"A Critical History of Bioethics."

John H. Evans; University of California, San Diego

To further define "critical disability studies bioethics," it is important to be aware of what I will call mainstream bioethics – the bioethics that dominates the public sphere and that disability studies (DS) bioethics will need to engage with or perhaps draw boundaries against. The DS scholar needs to not only be aware of this field and its history, but also its various biases that will constrain or promote the use of discourse from DS. In this chapter I offer a history of mainstream bioethics along with a description of, and explanation for, its various biases. I conclude with a discussion of the trade offs DS scholars need to be aware of when interacting with mainstream bioethics.

I begin with some disclaimers. First, I primarily write about the history of U.S. bioethics (for a history of UK bioethics, see (Wilson 2014)). That said, while every nation has their own particular bioethics, the influence of the U.S. on at least the Anglophone world has been large. Second, I do not have a disability and have also not previously engaged extensively with the DS field. I write as a historian of mainstream bioethics, and hope that my potentially outsider views will be productive for DS scholars. This text starts by summarizing the history of mainstream bioethics that I have more extensively described elsewhere (Evans 2002; Evans 2012).

THE JURISDICTIONS IN CONTEMPORARY BIOETHICS

To understand both the history of mainstream bioethics, and particularly its intellectual

biases that may or may not be compatible with DS, we have to think of bioethics as a "task" that various professions have been competing over. This is similar to how various professions have competed over the past 100 years for the task space or "jurisdiction" of controlling misbehaving children. The clergy once had jurisdiction, but now there is an ongoing struggle between psychology and psychiatry for this task. Similar stories can be had about competitions and jurisdictional settlements between nurses and doctors, lawyers and accountants and many others. I consider DS bioethics to be a distinct competitor to mainstream bioethics. I will largely gloss over how the competition between various professions shaped what we now know as bioethics, and instead start with a description of the contemporary situation. When the DS scholar hears of "bioethics," this term is actually referring to one of four possible jurisdictions.

Healthcare Ethics Consultation

The first jurisdiction is healthcare ethics consultation (HCEC) which concerns the issues having to do with medical care within medical institutions like hospitals. The topics are extremely limited to those that would occur within the medical setting. The goal in this jurisdiction is to facilitate ethical agreement among individual "stakeholders" such as medical staff, patients and the family of a patient. A typical debate would be whether to end the life support of someone in a permanent vegetative state. While DS scholars are interested in the topics in this space, mainstream bioethicists have iron-clad jurisdiction.

Research Bioethics

The second jurisdiction is research bioethics, which focuses on creating procedures for ethical research on humans. This activity occurs through Institutional Research Boards (IRBs).

In the U.S., every entity that receives government research money must have an IRB, although in practice essentially all human research is conducted with oversight from an IRB. This jurisdiction accounts for a large percent of all bioethical activity but, like the first jurisdiction, is constrained to a very narrow set of issues. A typical question would be whether a research protocol for a clinical trial to develop a treatment for Parkinson's disease using stem cells is conducted in an ethical manner. For this research to be considered ethical, researchers would have to demonstrate that the research accounts for the autonomous decision-making of individuals with informed consent; doing good for the subject and avoiding harm (technically called beneficence and non-maleficence) through risk–benefit analysis; and advancing "justice," which means not experimenting on disadvantaged groups like prisoners and orphans. Again, while DS scholars should be interested in this task, mainstream bioethics has an extremely strong jurisdiction, and DS scholars are largely not involved.

Public Policy Bioethics

The third jurisdiction is public policy bioethics which debates the ethics of technology and science affecting humans that can be incorporated into general policies that will be applied to all citizens. A recent example is the large group of recent commissions recommending policy concerning human gene editing. DS scholars occasionally participate in this jurisdiction – for example a DS scholar testified before the recent NAS panel on human gene editing. This activity is not just based on policy commissions, but any writing that ultimately is intending to influence law or policy. Jurisdiction is less settled in this task space, and since the topics in this

jurisdiction are much more broad than in the previous two, it will presumably be of more interest for DS scholars.

Cultural Bioethics

The final jurisdiction in bioethics is "cultural bioethics," which is the debate that tries to convince the public of the proper ethical course of action for – or proper understanding of – medical and scientific technology outside of the immediate framework of policy. For example, most philosophers are operating in this jurisdiction, debating questions like whether there is a moral obligation to genetically enhance one's children. My sense is that the majority of DS fits in this jurisdiction as DS scholars are debating topics such as what "ability" is, but with no direct connection to policy. Indeed, this very volume is largely in this task space. This is by far the most diffuse part of the debate both topically and, as I will focus on below, in terms of the forms of argumentation that are allowed.

A CRITICAL HISTORY OF BIOETHICAL JURISDICTIONS

The historical evolution of these jurisdictions shows their intellectual biases and points to the challenges for DS. For our purposes, the bioethical debate began in the 1960s, and originally there was only the cultural bioethics jurisdiction. During the 1960s, scientists were worried about the explosion of newfound technological abilities and had many meetings to discuss the emerging technologies of the time, such as birth control, genetic engineering, organ transplantation and much else. Critically, the debate was about what our ends or goals should be: "Where are we taking ourselves with our new technological abilities?" was the central theme.

Should our goal be the perfection of humanity? Obedience to God? The elimination of inequality? For example, Daniel Callahan, co-founder of the Hastings Center and one of the originators of contemporary bioethical debate, called for further debate over "some general, comprehensive, and universal norms for 'the human.'" (Callahan 1972:99) The point of one of the conferences was "not simply the question of the survival or the extinction of [humankind], but *what kind* of survival? A future of what nature?" (Jonsen 1998:13)

This debate was also inherently social or cultural, and not about the relationship between particular individuals, as later debates would be. To foreshadow my later discussion, it is this social not individual level debate about what our ends should be that contemporary DS scholars would be most comfortable in.

This social or cultural debate of the scientists about setting the goals of humanity attracted the attention of another profession that arguably held jurisdiction over this task in this era: theology (with some participants from sociology, law and philosophy). Theologians saw the scientists as infringing on their traditional professional tasks, and challenged the scientists' ability to set the ends or goals of society that should be pursued through biomedical technology.

The theologians and their allies were debating with the scientists what our goals or ends should be with technologies like human genetic engineering and the public began to pay attention, soon getting the attention of elected officials. Elected officials needed an ethics that could be executed by the bureaucratic state. The form of argumentation in the debate quickly changed when the bureaucratic state became the primary audience, and three new jurisdictions were soon formed that used this newfound form of argumentation.

The Emergence of the Public Policy Bioethics Jurisdiction

There had been congressional hearings as early as 1968 on creating a government commission to oversee research on emerging technologies such as behavior control, birth control, organ transplantation and human genetic engineering. The congress seemed to be engaged in the same fundamental debate as the scientists and theologians. For example, one senator started the hearings by saying: "Recent medical advances raise grave and fundamental ethical and legal questions for our society. Who shall live and who shall die? How long shall life be preserved and how should it be altered? Who will make decisions? How shall society be prepared?" (Jonsen 1998:90-91).

Scientists were fearful that Congress would try to directly determine which experiments could and could not be done. The scientists' attempt to avoid government involvement would not be fully successful as public concern increased. In 1972 it was discovered that the U.S. Public Health Service had been conducting a 40 year long experiment on poor black men in Tuskegee, Alabama by not treating their syphilis and waiting to see the results. Additional revelations of similar experiments on unknowing subjects occurred in the same era. Historian David Rothman concludes that the public attention to these scandals provided the final impetus for government intervention into the ethics of researchers (Rothman 1991:182-89). The state would develop bioethical policies and became the primary audience for ethical debate.

Congress could have, as the scientists' feared, directly decide what it thought were the goals or ends of the nation and banned certain technologies and certain practices – becoming the

regulator of science and medicine. They did not. They first implicitly created the jurisdiction of public policy bioethics, and established the government as the audience, through the 1974 creation of the first commission whose task was to suggest bioethical policy to the government.

One of the mandated tasks of the Commission was to "conduct a comprehensive investigation and study to identify the basic ethical principles which should underlie the conduct of biomedical and behavioral research involving human subjects" and "develop guidelines which should be followed in such research to assure that it is conducted in accord with such principles" (Jonsen 1994:xiv) In other words, they were to create an ethical system that could be put into public law, and which could be used in a bureaucratic context.

These principles were reported in the Belmont Report, which made a transformation in ethical argument critical to the future of bioethical debate (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978). The Commission did not decide what the ethics of the public <u>should be</u> regarding a public issue, but instead claimed to have discerned the <u>existing</u> values of all citizens in such a way as the values of the public can be used to create public policy – in this case, human research subjects policy of the executive branch. They were channeling what would later be called "the common morality."

The commission identified three primary principles that function like what a social scientist would call ends or values – and these principles were argued to be "among those generally accepted in our cultural tradition:" respect for persons, beneficence and justice. These three were satisfied through the practices of informed consent, risk-benefit analysis and the selection of research subjects, respectively (National Commission for the Protection of Human

Subjects of Biomedical and Behavioral Research 1978). These later were expanded and renamed as: autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 2009). To massively generalize, the ethical question in such an analysis is whether the means in question (human gene editing, cochlear implants, bone-lengthening surgery) maximize these four principles, ends or values.

The emergence of this form of ethical argumentation, called "principlism," would come to dominate mainstream bioethics in at least the U.S. and UK. Two British observers write that "by establishing itself as the state-sanctioned authority for converting discussions of good and bad in American medical science into a common language and concepts, the bioethics of principlism achieved the status of an ascendant political currency with global potential" (Salter and Salter 2007:651). These few principles became established as the ends or purposes, which would inform future debate – and would not need to be questioned. The earlier debate about what our ends should be was replaced by a debate about whether various technological acts would maximize these four institutionalized and un-debatable values.

Formation of the Other Jurisdictions

As described, the issue of the ethics of human experimentation was one of the first in bioethical debate, and the Belmont report was concerned with this topic. The government strengthened its control over research bioethics by mandating that more and more research be overseen by what are now called Institutional Review Boards (IRBs) (Rothman 1991). The principlism as articulated by the Belmont report came, through executive order, to be the ethical

system to use in IRBs. This meant that this jurisdiction would not allow debate about what ends would be, but rather the task is whether the particular act of research maximizes the set ends of principlism. As we can imagine, this task is not of interest to theologians, who want to debate what the ends should be, so they left.

A similar story can be had in HCEC. Up until this time the profession of medicine had rock solid control over medical ethics and the ethics to be used in health care settings. However, according to historian David Rothman, between 1966 and 1976 "the new rules for the laboratory," by which he means the principlist ethical system used in the research bioethics jurisdiction, "permeated the examining room, circumscribing the discretionary authority of the individual physician" (Rothman 1991:107).

Scholars agree that principlism is now equally dominant in HCEC as it is in research bioethics. For example, the Handbook for Health Care Ethics Committees, states that the "core ethical principles that support the therapeutic relationship and give rise to clinical obligations include respecting patient autonomy . . . beneficence . . . nonmaleficience . . . [and] distributive justice" (Post, Blustein and Dubler 2007:15). Similarly, one of the influential textbooks for HCEC writes that "there is general agreement that modern medical ethics depends on a small group of moral principles: respect for the autonomy of patients, beneficence, nonmaleficience, and justice." The principles are so set that the book has a four fold table with the principles, printed on card stock, so that it can be put in your pocket when consulting in the hospital (Jonsen, Siegler and Winslade 2006:2, 11).

WHY THE BUREAUCRATIC STATE PREFERS COMMON MORALITY PRINCIPLISM

Principlism is the utterly dominant form of argumentation in HCEC and research bioethics, and extremely strong in public policy bioethics. It is not the dominant form in cultural bioethics, where the consumer is not the bureaucratic state, but remains the general public and academia.

If DS scholars are going to engage the different jurisdictions in bioethical debate, it is important to understand the durability of principlism, because I will argue below that principlism is the main challenge disability studies scholars will have with interfacing with mainstream bioethics. Why does the bureaucratic state prefer principlism? The key is that the principles are portrayed as universally held values, goals or ends.

The bureaucratic state prefers principlism and its purportedly universal values because the unelected employees can not be seen as promoting their own values – they are simply promoting the universal goals of the American people. This makes their influence more democratically legitimate. Of course, this notion that bureaucrats cannot use discretion is very American, because in America, citizens do not trust government. Historian Theodore Porter writes that in other countries government officials are "trusted to exercise judgment wisely and fairly. In the United States, they are expected to follow rules" (Porter 1995:195). In this analogy, the principles are like rules, and the bureaucratic state does not appear to be using discretion. Imagine the outcry if the director of the National Institutes of Health were to say that they set a bioethical policy by reflecting upon their own personal moral beliefs.

Relatedly, the bureaucratic state likes a system with only a limited number of ends,

values or principles because it appears to be calculable and thus more transparent to the citizens. With only four non-debatable ends, all of a messy ethical discussion can be boiled down to four concepts. Moreover, since the principles can be set off against each other, we see a simple weighing or balancing decision, which also appears to be more transparent to those on whose behalf the decision is being made. (This is one of the allures of cost-benefit analysis). As one of the participants in the Belmont Report later concluded, the principles "met the need of public-policy makers for a clear and simple statement of the ethical basis for regulation of research" (Jonsen 1994:xvi).

The particular ends that have been institutionalized also make this system very durable. The principles are not only portrayed as the common morality, they are also part of the common morality because they are the basis of liberal democratic societies. That is, in a liberal democratic society everyone can pursue their own conception of what is beneficial (autonomy and beneficence), until the point they harm someone else's interests (non-maleficence). This makes principlism perfectly consistent with the nature of law, which clearly facilitates its use by the bureaucratic state.

Finally, principlism is durable not only because it is preferred by the bureaucratic state, but the principles are also held by institutional science and medicine, which have an outsized influence on these debates. Despite the founding myth of bioethics that it is an oppositional force to medicine and science, most analysts would agree with historian Charles Rosenberg that bioethics has, as a condition of its acceptance: "taken up residence in the belly of the medical whale; although thinking of itself as still autonomous, the bioethical enterprise has developed a

complex and symbiotic relationship with this host organism. Bioethics is no longer (if it ever was) a free-floating, oppositional, and socially critical reform movement" (Rosenberg 1999:37-38)

With the lack of independence in mind, we should consider that the principles are actually those that physicians largely held. For example, beneficence (doing good) and nonmaleficience (avoiding harm) are the moral basis of medicine. While the early bioethics debate pushed physicians to consider autonomy of the patients more seriously, physicians and scientists have easily adapted, as they have also to "justice," which never weighs very heavily on bioethical discussions. The original debate between scientists and physicians and those promoting the principles were not over the content of the principles but more over who would have discretion in applying them.

So, to summarize so far, the dominant form of argumentation in three of the four bioethical jurisdictions is common morality principlism. Participants in research ethics, HCEC, and, to a slightly lesser extent, public policy bioethics are explicitly or implicitly limited to arguing whether the means in question (e.g. human gene editing) maximize four pre-set goals, ends or values: autonomy, beneficence, non-maleficence and justice. The cultural bioethics jurisdiction is still somewhat more diffuse. Principlism is very durable because it is strongly preferred by the bureaucratic state and by bureaucratic organizations like hospitals due to its pseudo-democratic qualities, its consistency with liberal democratic reason and law, the relative transparency of its reasoning to the citizens, and its consistency with the ethics of scientists and physicians. With this description and explanation of the bioethical jurisdictions, and the ethical

system in use in each, the question is how critical DS scholars should engage with this field.

DISABILITY STUDIES ENGAGEMENT WITH MAINSTREAM BIOETHICS

The first challenge that DS will have interfacing with mainstream bioethics is that principlism is resolutely individualist in orientation. For example, IRBs only examine whether the interests of an individual research subject in a trial for cochlear transplants are violated by the particular researcher – whether the research subject's autonomy is violated, whether the research will harm them and whether they were selected to be in the trial because they have no social power.

On the other hand, DS is resolutely social in orientation. In the earliest days of DS the central claim was that disability is not a characteristic of an individual, but rather an orientation of society that constrained some individuals. In general, according to Goodley, critical DS "emphasizes the cultural, discursive and relational undergirding of the disability experience." (Goodley 2013:634). So, imagine a DS scholar trying to argue that a cochlear transplant research trials should consider that they will teach the broader society to devalue bodily diversity. This social conception cannot be argued in this jurisdiction, and any broader concerns such as this can only be brought in if they are translated into the language of individualist principlism. That is, the concern about society would have to be re-described as individual harm. That will not be effective.

The second challenge is that DS is "critical," which obviously has many meanings, but at minimum means the questioning of institutionalized social assumptions from the perspective of

the marginalized. How would we look at cochlear implants if we asked deaf people their view? Principlist bioethics is not critical but radically conservative in the technical meaning of conservative as aversion to change. Put bluntly, the ends or goals of the disabled are not universal, and thus this group must limit their concerns to the universal ends like everyone else. There is also not much room for critique if you must limit yourself to the four ends of principlism. DS scholars would have been more at home with the debate up until the mid 1970s where the point was not to maximize assumed ends, but how to convince others of what their ends should be. This debate is still alive in cultural bioethics, far from the three other jurisdictions of bioethics.

My third point is that DS actually has an advantage – at least compared to other challengers to mainstream bioethics – when interfacing with mainstream bioethics, which is that some of the concerns of DS are translatable to principlism. To contribute in a meaningful way to a jurisdiction that presumes principlism, one must translate your concerns into one of the four principles. To take an example from continental philosophers who challenge mainstream bioethicists, principlist bioethics does not accept deontological arguments that a technology is intrinsically wrong, and technologies can only be wrong if they violate one of the four principles. For example, if you want to argue that germline human gene editing is inherently wrong because humans should not have that power you will have to translate your claim into the idea that human gene editing somehow harms an individual. Indeed, in the history of debates over human genetic engineering, bioethicists struggled to identify any argument against germline editing that would fit with principlism, and the best they found beyond safety was that individuals who do

not yet exist have not given their autonomous consent to be experimented upon (Evans 2002). This is an ineffective way to describe inter-generational responsibility – but inter-generational responsibility cannot be translated into principlism.

It is hard to imagine that DS could translate all of its concerns into principlism without losing part of the claim – particularly the "critical" part. However, I can imagine DS claims translated into the principle of "justice." Garland-Thomson writes that DS has been rooted in "an expansion of rights for people previously marginalized or excluded from full participation in exercising the obligations and benefits of equal citizenship" (Garland-Thomson 2017:323). The idea that people with disabilities are not being treated equally, or are being harmed, is the easy interface with mainstream bioethics and explains why the DS perspective is actually invited into some mainstream bioethical discussions. Some of the concerns of DS can be translated.

CONCLUSION

While there is undoubtedly little consensus on what DS bioethics should be, whatever it is it will have to account for the already established mainstream bioethical debate. In this essay I have described the four jurisdictions of the field and how the dominant intellectual orientation of the field emerged. The dominant approach is common morality principlism, and by and large the concerns of critical DS may be hard to integrate. However, DS has the advantage of being concerned with justice, which is one of the principles of bioethics, so interface with the mainstream may well be possible, at least in part.

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