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## How Does the Way We Categorize Disability Influence the Morality of Preimplantation Genetic Diagnosis?

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In recent decades, the rapid expansion of medical technology has brought an onslaught of ethical debates. The increased understanding of human genetics and the popularization of in vitro fertilization has led to the bioethical conversation surrounding preimplantation genetic diagnosis. Preimplantation genetic diagnosis (PGD) is the process of screening and testing embryos that are produced through IVF for chromosomal and genetic disorders. This allows for the selection of embryos, based on the information provided by the tests. For example, this process allows a couple to identify Cystic Fibrosis in embryos and implant a specific embryo in response to that knowledge. This ability to pick and choose genetic traits raises concerns surrounding disability, and the ability to select for and against it. The debate deals with whether or not PGD, in relation to disabilities, is ethical. On one side of the debate is the argument that we have the ethical obligation to select only the healthiest embryos, in order to improve their future quality of life. On the other hand, people argue that selecting against disability only perpetuates the stigma against disabled people. This conversation depends on the definition of quality of life and can be addressed through virtue ethics. In this paper I will argue, through the lens of a virtue ethicist, that we need to modify our definition of disability when determining the ethicality of PGD in order to support human flourishing.

At its roots, virtue ethics emphasizes the importance of acting in a manner that makes you a more virtuous person. Most ethical theories lay out their premises in a manner that answers the question, “What ought I to do?”, whereas virtue ethics addresses moral philosophy in a manner that answers the question, “Who ought I to become?” Although this branch pays special attention to the concept of becoming a more moral person, it rests on the following three premises (Stanford Encyclopedia of Philosophy 2003). The first is *arête* which is considered excellence or virtue. The second is *phronesis*, or practical/moral wisdom, and the third is *eudaemonia* which

translates closely to flourishing. Eudaemonist virtue ethics evolved from works written by Plato and Aristotle. This branch of virtue ethics emphasizes *eudaemonia* and the importance of human flourishing. Within this practice of virtue ethics, we are also presented with the disagreement between Plato and Aristotle surrounding the role of external goods (Stanford Encyclopedia of Philosophy 2003). Plato argues that “virtue is both necessary and sufficient for *eudaemonia*” (Annas 1993), whereas Aristotle believed that “virtue is necessary but not sufficient—what is also needed are external goods which are a matter of luck” (Stanford Encyclopedia of Philosophy 2003). Even if a person is virtuous, they will also need auxiliary support in order to flourish. Aristotle’s view, with its emphasis on the role of the environment in one’s ability to flourish, is especially well suited for the debate surrounding PGD.

By applying this theory to various models of disability, we are able to draw out the tension between the sides of the conversation and analyze the morality of PGD. In this paper, I argue that the quality of one’s life is not totally subjective. Despite variations among general society, quality of life can be defined by a person’s ability to flourish in society. I argue that in order for a characteristic to be defined as a disability, it must make it impossible for that person to flourish. The modes of disability I will be using are categorized as purely medical, purely social, and a mix between the two (Stanford Encyclopedia of Philosophy 2003). The strictly medical model argues that a physical impairment is sufficient to impede human flourishing. On the other hand, the social model asserts that the only obstructions to human flourishing are social factors. This implies that the medical state does not impact flourishing (Stanford Encyclopedia of Philosophy 2016). However, by mixing these models, we find a more appropriate approach to defining disability. This model suggests that when a person has a physical impairment that induces social discrimination, the external goods make it impossible for the person to flourish,

ultimately classifying them as disabled. Keeping these models in mind, we must first address the conversation surrounding discrimination against disabled people through PGD.

Philosopher Jeff McMahan explores the morality of screening for disability by examining the argument used by people who are against PGD (2005, 571). McMahan cites the four major arguments against PGD and explores their implications in relation to the disabled community. The first major argument he references is that the purpose of PGD procedures can be viewed as an attempt to rid society of disabled people. The second is that these practices legitimize some forms of discrimination against disabled people. Third, eliminating disabled people would also lessen respect for differences. Finally, the procedure expresses the idea that it is worse for disabled people to exist than it is for non-disabled people (571). McMahan argues that these imply “the permissibility of certain types of action that most people believe are impermissible” (572). He explains that if it is “morally *mandatory* to *allow* oneself to have a disabled child rather than to try through screening, to have a child who would not be disabled, than it must be at least *permissible* to *cause* oneself to have a disabled rather than a non-disabled child” (572). I agree with McMahan’s reasoning through this point; however, he furthers his argument by saying that his conclusion, which implies the permissibility of causing the existence a disabled child, shows fault with reason of the those who oppose PGD. It is morally permissible to create a disabled child if we reject the purely medical model of disability. If two medically disabled parents decide to select for a disabled child, then we must assume that they believe their disability has not obstructed their ability to flourish and are making this decision in an attempt to *improve* the quality of their future child’s life.

First, I will present the case in which two deaf parents are attempting to genetically select a deaf baby. The ethical question at play is whether or not being deaf obstructs the child’s ability

to flourish. By using the medical model of disability, we conclude that being deaf does in fact limit the child's ability to flourish, thus making the selection of a deaf baby immoral. On the other hand, a purely social approach to disability would push us to conclude that a Deaf<sup>1</sup> baby only has a reduced quality of life due to discrimination against Deaf people. From this perspective it is the social factors that are affecting the child's quality of life. By keeping the two models separate, we arrive at the conclusion that it is unethical for the deaf parents to select for a deaf child, as it would irreversibly reduce her quality of life.

Now, we are presented with a similar case in which a couple is selecting for a child based on melanin. The parents must decide on whether or not they should implant an embryo that will grow up to be black. From a medical perspective, the levels of melanin in two embryos have no impact on their quality of life. Biologically, the white embryo and the black embryo would have equal chances at having a high quality of life and would have no physical impairment which would limit their ability to flourish. From a purely medical stance, there is no moral wrong in selecting for a black baby. Approaching it from a social stance tells a different story. From this perspective the embryo with higher melanin levels would be disabled. A black child would grow up in a world that discriminates against people of color and would therefore face exclusion from social settings. Ultimately, this would reduce the child's quality of life and obstruct her ability to flourish. This implies that it is immoral to select for a black baby. However, when we mix the two models we are presented with a more accurate assessment of the morality. The mixed model suggests that a disability hinders one's ability to flourish if the person faces discrimination and exclusion due to a physical impairment. Although the black child could face social exclusion, it

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<sup>1</sup> When discussing a medical disability, "deaf" is used, compared to the cultural "Deaf."

would stem from a systematic flaw, not from a physical impairment. This mixed model suggests that there is no moral wrong in selecting an embryo that will grow up to be black.

Imagine that a couple had the ability to select for an embryo that became Stephen Hawking. When Stephen Hawking was twenty-one, he was diagnosed with ALS. From a strictly medical standpoint Hawking was disabled, which would have limited his ability to flourish and greatly reduce his quality of life. However, using the social model, Hawking was not disabled, as he did not face social exclusion. Although this is not the case for every person with ALS, Hawking was able to continue his work and was not socially impacted by his disorder. Using the mixed model of a disability, we see that the social network Hawking had allowed him to flourish. He perfectly exemplifies the notion that someone's ability to lead a fruitful life does not depend on a medical impairment. Hawking had enough prestige, as an established physicist, that there were many social factors supporting him. Hawking's social support served as the "external goods" that Aristotle argues are necessary in order to flourish (Stanford Encyclopedia of Philosophy 2003). Hawking's incredible success proves that the social surroundings of a person can completely, or almost completely, account for a physical disability or impairment.

The concept of selecting for a deaf child has been debated greatly in the past. In her paper, "Genetic Dilemmas and the Child's Right to an Open Future," Dena Davis argues against deliberately creating deaf children. She explains that this moral issue arose in genetic counseling from the practice of "elevating patient autonomy above all other values," which creates a lack of moral attention for the child (1997, 575). She asserts that ignoring the child's future autonomy is unethical for two reasons. First, Davis explores the view of deafness as a disability and argues that intentionally creating a child with a serious disability closes off the child's right to an "open future" (581). Second, Davis argues that there is also moral harm in forcing a child to be Deaf,

even when treating Deafness as a culture, as many Deaf activists do (581). Davis argues that Deaf child may not fully grasp written word and will have significantly fewer job opportunities which is not only “a harm in its own sake but also is likely to continue to lead to lower standards of living” (583).

By approaching Davis’ argument with the various models of disability, we come to a different conclusion. From a strictly medical standpoint, the deaf child would be disabled and thus selecting for it would be morally wrong. From a purely social standpoint, the lack of resources for Deaf people, as Davis mentions, would limit the child’s ability to flourish and would make it unethical to select a Deaf embryo. However, when we look at the mixed model of disability, it becomes morally permissible to select for a Deaf child. If two Deaf parents believe that it would be better for their child to be Deaf as well, then we can infer that they do not see their Deafness as something that obstructs human flourishing, and therefore is not disabling. Additionally, it should be noted that growing up in a Deaf household and community would serve as the external goods that work in favor of raising the child’s quality of life and would encourage her flourishing, making the selection of a deaf embryo morally permissible.

In conclusion, the mixed model is the strongest view of disability under a virtue ethics framework as it allows us to relate multiple factors that influence human flourishing. Both the strictly medical and social models fail to acknowledge the intersection between physical impairments and an obstructive environment. The mixed model of disability leaves room for conversation surrounding the particulars of a case, as well as actively involves the sentiments of people with disabilities. By taking the whole picture into account through the mixed model, we can accurately account for the differences between something that will make human flourishing more difficult to achieve, and something that will make it impossible. This model supports the

notion that any choice made in order to create more virtuous people, by means of human flourishing, is morally permissible, if not morally mandatory.

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