Deciding against disability: does the use of reproductive genetic technologies express disvalue for people with disabilities?

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ABSTRACT

This paper focuses on one objection to the use of reproductive genetic technologies (RGTs): the argument known as the expressivist objection. According to this argument, the choice to use reproductive genetic technologies to prevent the birth of individuals with disabilities is an expression of disvalue for existing people with disability. Many have been persuaded by this impassioned perspective. This paper shows that this argument is misguided and so does not constitute a sound objection to the use of RGTs to prevent disability in future children. It first identifies some responses to the objection that may be sound but not completely convincing to proponents of the expressivist position. It then describes a thought experiment designed to demonstrate more clearly that choosing to use RGTs to prevent disability in future children does not convey a negative message about people who have disabilities. After describing a decision that clearly does not send such a message, the paper walks through a series of cases and shows how, despite differences that might seem to be morally relevant, each is morally equivalent to the previous one with respect to the extent that it expresses disvalue for such individuals.

INTRODUCTION

The increasing range of assisted reproductive and genetic technologies offers potential parents unprecedented control over the characteristics of their future children. A couple can use sperm-sorting technology to significantly increase the likelihood that they will conceive a girl in order to avoid having a child affected by haemophilia. A woman who carries the dominant gene for Huntington's disease can use in vitro fertilisation and preimplantation genetic diagnosis (PGD) to ensure that she will not pass the gene on to her offspring by transferring back only embryos that do not carry that gene. Potential parents can use chorionic villus sampling to determine whether their 11-week-old fetus has trisomy 18. At present, such reproductive genetic technologies (RGTs) are used primarily to select against certain traits; that is, they are used to prevent future children from having particular genetic conditions.

An array of ethical concerns has been raised about the use of these technologies. Some scholars have worried whether these technologies are safe for women and for the children they produce. Some have argued that such technologies are unnatural and that they may produce unintended consequences. Others have suggested that the routine use of RGTs could lead to diminished support for those with disability or that condoning such use will lead to a revival of Nazi-like eugenic programmes. This paper will focus on just one of the many objections to the use of RGTs: the argument known as the expressivist objection. According to this argument, selecting against embryos or fetuses with conditions that will lead to disability expresses disvalue for individuals who currently have those disabilities. Many have been persuaded by this impassioned perspective. In this paper I use a series of thought experiments to show that this argument is misguided and so does not constitute a sound objection to the use of RGTs to prevent disability in future children.

THE ARGUMENT

According to Parens and Asch, 'tests to select against disabling traits express a hurtful attitude about and send a hurtful message to people who have those same traits'.[1] In other words, the choice to use reproductive genetic technologies to prevent the birth of individuals with disabilities is an expression of disvalue for existing people with disability. The meaning of such a choice, proponents argue, is that people with disabilities are less valuable than people without disabilities. That choice therefore communicates a negative message to those existing people who have disabilities.

This conclusion seems to be built on the following reasoning: the choice to use RGTs to select against an embryo or fetus with a particular genetic trait implies that the value of that future child can be judged on a single characteristic. That choice therefore represents a problematic, reductionist understanding of the value of individuals in which their 'worth' is determined exclusively by the presence or absence of a disease trait. As Adrienne Asch, a consistent proponent of this position, has put it, such testing is 'a clear case of first impression … that first impression includes a decision never to learn about the rest of who that embryo or fetus could become after its birth'.[2] Selecting against a future child on the basis of a disability signals that a disabling trait can be so significant and so undesirable that it eclipses all of the individual's other traits. According to proponents of the expressivist argument, this negative evaluation of the lives of people with disability applies equally to future and present persons. Therefore, the choice to use RGTs communicates to people with disabilities that their disability is so important that it outweighs their other characteristics, a negative and hurtful message that reflects a lack of value for those individuals.

As Søren Holm has helpfully observed, proponents and critics have fleshed out the expressivist argument in a variety of ways.[3] Two points of clarification will help ensure that the argument is clearly and charitably understood for the purposes of the discussion below. First, there is some ambiguity about which types of practice generate the ethically worrisome messages in question. One version of the argument claims that individual choices to use RGTs send negative messages to those with disabilities.[1 4] An alternative version holds that it is only when medical professionals promote the use of RGTs or when such choices are promoted on a societal level that such messages are conveyed.[5] The distinction between these two versions is important, because they identify different practices as morally problematic. However, I believe the rebuttal laid out below applies equally to both versions of the argument. I will therefore discuss the two versions together in the arguments to follow.

Second, proponents and critics of this argument have both been less than clear about the nature of the message that is purportedly sent by the use of RGTs to prevent disability. It has sometimes been argued that the use of RGTs is discriminatory towards those with disability,[1 6] while in other cases authors have claimed that it simply reflects a negative attitude towards those individuals.[3 7 8] In the following pages, I will assume the weaker form of the argument—that such choices reflect a negative attitude rather than a discriminatory one. Discriminatory actions or policies reflect negative attitudes towards those people who are being discriminated against. The negative-attitudes version of the argument therefore encompasses the discriminatory-attitudes version. This weaker version also sets a lower threshold at which the argument is successful. It is therefore the more plausible version of the argument.

In what follows, I will first identify a few responses that may be sound but not completely convincing to proponents of the expressivist position. I will then describe a thought experiment designed to demonstrate more clearly that choosing to use (or encouraging the use of) RGTs to prevent disability in future children does not convey a negative message about people who have disabilities. I will take the reader through a series of cases and show how each is morally equivalent to the previous one regarding the extent to which it expresses disvalue for such individuals. In doing so, I will also identify differences that one might be tempted to view as morally relevant to the question at hand and argue that each does not, in fact, affect the moral evaluation of the cases considered.

SOME POSSIBLE RESPONSES

Some authors have argued on semantic grounds that such a choice does not, in and of itself, communicate anything about people with disability and may not communicate anything at all. Buchanan[9] holds that, in order for an action to send a message, the action must logically dictate that the agent is motivated by the beliefs that correspond to the message supposedly sent. Further, the action must be rational *only* if the agent holds those beliefs. A choice to use RGTs to prevent disability in future children does not necessarily meet these two conditions. That is, an individual or couple could choose to use these technologies for any number of reasons that have nothing to do with the lives of those with disability, and in such cases the choice does not communicate anything about those individuals. A related argument has been made by Nelson, who claims that actions or practices are 'not semantically well-behaved enough to send any particular message'.[4] Following Wittgenstein, he suggests that in order for a choice to convey meaning, it must have an established and shared significance. The choice to use RGTs to prevent disability has no such publicly settled meaning and so may convey nothing at all. These rebuttals may be sound. But they may not be convincing to proponents of the expressivist argument, because they rest on semantic technicalities. They derive from real-world ambiguities and contingencies rather than principled distinctions. A more robust response would therefore be helpful for an adequate rebuttal of the expressivist argument.

Another possible way of responding to this position would be to allow that the choice to use RGTs may convey a message but claim that the message need not be a negative one. Rather than viewing the use of these technologies as a choice *against* a disabled child, the decision could be understood as a choice *for* a healthy child. Viewed this way, the choice expresses value for normal traits but communicates nothing about disabling ones. This argument, however, seems too easy. Inherent in a choice to favour one option is at least *relative* disvalue for the choice not taken. Even if the choice is based on a positive evaluation rather than a negative one, that decision communicates that more value is placed on one option than the other, and so indicates that that second option is less valuable.

These arguments may be persuasive to some. However, for readers who are not yet convinced, let's assume that the decision to use RGTs to prevent disability *does* convey a message and that message is a negative one. Even given these assumptions, I will show in the following thought experiment that the expressivist objection can be refuted.

A THOUGHT EXPERIMENT

Scenario 1

Consider the following scenario: you are walking down the street one sunny morning to your local coffee shop. The walk signal flashes and you are about to enter the intersection when everything around you suddenly freezes. A disembodied voice claiming to be a guardian angel informs you that a driver approaching the intersection will momentarily be blinded by the early morning sun and run the red light; you will be hit by the driver in the crosswalk and paralysed from the waist down. Time then restarts and you are faced with the choice of when to cross the street. What would you do? Assuming that you can get on board with the idea that that you have a guardian angel with the ability to freeze time, it seems safe to say that you would stay put on the sidewalk.

By choosing to wait to enter the intersection, you are choosing one possible future over another. More specifically, you are choosing a future self without disability (assuming all other things are equal) instead of a future self with a serious disability. Would this choice send a negative message about those people who are paraplegic? I don't believe that it would. The decision suggests that there is something negative associated with disability that you hope to avoid by not walking into the path of an oncoming car. It may therefore constitute an expression of disvalue for the inability to use one's legs. The expression of disvalue for a *disability*, however, is not the same as the expression of disvalue for a *person* who has a disability. The choice to stay on the sidewalk would not suggest that a *person* who cannot walk is any more or less valuable than a person who can. It would not mean that you would think any less of yourself as a person were you to fall down a manhole on the other side of the street and lose the use of your legs. Does this choice express disvalue for other individuals who have paraplegia? Just as trying to prevent the occurrence of disability in your own life does not imply that you would find your own life less valuable if you were to become disabled, seeking to prevent disability in your own life does not imply that the lives of others with disability are any less valuable.

Given the opportunity, it seems highly likely that even those with (other) disabilities would make the same choice with a perfectly clear conscience. It would therefore be misguided to argue that the choice to wait to enter the intersection in the above scenario is ethically problematic because it expresses a negative attitude towards those with disabilities.

One might contend that the distinction between a disability and the person who has that disability is not as clear as this argument suggests. As Edwards has claimed, for some people with disability, 'disabling traits are, in fact, at least partly identity constituting'.[10] In other words, disabled individuals may consider their disability to be a central part of who they are. There are at least two reasons, however, to question whether this observation undermines the above distinction. First, Asch, the most consistent proponent of the expressivist argument, states that 'disability is not, and need not, be either a 'deep' or a valued part of identity for everyone who shares the disability critique'.[2] In fact, her primary objection to the use of RGTs to prevent disability in future children is that such use suggests a reduction of disabled people to their disabilities. She therefore clearly *rejects* the idea that disabled individuals should be defined by their disabilities. Second, even if a disabled person identifies strongly with his disability, such identification does not entail that the person and his disability are one and the same. The two can still be distinguished in a way that makes it possible to express a negative attitude towards one and not the other. Persons have inherent value that is independent of their characteristics or traits. Individuals are valued as persons to whatever extent they are persons, regardless of what else might be true of them. It is therefore perfectly consistent to express a negative attitude towards one of a person's traits without conveying a negative attitude towards the actual person. Because value as a person is independent of the person's characteristics or traits, the above distinction is defensible. It explains why choosing not to enter the intersection says nothing about people who have disabilities.

The above arguments have demonstrated that an individual would not convey a negative message about people who are paraplegic by choosing not to enter the intersection in the scenario above. But can this same conclusion be drawn about public policies or clinical guidelines intended to prevent similar disabilities? Yes, because analogous reasoning applies. A state law requiring drivers to wear seatbelts may reflect a negative attitude towards injuries caused by car accidents but does not send a message of disvalue to those people who have been injured in such accidents. When physicians encourage obese patients to lose weight they convey disvalue for the health complications caused by obesity, not for their overweight patients themselves. Such practices may express negative attitudes about certain traits but do not express negative attitudes about the persons who have those traits.

Scenario 2

You are walking down the street with your 9-year-old daughter to your local coffee shop. The walk signal flashes and the two of you are about to enter the intersection when everything around you suddenly freezes. A disembodied voice claiming to be a guardian angel informs you that a driver approaching the intersection will momentarily be blinded by the early morning sun and run the red light; your daughter will be hit by the driver in the crosswalk and paralysed from the waist down. Time then restarts and you are faced with the choice of when to cross the street.

The choice you must make in this case is different from the previous one because it involves making a decision on behalf of someone else rather than for yourself. Choosing to prevent a disability for another person suggests that the desire to avoid disability is not simply an idiosyncratic preference, but is based on a value that is presumed to be shared. The decision to prevent your daughter from entering the intersection in this scenario therefore suggests that having the ability to use one's legs is, all else being equal, a good thing. It could also be understood as presuming that an inability to use one's legs is, all else being equal, a bad thing. Even so, this variation does not introduce a negative attitude towards *persons* with paraplegia. The distinction made in the previous section applies to this case as well. Preventing your daughter from entering the intersection may signal that you associate something negative with paraplegia itself but does not send a negative message about *persons* who experience that condition.

As with the first case, the large-scale promotion of this type of choice through education campaigns, public policies or the development of professional practice guidelines is no more ethically problematic than individual decision-making with respect to the messages it may convey about the lives of people with disabilities. The 'Never Shake a Baby' campaign does not express disvalue for those babies who were shaken despite the fact that its goal is to prevent similar injuries to future children. When a physician encourages parents to vaccinate their children, that encouragement does not constitute an expression of a negative attitude towards children who have the diseases the vaccines are intended to prevent. Whether on the level of an individual or of a society, then, efforts to prevent disability on behalf of others do not express disvalue for those people who have disabilities.

Scenario 3

You are having a morning latte at your local coffee shop, thinking about when you and your partner should start trying to conceive a child. Everything around you suddenly freezes and a disembodied voice claiming to be a guardian angel informs you that if you conceive this month, your future child will have a congenital condition that will cause paraplegia. If you wait a month, however, your future child will not have this condition.

Would the decision to wait to conceive express a negative attitude towards persons with disability any more than a decision to prevent your daughter from entering the intersection would? In one case, you are acting to prevent future disability for your child when that child is 9 years old. In the other, you are acting to prevent future disability for your child before that child is conceived. The difference between the two choices is the point in the child's life at which the choice is made. Any negative attitude that may be expressed by the choice to prevent future disability is not dependent on temporal characteristics of that decision. In other words, the fact that these choices take place at different times in a child's life does not make a morally relevant difference to the issue of whether that choice expresses disvalue for those with disability. Therefore, if the choice to prevent your daughter from entering the intersection does not express such disvalue, the choice to wait to conceive doesn't either.

One might argue that this conclusion is unsound because there *is* a morally relevant difference between this scenario and the two above: in this third case, your choice changes the genetic identity of the individual who is brought into existence, whereas in the previous cases the same person (genetically defined) will continue to exist no matter which decision you make. It may be true that this is a difference between these two cases. However, this may not be a *morally relevant* difference, if the following reasoning is sound.

In ordinary decisions about conception, nothing specific is known about the characteristics of the possible future children. The decision to pick one possible future child over another is a choice between two unknowns. The choice is therefore a random one, just like the flip of a coin, with regard to the characteristics of those future children. (The decision would most likely be made on grounds unrelated to the characteristics of the future child, such as convenient timing for the parents.) The choice between two unknown possible future children does not express disvalue for people with disability.

In the scenario above, however, one piece of information about the characteristics of one of the possible future children is available. You know that if you choose to conceive this month, your future child will have a genetic condition that causes paraplegia. This is the only piece of information about that future child that you have. So a decision to wait to conceive could only be based on a negative attitude towards that disability and, as a result, reflects disvalue for the inability to use one's legs. However, the first two scenarios above established that the choice to select against a disabling trait, in and of itself, does not express disvalue for those with disability, but rather for the disability itself.

Putting these pieces together, it becomes apparent that the fact that the decision to conceive changes the genetic identity of the future child does not constitute a morally relevant difference for the purposes of this paper. That is, it does not introduce an expression of disvalue for those with disability. The choice between one unknown possible future child and another does not reflect a negative attitude towards such individuals, nor does the choice to prevent the existence of a disabling condition. Essentially, because nothing is known about the other characteristics of the possible future children, it does not make sense to say that the presence of a disabling trait takes priority over or eclipses the future child's other traits; it is simply the sole piece of information available. The potential parents do not add up the future child's characteristics and decide to weigh that child's disability as more important than all the rest. Instead, they decide that, all else being equal (which it is, because of the lack of information about the possible future children), it is better for their future child to not have a disabling trait. The choice to wait to conceive, therefore, is similar to the cases above in the morally relevant ways, and so does not express disvalue for people who have disability.

But would the promotion of such choices on a societal level be different with respect to the messages they send people with disabilities? The March of Dimes, a non-profit organisation created to prevent birth defects, premature birth and infant mortality, works to educate women about the importance of taking folic acid before becoming pregnant in order to prevent neural tube defects. Obstetricians encourage potential mothers to quit smoking, get treatment for drug or alcohol abuse and taper off certain medications before becoming pregnant. Following any of these recommendations would be likely to cause a change in the genetic identity of the child conceived. But such recommendations are not discouraged on the grounds that they express negative attitudes about those who are disabled because their mothers made different choices.

Scenario 4

You have just come from your local coffee shop and have arrived at your appointment with a genetic counsellor. You and your partner are thinking about trying to conceive a child but are aware that you have a family history of a serious genetic condition that causes those who inherit a particular gene to become paraplegic. The counsellor informs you that it is possible to use PGD to ensure that your future child will not have this condition. If you choose to take this approach, several eggs will be fertilised in vitro and allowed to grow into embryos. Those embryos will be tested for the genetic condition in question, and only those embryos that do not carry that gene will be transferred and given the chance to develop. You and your partner decide to use PGD to ensure that your future child will not have the genetic condition.

The primary difference between the third and fourth scenarios is that in scenario three, a single future child is conceived, whereas in scenario four, numerous future children are conceived and those with the undesired trait are discarded or frozen indefinitely. Does this difference introduce negative attitudes towards those with disability? The difference between these scenarios is morally relevant only if the embryos in question have moral status. The moral status (or lack thereof) of embryos is a highly controversial issue that cannot be addressed in this paper. Fortunately, it is not necessary to resolve the issue to determine whether the choice in this scenario devalues people who are disabled. If embryos do have significant moral status, scenario four is importantly different from scenario three. However, if embryos have moral status, it is the destruction of those embryos that is morally problematic for the use of PGD in this case, not the decision to implant some embryos but not others. If, in contrast, embryos do not have moral status, the choice to use PGD in this fourth case is not morally different from the choice to wait to conceive in the third scenario above. The choice to discard or indefinitely freeze some embryos is analogous to waiting a month or two to conceive. If embryos do not have moral status, the two decisions are essentially the same: the choice to prevent one's future child from having a disabling trait. So, for the same reasons cited above, that choice does not constitute an expression of disvalue for people with disability.

As argued above, the distinction between individuals choosing to use these technologies to prevent disability and the widespread promotion of such choices is a distinction without a moral difference. Analogous programmes and practices that are truly analogous to PGD are difficult to find, but if this distinction did not make a moral difference in the types of decisions discussed in scenarios 1, 2 and 3, it seems plausible to conclude that it also makes no moral difference in this fourth scenario.

Scenario 5

You have just come from your local coffee shop, and have arrived at your appointment with a genetic counsellor. You and your partner are 10 weeks pregnant and are aware that you have a family history of a serious genetic condition that causes those who inherit a particular gene to become paraplegic. The counsellor informs you that it is possible to use prenatal genetic testing to determine whether your future child will have this condition. You and your partner decide to undergo the testing, which shows that the fetus does have the unwanted gene. You decide to terminate the pregnancy and conceive again as soon as possible.

Once again, this scenario is morally equivalent to the preceding one with respect to the attitudes the potential parents' choice expresses about people with disabilities. In both cases, a few possible future children are conceived and testing is done to establish whether each future child will have a serious disabling condition. In scenario 4, the possible future children are conceived at the same time, whereas in scenario 5 they are conceived at different times. This temporal difference is a way of distinguishing the cases but is not a morally relevant difference for the purposes of this paper. There is nothing inherent in conceiving several possible future children over time that expresses disvalue for those people with disabilities if conceiving several possible children at one time does not. That is, the choice to spread out the conception of the possible future children does not introduce a negative attitude towards persons who are disabled.

The importance of the moral status question is even more obvious in this scenario than in the previous one. If the fetus has significant moral status, it is the destruction of that fetus (regardless of its genetic makeup) that is morally problematic. For those who take a gradualist position on moral status, holding that it increases gradually as the fetus develops, scenario 5 may be marginally more problematic than scenario 4 because the fetus is more developed. The objection, however, is generated by the inherent moral worth of the fetus at that stage of development and is unrelated to the fact that the fetus has a disabling condition. If, on the other hand, the fetus does not have moral status, there is a difference in kind between the fetus in this case and existing persons (whether disabled or not) who have full moral status. Because of this difference, the choice to terminate the pregnancy says nothing at all about those with disability.

CONCLUSION

In moving through the five scenarios above, I have argued that the choice to use reproductive genetic technologies to prevent disability in a future child is no different from the decision to protect oneself from becoming disabled with regard to the message that such a choice sends to those individuals who currently have disabilities. In each case, an individual is faced with making a choice between a life with a disability and one without. The choice to avoid creating a life with disability may reflect a negative view of the disability itself, but not of persons who have it.

It is worth emphasising that the expressivist argument is only one of several disability-based objections to the use of RGTs and that disability-based objections are only some of the many ethical considerations that must be taken into account in the ethical evaluation of these technologies. If the expressivist argument fails, there may be *other* good reasons to object to the use of RGTs to prevent disability. At the same time, if this rebuttal of the expressivist argument is not convincing, the soundness of that argument does not imply that the use of RGTs is, all things considered, a morally impermissible choice. Even if the use of these technologies does express a negative attitude towards people who have disabilities, that argument, in and of itself, may not be sufficient reason to avoid using RGTs. Other ethical considerations that support the use of these technologies may outweigh the force of the expressivist objection. As a result, the success or failure of the expressivist argument (and of its rebuttal) does not settle the question of whether the use of RGTs to prevent disability in future children is a morally acceptable practice.

I have argued that the choice to use RGTs to prevent disability in future children does not express disvalue for people who have disabilities. It would not be inconsistent with this argument to claim that people who have disabilities nonetheless feel disvalued by such choices. My conclusion must also be distinguished from the possibility that the routine use of such technologies will result in diminished support for people with disabilities. These are empirical issues that should be explored and taken into account in the overall ethical evaluation of the use of RGTs to prevent disability. However, the conclusion that such choices do not, in principle, communicate negative messages about people with disability shifts the burden of proof onto objectors. For their arguments to be persuasive, objectors will need to demonstrate that such negative effects will occur and that they cannot be ameliorated through any means other than refraining from the use of these technologies.

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