders. Linked to these efforts have been campaigns to promote autism awareness (Autism Speaks 2012), and acceptance (Autism Acceptance 2012), as well as debates about causal facts and fictions associated with the condition (Offit 2008, 2011). In Chapter Five, I developed the concept of "finding cause" to emphasize how participation

in research becomes one of *many* strategies mothers take up in navigating autism and autism risks. By following mothers during their experience as research subjects and as they prepare to have another child, my analysis reflects how causal explanations for autism are made meaningful based on mothers' lived experiences of their affected child's condition, their own actions, and their hopes for the future. I argue that their experiences of autism risk are situated within a discourse of proliferating risk factors, which encourages them to consider their own bodies and the bodies and actions of their children in order to establish *what* is risky and *when*. As mothers prepared for and then brought a new child into the world, ongoing assessments of their new child brought their past experiences with their older children, other pregnancies, extended family histories, and specific exposures to bear. This created meanings and actions that were oriented not only to the future but also backwards in time, crystallizing through their ongoing assessments that things could have, or perhaps could never have been, otherwise.

The concept of "finding cause" contributes to scholarship on risk (Lupton 1999), anticipation (Adams, Murphy and Clarke 2009) and biomedicalization (Clarke et al. 2010) through highlighting how surveillance becomes an important aspect of "good mothering" in the face of the uncertainties surrounding autism. By tacking back and forth between the past, present and future, mothers re-imagine missed chances as opportunities for the future (Jain 2007). These possibilities increasingly rely on the hopeful possibility of knowing *better* through knowing *earlier*. In these ways, "finding cause" builds on and contributes to work on abduction as articulated by Adams, Murphy and Clarke (2009). The authors note that, "abduction is a means of determining courses of action in the face of ongoing contingency and ambiguity" (271). For mothers of children diagnosed with

autism, "finding cause" is an experience of abduction. It is a process of trial and error with advances and setbacks that fluctuate continually and inconsistently along the way. Faced with something they cannot know for certain, they look toward the future in reference to the past, articulating ways that something could be otherwise, while also living in the best possible ways *with autism*, in the present.

Limitations and Future Research

This dissertation offers an in-depth study of one area of autism science at a particular moment in time. As such, the findings presented here are necessarily local and are not an attempt to characterize the field of prospective pregnancy studies on autism as a whole, nor the breadth of approaches taken up to account for gene-environment interactions. Rather, I have focused on the shifts in the field of autism science generated by recent causal debates, their bearing on the breadth and specificity assigned to "the environment" in the field, and their relationships to one particular area of autism research. By focusing on a particular research study, the dissertation considers the local practices, forms of knowledge production, and relationships woven in and through that prospective pregnancy study. This dissertation offers a window onto how both researchers and mothers' of children diagnosed with autism navigate science, uncertainty and care related to autism. In detailing these conditions of possibility and the relationships they engender, I provide a glimpse at mothers' experiences at a unique intersection between knowing and not knowing – following the diagnosis of at least one child with autism, but before the potential diagnosis of another child.

There have been many benefits of drawing on such a specific research project and population of participants for the dissertation. However, there are also limitations of my

study design. While the methods, population, samples and forms of data collection of MARBLES are characteristic of other prospective pregnancy studies in the field (such as EARLI and the ABC study), my findings are by no means generalizable to all participants in such studies, nor to the breadth of perspectives held by autism scientists, advocates or individuals with autism. In particular, this dissertation does not engage centrally with the larger disability and neurodiversity communities (see Savarese and Savarese 2010; Solomon and Bagatell 2010; Singh 2010). As a result of not interviewing adults with autism, the results presented here are necessarily limited. In future iterations of this research, such perspectives should be considered, and the sciences and experiences of mothers presented within this dissertation should be situated in relation to the diversity of perspectives within broader autism communities. Such perspectives will no doubt bring new insights to the study of autism gene-environment interaction research that are important for questions of care raised in Chapter Three, as well as for the politics of prevention engaged throughout this dissertation.

An additional limitation of this research is that the participants who are included in this study have been specific and self-selecting. I attempted to situate these voices in the larger autism communities through subscribing to multiple mailing lists, regularly reading websites and blogs, attending meetings, listening to radio programs and watching documentaries. However, most of the scientists, advocates and mothers I contacted were specifically aligned with the fields I aimed to study. While many of those I contacted agreed to participate, others did not. As a result of my own selection and their self-selection, there are many individuals whose experiences are not reflected here, including many other autism scientists. As autism science has become increasingly interdisciplinary

(as illustrated in Chapter Two), the importance of considering the various forms of expertise and experts who interact and help to produce the relationships I highlight in this dissertation increases, as does the study of other relationships not discussed here.

The mothers who agreed to take part in my study were also from a quite specific population. This was in part intentional, as I was interested in recruiting through the specific studies of autism in order to consider what it meant to be "at-risk" and to better understand the interactions and effects related to this particular study design. However, these individuals are a specific population as defined by MARBLES, further limited by those within the MARBLES study who were willing to participate in my study. I have paid close attention to the implications of this limitation and attempted to be attentive to the boundaries of my findings that might emerge differently in the experiences of other mothers. A very clear counterpoint to my choice to interview mothers would be to study fathers' experiences of autism, and those of siblings. These are critically important to account new families are increasingly enrolled as subjects in autism research. Paying attention to the similar and distinct subjectivities that emerge in relation the themes of uncertainty, care, risk and responsibility would offer additional angles of understanding beyond those presented in this dissertation.

Future research may also pay particular attention to how concepts developed in this study play out in different settings. For example, how might individuals, families or groups take up some of the processes that make up anticipating autism with regard to other conditions? How might we theorize *anticipating illness* as an orientation in science, medicine and society? This extension dovetails with other literature in the sociology of health and illness, including recent work by Timmermans and Buchbinder (2010 and

2012), which identifies "patients in waiting." Still others (e.g., Metzl and Kirkland 2010) have reflected on the emergence of more and more categories of the pre-ill and the relationships among these states and responsibility. These will become increasingly important areas of study.

Two sites where these questions might be further explored are during diagnosis and within other scientific research settings. Future research might explicitly follow the process of diagnosis for individuals across various age groups and demographics. Or it might ask how comparisons of autism genetics, neuroimaging and epidemiology studies produce different analyses of knowledge production, uncertainty and care: what other subjects and subjectivities might become visible in studies focused on other fields of scientific or medical inquiry? As the data presented in Chapter Four of this dissertation make clear, these experiences are also influenced by space and time. What are the effects of age, location, education level, race and gender, for experiences of diagnosis and service procurement? Further, how are the interactions among physicians, patients and their families framed by the availability of services or insurance coverage? These dimensions of autism became important in the stories of diagnosis I detail in Chapter Four. Longitudinal, qualitative research following these experiences across various sites would be a valuable addition to the literature.

Finally, while this study has highlighted the growing importance of the environment in autism science, future research may provide an in-depth exploration of the specific forms that the environment takes in these and other experiments. How are these articulations related to social movements, technological changes and existing theories of causality in other disease areas? A particular iteration of these questions might

follow the social, scientific and political conditions surrounding what is commonly referred to as fetal origins research, or the "developmental origins of health and disease" (DoHaD). This identifies a growing field of scientific research that explores how conditions before and during fetal development alter the structure and function of the body, influencing the life course and later onset disease. Tenets of this approach were central to many of the samples collected in the studies I followed. This area of research has wide ranging implications for how we come to understand genetics and the environment, risk, and disease onset. A study focused on these sciences would provide an important extension of many of the questions raised by this dissertation.

Afterward

Drawing on and contributing to literatures in sociology, the sociology of health and illness, and science technology and medicine studies, I have illustrated how contemporary processes of knowledge production surrounding autism provide paradigmatic examples of how uncertainty and ambiguity surrounding post-genomic diseases compel action toward the future. In detailing the process of *anticipating autism*, I have articulated the social dimensions of these actions and their consequences for understandings and experiences of risk, as well as for scientific infrastructures and forms of care. In doing so, I have presented the various ways that scientists, policy makers, researchers and families, but especially mothers' of children with autism, navigate science, uncertainty, and care in the post-genomic era. My hope is that this dissertation illustrates the complex relationships that are increasingly part and parcel of experiences of health and illness in the twenty-first century. Importantly, these are constantly moving. As I complete this dissertation, the studies I've focused on move forward, in new

directions, with new participants and findings. While families live *with* autism, their samples remain, stored in freezers and bundled in filing cabinets, classified with inventory numbers. Their ambiguities, uncertainties and meanings are in limbo, waiting as open questions, for the future.

APPENDIX A: SCIENTIST INTERVIEW GUIDE

Thank you for taking the time to talk with me today. As you know from our correspondence, this interview is part of a larger study exploring research on the role of environmental factors and gene-environment interactions in autism spectrum disorders (ASD). During this interview we will discuss a bit about your background and professional training, your research and perspective on autism spectrum disorders, and the role of your research in the larger autism community. Do you have any questions before we begin? [Pause for Questions] Okay, let's get started.

Training and Professional Background

1) First off, can you tell me about your background?
    a. What is your professional title?
    b. Where did you go to school and in what discipline were you trained?
    c. Could you briefly explain your professional trajectory up until now?
    d. How would you describe yourself professionally?

2) How did you get into research on ASD?
    a. How do you think your professional background influences your research?
    b. How have your personal experiences shaped your work?

Research on ASD

3) Could you describe your current research on autism?
    a. What are the studies you are currently involved in/with?
    b. What role do you play in those studies?
    c. How is that research funded?
        i. How did or does the funding influence your research?
            1. Does it at all affect the questions that are asked and how the study is structured?

4) When did you first get the idea for this study?
    a. Can you tell me a bit about the central hypotheses of the studies you are involved in?
        i. What are your goals for this research?
        ii. What implications do you think the results might have? For who?
    b. Where did the idea for those projects come from (for example: other complex disease research, models for understanding causation, training or collaborative efforts, debates in the literature)?

5) With who do you work with on each study?
        i. What other disciplines work with you on this research and what expertise do they bring to the study?
        ii. What are some of the benefits of working on an interdisciplinary team?
        iii. What are some of the challenges and how do you manage them?

6) Can you talk a bit about your research design?
    a. Can you tell me a little bit about the protocol?
        i. What samples are taken, when and from whom?
        ii. Are families explicitly involved in the study? How?
        iii. How are advocacy or community advisory boards involved in the research?
    b. How would you characterize the challenges of the research you are involved in now?
    c. If lay individuals or groups are included, what are some of the challenges or benefits you see of their involvement?

7) Can you tell me what you think the impacts of your research will be?
        i. On who (examples include: families, policy makers, regulatory agencies, advocacy groups, others)?
        ii. How and in what ways (i.e. in relation to treatment, prevention, risk communication, increased knowledge of phenotypic expression, etc)?

8) What is most interesting to you about ASD?
    a. Of the studies you are involved with, or have been involved with, which is most interesting or exciting to you, and why?
    b. What motivates you about researching autism?
    c. How do you feel your perspective and research approach fits into the larger field of research on autism?

9) How would you compare your research on autism to other researchers in the field?
    a. In different disciplines?
    b. How would you describe the relationships among researchers and research agendas related to autism?
    c. How would you describe the relationships among your research and other autism interest groups, foundations or organizations?

10) What ethical, social or policy issues do you see as arising out of this research?
    a. Why and in what ways do you see these as potential issues of relevance to this project?

11) How would you describe autism spectrum disorders (ASDs)?
    a. What do you think causes autism?
    b. How will your research explore this question?
    c. What do you perceive to be the implications of your research?
    d. How would you say your disciplinary and professional experience shaped your understanding of autism and what causes autism?

12) Do you see any particular views or approaches in the field of research on ASD as divergent from your own?
    a. How would you characterize those approaches?
    b. How would you describe them as distinct from your own?

Broader Arenas of Influence: Autism Community, Media, Families & Research Subjects

13) Can you describe your involvement with the autism community?
    a. How would you describe or define the autism community?
    b. How did you become involved in that community or with those groups, families, etc?
    c. How is the community involved in the research you are a part of?
    d. How do you think your research will affect the larger autism or ASD community?

14) Can you talk a little bit about experiences you have had around media reporting and autism?
    a. Have you seen any of your findings reported in the mainstream media?
    b. If so, or if you've seen related work reported, what has been your reaction and interpretation? Are those reports accurate?
    c. How have reports impacted your work and research? Your relationships with participants, your experiences of recruitment or conversations with community advisory boards?

15) What has your experience of funding this project or projects similar to this one been like?
    a. Recently, or in the past?
    b. Had this changed? When and, if so, why do you think it has?

16) How do you think the vaccine controversy has affected your research?
    a. How do concerns about vaccines play into your research?
    b. How do or might they affect risk communication related to your results?

17) How are families involved in your research?
    a. Why do you think they are enrolled in the study?

18) How do you anticipate sharing the results of your study?
    a. When and with whom?
    b. Have you had experiences with this approach before?

19) Are there other groups of individuals you would recommend I speak with?
    a. Who and why?

APPENDIX B: PARENT INTERVIEW GUIDE

Thank you for taking the time to talk with me today. As you know from our correspondence, this interview is part of a larger study exploring research on the role of environmental factors and gene-environment interactions in autism spectrum disorders (ASD). During this interview we will discuss a bit about you and your family, your experience with autism spectrum disorders, and your involvement in autism research and the broader autism community. Do you have any questions before we begin? [Pause for Questions] Okay, let's get started.

Family Experience & Descriptions

1. Can you tell me about yourself?

2. Can you describe your family for me?
    a. Family size, ages, professions, interests, children, etc.

3. Can you describe your experience with autism spectrum disorders?
    a. Can you take me through the experience of having your child diagnosed with autism?
        i. What did that mean for you?
        ii. What did that mean for your family?

4. Can you describe what you feel to be the cause or causes of autism?
    a. For your child?
    b. More broadly?

5. How would you describe the role of genetics in autism?

6. How would you describe the role of environmental factors in autism?

7. How has your understanding of autism changed since your child was diagnosed?

8. Can you describe what a typical day is like for you?

Pregnancy Experience & Plans

1. Can you tell me about your pregnancy?
    a. How has it been going so far?
        i. Is it similar or different from your prior pregnancy(ies)?

2. In what ways has your participation in the study affected your experience of pregnancy?

3. What are your plans for your delivery?
    a. Is that similar of different from your other child(ren)?

Research Experiences & Participation

1. How did you hear about the study you are involved in now?
    a. What motivated you to participate in this study?
        i. What interested you about the study you are involved in specifically?

2. Have you been involved in other research studies?
        i. What were they and how did you find out about them?
        ii. What motivated you to be involved?
        iii. What was your experience like in those studies?

3. Can you describe your experience in the study to date?
    a. In what ways has your experience influenced you?
    b. In what ways has your experience influenced your family?
    c. In what ways has your experience influenced your experience of pregnancy?
    d. How has your experience influenced your understanding of autism?

4. What do you see as the main goals of this research study?

5. What kinds of funding do you see as important for autism more generally?
    a. Where does research fit into that?
    b. What kind of research do you think is needed on autism spectrum disorders?

Experience in Broader Autism Communities, with Media Representations & Advocacy

1. How would you characterize your experience in or with the broader autism community?
    a. How would you define the autism community or communities? With what parts of that community do you identify with most?
    b. Have you been involved in any advocacy or special events related to autism?
    c. How did you become involved in that organization, community, with those groups, or other families, etc?
    d. How do you think the research you are participating in will affect the larger autism community?
    e. How do you think the research will affect you and your family?

2. Can you talk a little bit about what sources you use to learn about autism?
    a. What kind of information about autism is most important to you?
    b. What are your thoughts on media representations of autism?
        i. Can you give me an example of a report, article, story or campaign that affected you, in what way and why?

3. What are your thoughts or feelings about how families are portrayed in the media?
    a. What about their representation in educational resources you have used?
    b. Clinical encounters with physicians or therapists?
    c. And within research studies you've participated in or heard about?

4. How would you describe the relationship between individuals with autism and their family members?

5. What are some of the best moments you have with you son or daughter?

6. What are your hopes for your current pregnancy?
    a. For your new son or daughter?

7. Is there anything I didn't ask you about that you'd like to talk about before we finish?

APPENDIX C: ADVOCACY REPRESENTATIVE INTERVIEW GUIDE

Thank you for taking the time to talk with me today. As you know from our correspondence, this interview is part of a larger study exploring research on the role of environmental factors and gene-environment interactions in autism spectrum disorders (ASD). During this interview we will discuss a bit about your background, your professional position, and your experience and perspective on autism spectrum disorders including the relationship between your work and the broader autism community. Do you have any questions before we begin? [Pause for Questions] Okay, let's get started.

Professional Position, Focus & Background

1. Can you tell me about your current position?
    a. What is your professional title?

2. How did you get involved in the organization you are working with now?

3. Could you briefly explain your professional trajectory up until now?

4. Can you tell me about your experience with Autism Spectrum Disorders?
    a. How have your personal experiences shaped your work?
    b. How have your personal experiences shaped your choice to work for your organization?

5. How would you describe autism spectrum disorders (ASDs)?
    a. What do you think causes autism?
    b. What does your organization feel is the most appropriate response to autism?

6. What is most interesting to you about ASD?
    a. What motivates you to be involved with projects related to autism?

Projects, Campaigns or Responsibilities Related to ASD

1. Can you describe your organization for me?
    a. Does your organization you have a strategic plan?
        i. If so, what role does autism play in that plan?
        ii. What aspects of autism are most critical to your organization?

2. Could you describe your current responsibilities in the organization and the specific projects or campaigns you are working on?
    a. What role do you play in those projects?
    b. What percentage of these would you say are focused on autism?

3. Whom do you work with on each project?
    a. What other organizations, groups or individuals are involved in this work?

b. What was the impetus for this project or focus?
c. What are your goals for this project or campaign?
d. What are some of the challenges of this project and how do you manage them?

4. Can you tell me a bit about how your organization decides on funding priorities?
    a. Do you have parent or community advisory panels or groups?
    b. Are these specific to autism related funding, or do they influence decisions across various areas of your organization's work?
    c. What are your goals for this research?
    d. What implications do you think the results of that work might have? For who?

5. Can you tell me what you think the impacts of your organization are now, and what they will be in the future?
        i. On who (examples include: families, policy makers, regulatory agencies, researchers, others)?
        ii. How do you think those impacts will influence autism specifically?
        iii. How and in what ways (i.e. in relation to treatment, prevention, risk communication, increased knowledge of autism, or the effects of environmental contaminants, etc)?

6. How would you compare your organization to other organizations in the field?
    a. How would you describe the relationships among other organizations and your own?
    b. How would you describe your relationships with families, parents, and individuals with autism?

7. Do you see any particular views or approaches to funding ASD research or supporting programs related to autism as divergent from your own?
    a. How would you characterize those approaches?
    b. How would you describe them as distinct from your own?

<u>Broader Arenas of Influence: Autism Community, Media and Families</u>

1. Can you describe your involvement in the broader autism community?
    a. How would you describe the autism community?

2. Can you talk a little bit about experiences you have had around media reporting and autism?
    a. How have reports about autism impacted your organization? Your relationships with members, or autism communities more broadly?

3. Have there been any shifts in your organization since it began?

4. Have there been any shifts in the focus of your campaigns, projects or research funding in recent years?
    a. How and for what reasons?
    b. In what directions?
    c. How so for autism specifically?
        i. Why do you think this has taken place?
        ii. In what ways has this affected work surrounding environmental factors and autism?
        iii. How are environmental factors defined by your organization?
            1. For autism?
            2. More broadly?

5. What do you see as the most challenging aspects of your work?

6. What do you see as the most rewarding part of your work?

7. Are there other groups of individuals you would recommend I speak with?
    a. Who and why?

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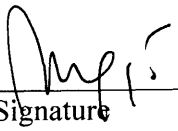
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