



Is Prenatal Diagnosis Discriminatory Towards People With Disabilities?

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INTRODUCTION

The recent dialogue on abortion, largely implicating the life of the child-to-be, has been a fiery one—but little has been said about possible effects on the *living*, an oft overlooked locus of interrogation in this debate. While recent genetic techniques that locate disability in fetuses have been frequently proclaimed as opportune advancements in our culture, it has been argued by those in the disability rights community that such procedures have discriminatory effects on the currently disabled members of our society. It is argued that restricting a potential life due to the presence of a disability directly sends a message that the lives of those *living* with the same disability are of marginal value.

I plan to show that many abortions which aim to prevent the birth of a disabled child can indeed be regarded as discriminatory. When abortions are acts that are based on uninformed societal views of the undesirability of a specific disability, then those who opt for an abortion may be implying that their disabled fetus has no right to life. In utilizing such unenlightened views to categorically prevent a fetus' *prospective* life, a prima

facie form of discrimination directed towards those currently living with a similar disability is expressed.

PRENATAL DIAGNOSIS PROCEDURES

Current screening procedures can test for disorders and diseases such as Down's syndrome, Fragile X syndrome, Turner's syndrome, Alzheimer's disease, hemophilia, muscular dystrophy, cystic fibrosis, and diabetes. In *preimplantation genetic diagnosis* (PID), embryonic cells are cultured outside the womb (*in vitro*) by allowing sperm to inseminate a female ova cell and are subsequently screened for genetic abnormalities. There also exist *in utero* diagnoses: Through amniocentesis, which involves examining a withdrawn sample of the amniotic fluid after the 15th week of pregnancy, fetuses already developing inside a mother's uterus are tested for any prevailing diseases or genetic abnormalities. Mothers with positive tests are given the option of genetic abortion or, alternatively, of preparing for a handicapped child if they decide to bring the child to term.¹

DISCRIMINATION DEFINED

Lynn Gilliam, author of the article "Prenatal Diagnosis and Discrimination Against the Disabled," defines discrimination as "*making* judgments about people purely on the basis of their membership of a group, which is seen

1. Gregory E. Pence, *The Elements of Bioethics*, (New York: McGraw Hill, 2007), 196-197.

by the dominant part of society as inferior in some way.”² *Wordnet*, Princeton University’s dictionary, defines discrimination as *acting* based on a biased belief,³ while the *Merriam-Webster Online Dictionary* regards discrimination similarly, as a specific *act* of making a distinction “categorically rather than individually.”⁴ It is not surprising that a common denominator in the previous definitions of discrimination is the presence of a specific *act*. One will notice that the definitions stated here work well as many historical cases of discrimination fall under their purview. Nineteenth century slave owners in the United States, for example, exhibited prejudiced mindsets when they viewed African-Americans as inferior and *acted* on this mindset by taking them as slaves. In other words, discrimination requires manifestation of a prejudiced mindset through physical actions—necessarily giving an *action* more weight in accounting for discrimination than one’s *beliefs*. Accordingly, an acceptable, far-reaching definition of discrimination could be as follows: *Action usually based on an unfounded preceding judgment of an individual or group.*

THE PROSPECT OF A FUTURE

Issues regarding the moral personhood of fetuses, when

2. Lynn Gillam, “Prenatal Diagnosis and Discrimination Against the Disabled,” *Journal of Medical Ethics*, no. 25 (1999), doi: 10.1136/jme.25.2.163, <http://jme.bmj.com/cgi/content/abstract/25/2/163>.

3. *Wordnet*, s.v. “discriminatory,” <http://wordnetweb.princeton.edu/perl/webwn?s=discriminatory> (accessed January 15, 2009).

4. *The Merriam-Webster Online Dictionary*, s.v. “discrimination” <http://www.merriam-webster.com/dictionary/discrimination> (accessed January 15, 2009).

they actually start to “live,” and whether they should be regarded as persons have dominated the abortion debate for years. An important point to make, though, is that in coming to a conclusion about genetic abortions’ discriminatory effects on the *disabled*, we do not need such a completely sufficient assay of a fetus’ moral status. Regardless of the moral implications on the embryo, the *living* remain affected by genetic abortions because it is often the *prospect* of disability in a fetus which leads to its termination. This implies that life with disability is not worth living. Hence, our locus of concern remains fixed on actual people who have full moral rights and may feel offended by such abortions.

Prevailing views have often excluded embryos and developing fetuses from membership within the moral community of persons. Such views imply that fetal and embryonic life prior to gestation are undeserving of moral rights, and thus discarding such life via abortion is as morally neutral as “cutting one’s hair.”⁵ Such a position, though, regardless of its popularity, fails to elucidate why some abortions can be viewed as non-discriminatory in nature. It is worth repeating that whether the fetus is or is not a person is of little importance here—what is of concern is the specific *act* that is lending to the discrimination, for discarding a fetus that is (arguably) not a person yet, implies at least some *prima facie* undesirability of its future life when it *does* come into what we can all define as personhood. Otherwise, why would some be aborting these fetuses at all? Discrimination can be viewed as an intrinsic aspect of PID and genetic

5. Gregory E. Pence, *Classic Works in Medical Ethics: Core Philosophical Readings*, (New York: McGraw Hill, 1998), 170.

abortions, if abortion is chosen, since fetuses are being deprived of a *potential* life namely due to their disability; and, knowingly or unknowingly, we are thus implying judgments about the value of that future life.⁶ In this way, genetic abortions can be seen as holding similar moral weight to, say, actually telling a disabled person that you might come across at a local mall or gym that he or she does not deserve to live. Those who, countering this point, claim that some abortions are carried out to salvage the quality of a mother's life or in order to avoid probable economic hardship, may be unaware that they are still portraying some lack of desirability for the fetus' life simply based on its *prospect* of disability. This distinction would bring some transparency to the debate if accepted.

DISABILITY AND QUALITY OF LIFE

The number of genetic abortions carried out in North America continues to climb.⁷ While the reasons for genetic abortions vary, mothers may choose abortion in order to avoid any *harm* to their potential child or to evade any harm of themselves. Some mothers opt for abortions due to the potentially spiteful effects the disabled individual may have on family life, such as major financial implications or divorce. Although couples have a point in

6. I have been most influenced in this matter by Don Marquis. For an interesting discussion on the "future like ours" argument, see Gregory E. Pence, *Classic Works in Medical Ethics: Core Philosophical Readings*, (New York: McGraw Hill, 1998), 183–200.

7. David Mutton, "Trends in Prenatal Screening for, and Diagnosis of, Down's Syndrome" *British Medical Journal*, no. 3 (1998), <http://www.bmj.com/cgi/content/full/317/7163/922>.

thinking this way, it behooves us to inquire into these views and give them a fair hearing.

T. S. Petersen, author of the article “Just Diagnosis? Preimplantation Genetic Diagnosis and Injustices to Disabled People,” contends that disabled children are harmed by being brought into existence and that, with the help of PID, it would be more beneficial if healthy children instead would take their place.⁸ But who can tell? Petersen’s judgment here is a somewhat *a priori* assumption. In fact, others maintain that the idea of disability results from a lack of awareness and reflection that prevents some from realizing that the quality of life of disabled people can be as rich and rewarding as those without disabilities.⁹ Many philosophers, such as Asch, hold the view that most persons with a disability are not truly “sick.” Terms like “health” and “normality” are all relative terms—a product of the perceptions of society at a particular time, and not as largely based in fact as some believe. The majority of people with Down’s syndrome, for example, exhibit relatively high IQs and even perceive themselves as healthy.¹⁰ Plus, studies have shown that people with parentally diagnosed abnormalities, such as cystic fibrosis, can live up to the age of 70 and thrive in society.¹¹ The truth is that many disabled people live with a quality of life that is on par with non-disabled persons,

8. T.S Petersen, “Just Diagnosis? Preimplantation Genetic Diagnosis and Injustices to Disabled People,” *Journal of Medical Ethics*, no. 31 (2005), doi: 10.1136/jme.2003.006429, <http://jme.bmj.com/cgi/content/extract/31/4/231>.

9. Gillam, “Prenatal Diagnosis and Discrimination,” 165–166.

10. Bonnie Steinbock and others, *Ethical Issues in Modern Medicine*, 7th ed. (Toronto: McGraw Hill, 2009), 678.

11. Bonnie Steinbock and others, *Ethical Issues in Modern Medicine*, 6th ed. (Toronto: McGraw Hill, 2003), 528.

or even better.¹² While some individuals with Down's syndrome or Fragile X syndrome may exhibit a decreased level of mental or physical capacity, this does not imply that their overall quality of life is somehow compromised.

While disability is partly a biological condition, many negative views of the disabled may be ultimately seated in social arrangements and constructs that turn disabilities into "handicaps." A person with an abnormal gait due to Tay-Sachs disease, for example, only becomes handicapped when a shopping mall fails to provide ramp access onto the premises and, therefore, contributes to the person's inability to maneuver in public places. It is through overlooking such factors, while putting emphasis on the biological reasons that make it seem as if disabilities bring much "harm" and render life with disability as inherently undesirable. Thus, Petersen's claim of disabled peoples being "harmed" by being brought into existence may be misguided and limited to only those with severe disabilities, in which death is imminent directly after birth. Acting on such a relative criterion to categorically abort most disabled fetuses can, then, be seen as at least some *prima facie* form of discrimination, in that prevailing (yet largely misguided) societal views are being used to categorically abort fetuses found to have *any* form of disability.

THE "LACK-OF-EVIDENCE" ARGUMENT

Some keep their opposition simple by rightfully claiming that no *empirical* evidence exists to show that

12. *Ibid.*, 529.

discrimination is occurring.¹³ This is indeed a fact, but the conclusion based on this fact is deceiving. Phrased in this manner, this assertion implies that research has been carried out, and researchers have concluded that there is no positive relationship between PID and any discriminatory effects. What these advocates are actually implying, though, is that there is a *lack* of research in this field, and thus no conclusions can be made. But, if this is truly the case, then claims of the neutrality of genetic abortions must also be refuted since no research has been done to assess *these* views either. Surely, few scientists have studied such discrimination with t-distributions or ANOVA tests, not only because it would be quite difficult to demonstrate this specific type of discrimination in a scientific manner, but perhaps because many do not believe it exists, or because some believe that any discriminatory implications are outweighed by other societal values (such as reproductive autonomy, for example) and thus opt not to conduct research. Thus, the “lack-of-evidence” claim is actually grounded in the *inexistence* of any evidence on the connection between genetic abortions and discrimination, rather than actual evidence showing that discrimination is not taking place. In essence, this argument ought to serve as an indicator that further understanding of the issue is required; it certainly does not end moral deliberation.

THE “WHAT-WE-DON’T-KNOW-WON’T-HURT-US”
ARGUMENT

Gregory Pence has asserted that if genetic abortions and

13. Bonnie Steinbock and others, 2009, 693.

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PIDs are carried out privately, then, technically speaking, parents cannot possibly be sending the “wrong message” to people with disabilities since no one will ever know about the abortion taking place. In Pence’s view, such abortions have little or no social implications.

“If you don’t know that I’ve ever had a first-term abortion, how can my abortion send a message to you?...the earlier the abortion, the more private it is. And the more private and earlier it is, the less realistic it is to claim that it sends any message at all to people with disabilities.”¹⁴

Even those new to the field of philosophy may be familiar with Pence’s argument, which sounds strikingly similar to the popular question, “If a tree falls in the forest, and no one is around to hear it, does it make a noise?” Similar to the saying, Pence’s argument here is somewhat elementary. One might wonder whether proponents of this family of argumentation might, for example, also come to the conclusion that enzymatic activity occurring in our bodies does not exist because we cannot necessarily perceive it occurring in real time. Such a conclusion, of course, is far from the truth, as it has been proven that enzymes and proteins are largely responsible for bodily growth and tissue regeneration. What about the person who regularly slanders and spreads rumours about his best friends—can we truly label this person as virtuous

14. Pence, *The Elements of Bioethics*, 199–200.

simply because we do not know about his immoral habit? Ultimately, the argument that discrimination must be announced for it to be present leads inescapably to the conclusion that any bona fide discrimination that takes place behind closed doors cannot be categorized as discrimination. Reducing one's actions to being unimportant, strictly because they are unknown by others, strikes me as being unduly imprudent, and leaves something to be desired.

THE "GOOD INTENTIONS" ARGUMENT

Some, opposing our previous definition of discrimination, may assert that the lack of a discriminatory *mindset* can on its own reduce an action to being morally neutral, if not commendable. Put another way, it is the mother's *intention* of a "better" life for herself or her future child that predominantly motivates her to choose abortion, and thus it is argued that only one's intentions must be used to judge the vices or virtues of one's actions. After all, if a mother doesn't *intend* for her choice to be discriminatory, why label it so?

While this argument has some intuitive appeal, it does not follow that just because a mother does not mean to be discriminatory, any form of discrimination, however much unwilled, does not take place. It may be obvious, but an important point to make is that some of the most devious acts can be done with the best intentions, or, perhaps, with no intention at all. Hoping to help his sister who is in financial difficulty, for example, one might take into consideration robbing a local bank and providing any stolen money to his poverty stricken kin. Surely, his intention is in the right place—helping out a family

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member is a commendable path to take—but it is one's *actions* that matter most. Rational reflection leads us to find that an ulterior motive is not a necessary requirement for an act to be truly labeled as reprehensible, as it would surely be this man's actions that would lead us to abhor his decision to steal, regardless of his well-minded intentions. Similarly, discrimination is largely manifested through actions—regardless of morally neutral intentions. If discrimination can be accepted as action based on unsubstantiated prejudgments, then many genetic abortions express at least some *prima facie* form of discrimination since, as we have shown, the reasons some give for choosing abortion may be largely based on unfounded quality of life judgements.

CONCLUSION

Nazis massacred the “inferior” homosexuals and Jews based on biological criteria that were really a “behind-the-scene” social judgment of their value as human beings. Furthermore, researchers in North America in the mid-twentieth century conducted research that helped affirm that women were inferior to men, a prevailing social view at the time. Our views towards disabled fetuses as inferior and unproductive members of society, largely based on our social constructs of disabled peoples, seem to be based on similar routes of measuring worth. What I am proposing should not be mistaken—I am not speculating that abortions have the same reading on the “repugnant metre” as the Nazi sterilizations. What I am implying is that the *criteria* that made those acts discriminatory, and many like them for that matter, are ironically similar to the criteria some hold today for choosing genetic abortions.

One underlying point in my argument is that what makes some genetic abortions and PIDs wrong is that they may influence people to *act* on a largely fictitious and socially constructed belief that life with disability is inherently less valuable than what we erroneously define as “normal” life. Utilizing beliefs pertaining to the undesirability of disability, whether inaccurate or correct, to categorically group fetuses under one heading, and then subsequently using this grouping to justify their termination can be regarded as discriminatory. I regret using such harsh comparisons to prove my point, but while some comparisons may not fit flawlessly with the topic of genetic abortions, I feel the connections made here do have the advantage of being true.

The desire for a healthy child is in no way imprudent. It is not unreasonable to assume that the majority of parents, and perhaps even some who live with a disability, desire a disability-free boon. Yet there is some importance in acknowledging that PID and prenatal diagnosis may be sending a discriminatory message, while concurrently accepting that abortion ought to be an option all women should be allowed to exercise; *the two positions are not mutually exclusive*. Conceivably, through maintaining such an outlook, some may become increasingly aware of, and question, any personal uninformed views of disabled people as exhibiting abnormally low, and unworthy, qualities of life. As a possible solution to the problem, society may even strive towards recognizing and breaking down the social barriers and misconceptions that disabled people face. Rather than implementing some sort of knee-jerk anti-abortion legislation, public health representatives should instead focus on shifting social arrangements and prevailing societal outlooks that marginalize the disabled.

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In the end, we may not be justified in opposing abortion unless we can show that a *mother's autonomy* is somehow less important than discrimination and so permissibly forfeitable in order to defend ideals more significant than autonomy—which, many would argue, is hardly the case. While the discrimination that may be taking place is unfortunate, abolishing its method of transmission may not be the most prudent option. Perhaps re-examining the very source of the discrimination (as mankind has done for verbal discrimination), and judging it in terms of its validity and rationality may be best. Still, we must not trivialize disability advocates' claims or push their arguments under a proverbial carpet.

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