

# compos mentis

## Pre-Implantation Genetic Diagnosis: Limiting Personal and Societal Knowledge Through Genetic Discrimination

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### **ABSTRACT**

This paper looks at an interesting moral question regarding prenatal genetic diagnosis and the selection of traits. Should prospective parents using assisted reproductive technologies (ART) have a right to use pre-implantation genetic diagnosis (PGD) to select against embryos with known genetic ailments? In light of this question, I will argue against the use of PGD and illustrate the problems of using PGD on both an individual and societal level. I begin by addressing an argument given by Janet Malek and Judith Daar in favor of the use of PGD. The argument claims that society must allow parents to use PGD as an act of beneficence, giving children the best lives possible. I maintain that this argument is insufficient in its analysis of the issue regarding the objective good life. I rather argue for a subjective notion of the good life, which is more in line with our Millian Liberal society. The negative implications of the argument for the use of PGD, is a limiting of living individuals with abnormal genes in terms of their ability to potentially gain self-knowledge. In light of this, I provide reasoning to show how the use of PGD is a form of genetic discrimination because of the disregard of each embryo's claim to life. This discrimination will then be shown to cause harm to society due to the limiting nature discrimination has on the marketplace of ideas. A counter argument, given by Jeff McMahan, will attempt to show the unwanted consequences of accepting the genetic discrimination argument. I uphold my argument's validity and show how McMahan is misguided in his reasoning regarding the implications of the discrimination argument. Ultimately, I will conclude that prospective parents using ART should not be permitted to select against embryos with known genetic ailments because of the negative effects on self-knowledge and the limits this type of practice will impart on the market place of ideas in our society.

### **KEYWORDS**

Bioethics, Epistemology, Genetic Ethics, Subjective Good Life, Disability Rights, Liberty, Discrimination, Beneficence, Self-Knowledge, Reproductive Rights

## INTRODUCTION

In the fall of 2017 Frank Stephens spoke before a congressional hearing to discuss funding for Down syndrome research and stated,

Sadly, across the world, a notion is being sold that maybe we don't need research concerning Down syndrome. Some people say prenatal screens will identify Down syndrome in the womb and those pregnancies will just be terminated. It's hard for me to sit here and say those words. I completely understand that the people pushing this particular 'final solution' are saying that people like me should not exist. That view is deeply prejudice by an outdated idea of life with Down syndrome. (C-SPAN 2017)

During this hearing Mr. Stephens brought up points regarding the societal importance of individuals with Down syndrome, while also stating "I am a man with Down syndrome and my life is worth living" (C-SPAN 2017).

Mr. Stephens's testimony brings about an interesting moral question regarding prenatal genetic diagnosis and the selection of traits. Should prospective parents using assisted reproductive technologies (ART) have a right to use pre-implantation genetic diagnosis (PGD) to select against embryos with known genetic ailments? This paper will analyze this question, with a specific focus on conditions such as Down syndrome, and illustrate the problems of using PGD on both a personal and societal level. I begin by discussing the background terminology required for understanding this issue so as to reduce any confusion caused by the use of these medical terms. I then address an argument in favor of the use of PGD given by Janet Malek and Judith Daar. The argument will claim that society must allow parents to use PGD as an act of beneficence, giving children the best life possible. I maintain that this argument is flawed in its analysis of a plausible definition of the good life for individuals with genetically different backgrounds. My response to the argument will further illustrate how the flawed analysis leads to negative consequences for specific individuals who currently live in society. Ultimately, I argue that the byproduct of Malek and Daar's argument is a limiting of living individuals, with abnormal genes, in terms of their ability to attain self-knowledge or knowledge of their personal identity.

In light of this, I provide reasoning to show how the use of PGD is a form of genetic discrimination because of the disregard of each embryo's claim to life.

This discrimination will then be shown to cause harm to society due to the limiting nature discrimination has on the marketplace of ideas. A counter argument, given by Jeff McMahan, will attempt to show the unwanted consequences of accepting the genetic discrimination argument. I uphold my argument's validity and show how McMahan is misguided in his reasoning regarding the implications of the discrimination argument. Ultimately, I conclude that prospective parents using ART should not be permitted to select against embryos with known genetic ailments because of the negative effects on self-knowledge and the limits this type of practice will impart on the market place of ideas in our society.

### **BACKGROUND TERMINOLOGY**

First, we must be clear on the terminology required for understanding this issue due to the use of multiple technical terms. Assisted reproductive technology (ART) procedures include "all fertility treatments in which both eggs and embryos are handled" (CDC 2017). This type of treatment includes the removal of egg cells to be combined with sperm cells in a laboratory, which will ultimately be returned to the individual or can be donated to another woman. This means that ART does not include artificial insemination where only sperm is handled. Pre-implantation genetic diagnosis (PGD) is a "procedure used prior to implantation to help identify genetic defects [and traits] within embryos" and is performed using "egg retrieval and fertilization in a laboratory", a retrieval process also referred to as ART (APA 2017). While PGD can test for hundreds of genetic diseases, some of the most common are "single gene defects such as Cystic Fibrosis, or chromosomal abnormalities like Down syndrome"(UCONN 2017). By allowing the testing of embryos for genetic abnormalities this allows prospective parents to select against embryos that have genetic abnormalities. This results in the physician not implanting the embryos with known genetic abnormalities into the potential mother. Selecting against certain characteristics is historically less controversial than selecting for a specific trait in a child. I argue however that in spite of any liberal interest or right to use PGD for selecting against certain traits, the resulting harms to currently disabled people and society in general supply sufficient reasons to limit the use of this technology.

## **THE RIGHT TO GIVE CHILDREN THE BEST LIFE**

Given the technical terms outlined above, I will illustrate an argument in favor of allowing parents the liberty to select against embryos with genetic abnormalities. The first argument is an appeal to acts of beneficence, or “forms of action intended to benefit or promote the good of other persons” (Beauchamp 2008). In other words beneficent acts are those that do good for an individual where the individual receiving the good is not the individual performing the act. From this definition it is then argued that the selection of traits based on PGD is an act of beneficence meaning the act is not only something that a parent can do but is also something they ought to do. The distinction being that an “ought to do” is a moral claim, thus it would be morally permissible for the individual to do that action and morally wrong for the person not to do that action given the option.

The argument for allowing parents to select against embryos with genetic defects given by Janet Malek and Judith Daar would be as follows. Parents have the duty to give their children the best possible life. Thus they ought to use PGD because by selecting against embryos with genetic defects the child they have will be able to live a life better than that would have been lived by one with a genetic defect. In other words, due to beneficence and given the option to improve their future child’s life, a parent ought to do so. The use of PGD as a means to achieve the best life of a child would be to “reduce suffering overall” for the potential child (Malek and Daar 2012, 5). From this we can see that the argument stems from a moral obligation to give children the best possible life, in turn avoiding suffering.

In light of this, it must then be questioned, what does it mean for a person to lead the best life or rather what it means to have a high level of well being? Janet Malek and Judith Daar argue, “under any plausible definition of this concept, a life without a disabling genetic condition is likely to be lived at a higher level of ‘well-being’ than one with such a condition” (Malek and Daar 2012, 5). In other words, according to Malek and Daar, people who are not disabled lead a life with a higher level of well-being than a that life led by a disabled person. In sum, parents using ART ought to use PGD to select against embryos with genetic abnormalities as this is part of their duty to give their child the best possible life.

Given the argument described above, I maintain that the argument is flawed and will argue against the notion that a person with a non-normal genetic background is not able to lead a good life. One way in which the argument is

flawed is due to its appeal to the notion of “any plausible definition” when trying to decide what represents the good life. The phrase “any plausible definition”, regarding what a good life represents, implies that the good life of for an individual is objectively knowable by any individual in a society. This notion can be taken further to say that it is then up to the society to decide what is the good life because society dictates what is plausible. But this is not how the notion of a good life works in a Millian Liberal society, like our own society. The good life is a subjective notion that is decided by the individual rather than constructed by society. This subjective good life means that the individual creates their own idea of what it means to lead a good life based on their individual experiences of the world.

The notion of creating one’s own best life can be illustrated using an example. In the example a person is born with a different genetic background, such as Down syndrome. This individual assesses his or her well being based on a life lived with Down syndrome. Contrast this with a second person who is born with a classically “normal” genetic background. This individual will assess their well being based on living with the classic genetic background. These individuals assess their individual lives based on the individual life they are living, one with Down syndrome and the other with a classic genetic background. Individuals of classic backgrounds cannot accurately assess what it would mean to live the best possible life of a person with a different genetic background because the individual does not have access to the relevant experiences of the life lived with Down syndrome. In other words, we are limited by our own experiences of the life we lived because we do not have access to the experiences of another.

In light of this, when we are to assess the good life of a person with a genetically different background we are not able to do so based on our conception of the good life. We must rather ask the individual person with said genetic background about their notion of their own best life because they are the only individual with access to the relevant experiences necessary to create their subjective notion of a good life. When we take the testimony of Frank Stephens, shown earlier, he is clearly living his best life, as shown when he states outright, “my life is worth living” (C-SPAN 2017). This illustrates that individuals of genetically different backgrounds can not only create a notion of their own best life but can then go on to fulfill this notion and lead their best life. The notion of the subjective good life shows that the argument given by Malek and Daar is not concerned with

people leading the good life for that specific individual. Rather the argument is concerned with people leading a life that conforms to societies understanding of the best life, the life described by a person of the classic genetic background.

A second problem with Malek and Daar's argument is that the line of reasoning used has damaging implications for those individuals currently living with a genetically different background in our society. The creation of a social standard of a good life or the objective good life is at the center of the damaging for these individuals. The standard is damaging because of the stigma it creates against disabled individuals and their potential quality of life. This stigma being that disabled people lead less fulfilling lives than non-disabled people, a notion that is hurtful to all individuals who society considers disabled. The stigma facilitates individuals in our society seeing genetically abnormal people for only one part of their personal identity, the fact that they are different than the rest of society. The individuals with a genetically different background are then treated as if the abnormality of their genetic background defines who they are as an individual.

When an individual is only viewed as abnormal it can cause a potential limiting in the individuals ability to acquire self-knowledge and personal understanding. When society defines you only by one aspect of your personhood you may begin to focus only on that one aspect of your idea of self. This results in the individual seeing this aspect as the only feature that defines them as a person because it is the only characteristic that society recognizes. From this a person begins to have a degraded understanding of their self-worth because the only aspect of themselves they identify with is an abnormality, which society tells them is not valuable and should be selected against. This results in these individuals not only feeling that society doesn't care about their existence but also limits their understanding of themselves as complex individuals outside of their genetic background. The limiting of knowledge then results in the individual not being able to understand who they are as a person and how they should live their best life. The reasoning put forth by Malek and Daar tells individuals with a different genetic background that their life is not worth living, that they should be pitied and it would have been better if someone else were born instead of them. In light of this, the use of an argument, like Malek and Daar's, limits those individuals who are currently living by not allowing the individuals to reach a full understanding of who they are as a person and the positive impact they can have on society.

## **THE GENETIC DISCRIMINATION ARGUMENT**

A second argument against PGD arises from the use of this technology as being detrimental to society as a whole. The use of PGD can be detrimental to society because it can fuel the systematic discrimination of individuals with genetic ailments, pushing these individuals to the fringes of society. The genetic discrimination argument would be as follows, by allowing parents to select against embryos with known genetic defects we are discriminating against other fertilized embryos, which have an equal claim to life as the embryos without any genetic defects. An equal claim to life means that if two things are equal in all relative factors then they each have the same claim to become actualized and thus begin the process of development in the womb.

I have previously argued that those individuals with a genetic abnormality have the same ability to live a good life as a person without a genetic abnormality. Given my reasoning, these two are equal based on the relevant factors of ability to lead a good life. From this we can say that any selection of one embryo over another would then be considered discrimination because the two embryos are equal and thus have the same claim to life. In other words, by actualizing one embryo over another you are saying that this specific embryo has a greater claim to life than the other embryos. By using a selection criterion that is based on an absence of genetic abnormalities you are discriminating against those embryos with the abnormalities even when they all have the same claim to life.

This type of discrimination has negative implications when discussing the marketplace of ideas in our society. This discrimination causes the reduction of the number of individuals with the genetic abnormalities. This fuels the type of systematic discrimination that is already happening in our society, where individuals that society views as different are not given a voice. By not allowing people of different genetic backgrounds have a voice in society or even be actualized we are limiting the understanding of different ways individuals can live their lives. This goes directly against our understanding of a good liberal society, like our Millian based society. The reduction described above can cause a societal loss of interactions between individuals, resulting in less communication between different people. This loss of communication will then cause a loss of knowledge potential on the part of those people living in society. This potential knowledge coming from the market place of ideas, a theoretical location were ideas a shared and available to all individuals in the society. The loss of potential knowledge in

the marketplace is due to the marketplace being fueled by difference. In other words, a lack of interaction or observing a different way of life limits the knowledge potential stored in the marketplace. This loss of knowledge potential limits the future of the society and can result in a society of stagnation due to all individuals leading similar lives resulting from less marketplace diversity.

While we can limit the use of PGD using an appeal to the marketplace of ideas we should not limit the use of this technology completely. I maintain that the use of selecting embryos based on PGD limits the availability of different tastes and pursuits in the marketplace of ideas and this is why this type of discrimination should not be used. However, if the embryos were in fact not equal we could potentially use the PGD as a way to limit, without any harmful repercussions on the marketplace. If one embryo was found to have the genetic markers for a specific very painful disease that limited the ability of that potential person to live their life, then we could actively select against that embryo. An example would be Lesch-Nyhan Syndrome, which can be detected with PGD. Lesch-Nyhan Syndrome is an alarming disease that causes "involuntary muscle movements, jerking movements and flailing of the limbs" (U.S. Library of Medicine 2017). This behavior worsens and usually involves self-mutilation "including biting and head banging" (U.S. Library of Medicine 2017). Individuals with Lesch-Nyhan Syndrome often need to be forcibly restrained so as not to cause themselves extreme injury, severe lip biting can still occur. These individuals also live a very short life often not reaching the age of ten years old (U.S. Department of Health and Human Services). The short life lived with this genetic disease is incredibly painful, marked with constant self-torture and low cognitive efficiency.

Selecting agents those embryos with Lesch-Nyhan Syndrome would not be an act of discrimination because the relevant factors of equality, ability to lead a good life, are shown to not be equal do the incredible pain this person with the disease would need to go through every day of their life. Due to the immense pain the individuals would not be able to partake in society and contribute to the marketplace of ideas. Their painful disease would not allow them to actively go out into the world and express the way they live their life and experience anything outside of pain. This ultimately shows that in very specific circumstances we can use PGD to select against some genetic disorders but only when the disorders cause unlivable pain and result in the individual inability to make a meaningful addition to the knowledge potential in the marketplace of ideas.



## **COUNTER – THE IMPLICATIONS OF THE DISCRIMINATION ARGUMENT**

Now, I will analyze a counter argument as a way to better understand any unintended implications of the argument I have constructed. I will be utilizing an argument put forth by Jeff McMahan as he describes the implications of approving the claim of genetic discrimination, an argument that is similar to the claim I have put forth in this paper. McMahan argues that those who agree that the practice of prenatal screening is genetic discrimination must then also approve the permissibility of causing oneself to have a disabled rather than a non-disabled child. His reasoning is as follows, "most of us think that if it would be wrong to cause an already born child to become disabled, and if it would be wrong to cause a future child to be disabled through the infliction of prenatal injury, it should also be wrong to cause a disabled child to exist rather than a child without a disability" (McMahan 2005, 130). In other words, McMahan is claiming that if we believe it is wrong to cause a child to be disabled, which he believes it is wrong, then it should also be wrong to have a disabled child rather than a non-disabled child, given the option.

There are two problems with McMahan claim regarding the implications classifying this issue as genetic discrimination. The first is with the appeal to "most of us"; this is a claim that due to the majority of individuals viewing an instance as valid then the instance must be true. This reasoning is flawed because of an appeal to the majority; a majority opinion does not necessarily mean that opinion is correct. If we as a society followed this reasoning, we would still believe that the sun revolved around the Earth. Due to the Copernican revolution however we have seen that the majority opinion of a geocentric, earth centered, solar system has shifted to a heliocentric, sun centered, solar system. If the majority view were correct then we could have never made this switch and would continue to have an incorrect view of the solar system.

The second issue in McMahan's claim has to do with the notion of causation. There is an essential difference between causing oneself to have a disabled child through some action and simply having a disabled child by genetic chance. The difference is that an action is done to create a new circumstance where the embryo is altered resulting in a new individual. If a person were to have a child that had a genetic abnormality then that child would be the potential child that started as an embryo, but if we take an embryo and do something to it to change the future of the potential person, then we are changing this individual.

This difference is significant because in PGD the embryos already have different genetic backgrounds and thus parents are not in any way causing the child to be harmed. The embryo would develop exactly the same way as any other embryo regardless of if there were a genetic abnormality present.

McMahan recognizes that there may be individuals who accept the implications of classifying this issue as discrimination. He then attempts to show that the objections to the causation argument are underlined by “the view that it can be worse to be disabled than not to be, which seems unobjectionable” and that this too should be reasoning enough to not consider this to be discrimination (McMahan 2005, 131). He makes this claim to show that we as individuals have a problem with causing someone to become disabled because it will make the individuals life more difficult. He then reasons that this means there is a fundamental and distinct difference in the two potential people, disabled and nondisabled. If we accept this claim that the two individuals are fundamentally differently then, McMahan argues, this would show that the two individuals are not fundamentally equal because they are distinct. In other words, there would be no discrimination involved in selecting against embryos with genetic defects because the two embryos are not equal. Discrimination requires the two embryos to be fundamentally equal but not treated equal in reality. In this case, his causation argument shows that we see a fundamental difference in the embryos.

Now, let us examine this claim that there is a fundamental difference between a disabled and a non-disabled person, resulting in the perception that it is worse to be disabled and thus not lead a life equal to a non-disabled person. I would agree that to cause someone to become disabled would harm this person in our current western society, but being disabled does not make a person inherently worse off or different than a nondisabled person. While these individuals are distinct in identity and personal traits, they are not distinct in any way that differentiates them from being a person and their ability to lead a good life. In other words, when considering the relevant factors for equality these two embryos are equal. Ultimately, this means that the underlying difference in causation he describes is not fueled by a fundamental difference between the two embryos but is rather due to how society values the embryos.

The reason why it is currently more difficult to be a disabled person in society is because our society was built by non-disabled people for non-disabled people. This is the same reason why it is harder to be black, a women or any minority in our

society, it was created by white men for white men. If we had a society that valued the input and existence of genetically different individuals, then we would have a society that was more open to caring for the specific needs of those individuals. This shows that being disabled is not inherently more difficult; it is our society that makes it much harder for disabled individuals than those who society considers to be of a normal genetic background.

From this we can see that there is a fundamental societal change that must occur. We must recognize the prejudices we have in our social structure and do everything in our power to remediate these inaccuracies and systemic discrimination. We should not maintain the status quo of seeing people with different genetic backgrounds as an "other"; this starts with allowing these individuals the ability to be actualized. With this step we can begin to change the negative connotation around being disabled and begin to converse and share ideas to allow society to no longer benefit only one gender, of one race, of one genetic background, but to rather be a society for all individuals. It will be at this moment when humanity takes its next step into the future with all individuals on equal ground.

In light of this, it is clear that the use of PGD should not be a technology used by the majority of people in society but as I previously articulated it is a technology that should not be prohibited entirely. I maintain that this technology should not be encouraged because of the negative personal and social implications. The distinction of not being encouraged in society is a difference that is note worth and should be explained in greater detail. By not encouraging the use of PGD, as a way to select against non-painful diseases, it would entail that publicly funded hospitals would not be able to perform this type of procedure. By not having it be done at publicly funded hospitals means that tax payer funds are not being used to facilitate this discrimination. This would dispel the concern of systematic discrimination because the use of the technology would not be condoned or funded by the government. It would however allow for private hospitals to perform this type of procedure and would result in the wealthy having access to this option. The private availability of specific expensive procedures is not uncommon as wealth in our current society gives increased access to many things the average or below average individual does not have access to. Thus allowing those wealthy enough to have this procedure can exercise their liberty to do so. This doesn't however give a good enough reason to support or fund technologies

that we wish the wealthy were not performing. Given this, it is clear to see that there is good and sufficient reason to partially prohibit and not fund the use of PGD for selecting against embryos with genetic abnormalities because of the negative implications on living individual's ability to accurately create a personal identity and for the negative implications on our societies marketplace of ideas.

## **CONCLUSION**

In this paper I have illustrated an argument given by Malek and Daar in favor of selecting against embryos with genetic defects, with the argument originating from beneficence and an appeal to autonomy. From this I showed how the argument is insufficient in its analysis of the good life and in turn propagates inaccurate and hurtful stigmas against individuals of different genetic backgrounds. This type of propagation was shown to lead to the loss of self-knowledge for the individuals with genetic abnormalities. I then described my argument, that allowing parents to select against embryos with genetic abnormalities is a form of genetic discrimination. I showed that based on the relevant criteria of leading a good life each embryo had the same claim to life. This discrimination was then shown to limit the knowledge potential of the society, which in turn shows the negative implications of using PGD. I showed that there are some applications of PGD that should be used; Lesch-Nyhan Syndrome was then used as an example. The use of PGD was limited to be used only when the genetic abnormality brings about a physically painful or unbearable life for the child because the embryos were then considered to not be equal. A counter argument given by Jeff McMahan states that there are implications to the discrimination argument that seems immoral. I then illustrated how this counterargument was misguided and showed that rather than not allowing these individuals with genetic abnormalities to be actualized, we should change our social structure to be more accommodating for the needs of all individuals. While there are some instances where PGD can be used, I ultimately concluded that prospective parents using ART should not be permitted to select against embryos with known genetic ailments because of the unjust way it classifies individuals resulting in the loss of self-knowledge and the limits this type of discrimination forces upon the market place of ideas, which in turn limits social knowledge.

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