

# Just diagnosis? Preimplantation genetic diagnosis and injustices to disabled people

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Most of us want to have children. We want them to be healthy and have a good start in life. One way to achieve this goal is to use preimplantation genetic diagnosis (PGD). PGD enables people engaged in the process of in vitro fertilisation (IVF) to acquire information about the genetic constitution of an early embryo. On the basis of this information, a decision can be made to transfer embryos without genetic defects to the uterus and terminate those with genetic defects.<sup>1</sup>

However, is it morally acceptable to use PGD to reduce the probability of children with severe genetic diseases being born? Is the current routine use of PGD in public healthcare services to select against severe genetic diseases like anencephaly, spina bifida, cystic fibrosis and Down's syndrome morally acceptable?

These are complex questions involving a range of difficult ethical issues—for instance, critical discussions about the morality of embryo research and embryo termination.<sup>2</sup> They also involve awkward conceptual issues concerning such matters as the meaning of words such as “disability”<sup>3</sup> and “severe” in “severe genetic diseases”,<sup>4</sup> which will not be discussed here.

In this paper I examine an argument which aims to show that efforts to prevent the birth of severely disabled children using PGD are morally unacceptable. Essentially, this argument appeals to our concern for disabled people and the belief that PGD, through a slippery slope process, will have bad consequences for them. I conclude that the argument is problematic for a number of reasons. But before I examine the argument itself, it will be helpful to separate two types of slippery slope argument since these involve different kinds of reasoning.

## TWO TYPES OF ARGUMENT

Many of the arguments against PGD point to the bad consequences it can be expected to have for disabled people. Central to all these arguments is the idea that the use of PGD will cause increased injustice, stigmatisation, and discrimination against people with disabilities. The arguments differ, however, in the way in which they explain how PGD will result in bad consequences, and, roughly speaking, fall into two types. Firstly, there are those arguments in which a risk of PGD “misuse” is emphasised. PGD can allegedly be misused by putting pressure on people to select against embryos that do not have a severe genetic disease. This kind of misuse is believed to change people's attitudes in a way that will increase or support injustice, stigmatisation, and discrimination towards disabled people. Secondly, there are those arguments which aim to show that PGD will have bad consequences for disabled people even when it is not misused—even when it is used only to select against embryos with severe genetic diseases. The latter type of argument has been widely discussed in the literature,<sup>5</sup> but the former has received less attention. In what follows, I will discuss the first

type of argument: first I sketch the argument in detail and then I offer a critical evaluation.

## FREEMAN'S ARGUMENT AGAINST PGD

The following slippery slope argument, presented by Jeanne S Freeman, seems to represent the worries many people have about PGD<sup>6</sup>:

as researchers refine pre-implantation diagnosis techniques for genetic diseases, it will be difficult, if not impossible, to contain the uses of such research (there is already considerable pressure to permit pre-implantation diagnosis for sex selection for “elective” purposes). There will likely be increasing pressure, whether subtle or overt, on people to take advantage of these techniques and not to bring even a mildly disabled child into the world, particularly if the disabilities will entail higher medical costs paid by third party insurers. Aside from the disturbing tendency toward eugenics this could bring (either voluntary, or coerced subtly or overtly), this development could undermine our notion of the moral equality of all human beings, particularly the disabled, and could erode respect for human life generally.<sup>7</sup>

Although it does not entail an explicitly moral conclusion, Freeman's argument can be interpreted as follows<sup>8</sup>:

- (1) As situation A (the use of PGD to select against severe genetic diseases) is refined, “it will be difficult, if not impossible, to contain the uses of such research”. A will therefore bring about situation B, where PGD will be used to select against mild or perhaps non-medical conditions.
- (2) Besides the refinement of A, B will be brought about because “There will likely be an increasing pressure ... on people to take advantage of these techniques, and not bring even a mildly disabled child into the world ...”.
- (3) Finally, we could reach a morally abhorrent outcome Z, which is disturbingly close to eugenics, where our notion of the moral equality of all human beings, including those with disabilities, is undermined.
- (4) Z is so morally bad, that it outweighs the benefits of undertaking A.
- (5) Therefore, A should not be undertaken.

Freeman seems to be worried by two effects of PGD, one supporting the other. Firstly, she believes that the use of PGD will be difficult to control and that it will be sought by parents (under coercion or voluntarily) for less and less severe medical conditions as time goes by. Secondly, she believes that this expansion of the use of PGD could lead to eugenics and “undermine our notion of the moral equality of all human beings”, particularly those with disabilities.

Evaluation of Freeman's argument rests on the plausibility of the following two predictions and the subsequent moral evaluation:

- Prediction 1: If we pursue A, this will *very likely* lead to outcomes such as B.
- Prediction 2: Outcomes such as B *could* lead to an outcome such as Z.
- The moral evaluation: Z is so morally bad that it outweighs the benefits of undertaking A.

In the next section I shall deal with the two predictions and following that, I shall discuss the plausibility of the moral evaluation.

## A CRITICAL DISCUSSION OF FREEMAN'S ARGUMENT: THE PREDICTIONS

### Prediction 1

Freeman's way of using the predictions given above in her argument is problematic. As regards the first prediction, her argument does not provide us with (or refer to sources of) empirical data that could be used as evidence for the claims that it is very likely that PGD will be "misused" to select for conditions other than severe genetic diseases by pressurising people to use PGD to avoid bringing even mildly disabled children into the world.

Studies in non-Western countries suggest that established prenatal screening techniques (amniocentesis, ultrasound, etc) are already being used by pressurised parents to avoid bringing mildly disabled children into the world.<sup>9</sup> But these studies also point to the failure of counsellors to give clear, comprehensive, and unbiased advice, and who might even be forcing the parents to make specific choices. Obviously this is morally unacceptable, and action should be taken to discourage or prevent such unprofessional behaviour.

It would be difficult in non-democratic countries to prevent dictators with crazy eugenic ideas from using compulsory PGD to achieve their aim. I think there are two reasons why we should not worry so much about this kind of misuse. Besides pressure from the international community, which could change the eugenic ideas of a dictator, history teaches us that dictators do not need to use sophisticated technology to engage in eugenic policies. They use compulsory sterilisation, abortion, concentration camps, or they simply murder the people they disapprove of. Compared to these alternatives it would in fact be better if instead dictators used compulsory PGD, since the citizens of the non-democratic state would then stay alive and probably have children.

Studies in North America and western Europe show that following prenatal diagnosis it is very likely that genetic counsellors will try to be as unbiased as possible and support the autonomy of reproductive choice.<sup>10</sup> We cannot, of course, draw any firm conclusions from these studies, but they support the belief that, in democratic countries, prenatal diagnosis is carried out within certain limits (depending on the seriousness of the disease being screened for).<sup>11</sup> Furthermore, the moral ideal of most ethical boards, counsellors, and politicians is that genetic counselling is done without putting pressure on parents to make a specific choice.<sup>12</sup>

It might be claimed that it is more likely that PGD will be misused than traditional prenatal diagnosis because selection by PGD does not require the distressing intervention of abortion.<sup>13</sup> It is true that selection by PGD is in this way easier to use (and misuse) than selection by traditional prenatal diagnosis, but in other ways PGD is more difficult to use (or misuse). It seems reasonable to say that people who do not have a known risk for a disabled child are probably not going

to use PGD, because it entails the burdens and risks associated with IVF and PGD. These observations, combined with the belief that democratic countries can and will control the use of private and public use of PGD, speak in favour of the claim that it is just as unlikely in these countries that PGD will be prone to greater misuse than traditional prenatal diagnosis.

One could still be worried whether the autonomous choices of parents in PGD may lead to a *widening* of the criteria for selection—especially if PGD becomes more available.<sup>14</sup> Let me discuss this in a chronological way.

### The present situation

As things are at present, I do not believe that couples who are fertile and are not at any known risk for having a severely disabled child would use PGD to select for, say, mild conditions. First of all, many of these conditions are amenable to treatment and prevention. Secondly, the burdens and risks currently involved with IVF (which is necessary if one wants to use PGD) and PGD limit its attractiveness. Since PGD is a relatively new kind of prenatal diagnosis we do not yet exactly know whether it constitutes a risk for the child born from a pre-embryo that has been tested by use of PGD. Finally, it is more fun and less time consuming to have children in the good old way than to engage in PGD. However, for infertile women who want IVF, the situation is slightly different. Since these women will anyway be exposed to the burdens and risks of IVF, they may want to have their embryos tested for severe as well as mild conditions. If they choose to do that without being pressurised to do so—and PGD is safe for the child compared with other kinds of prenatal diagnosis—they should, everything else being equal, be allowed to do so. The *ceteris paribus* clause indicates that their autonomy should be limited (as it is made clear at the end of the paper) if, as a result of their choices, the total sum of welfare would decrease.

### In the future

As regards the future, I think that Freeman is probably right in believing that the widening of criteria for selection may likely come about, as the technique is refined, (and, I will add, becomes less expensive and fraught with risks than other kinds of prenatal diagnosis, etc and therefore becomes more easily available). But, once again, she does not refer to any data in support of her beliefs that (a) this widening will only come about by not respecting the autonomy of the parents and (b) that this will lead to a scenario which is disturbingly close to eugenics, where our notion of the moral equality of all human beings (particularly those with disabilities), is undermined. The important thing is that the desire for widening the criteria is the result of parents' autonomous choices, and, if this is done in the future (as it is being done at present), I do not think the widening, in itself, will be regrettable.

Finally, in public health care, where resources are limited, it seems reasonable to give priority to the use of PGD against conditions which are clearly severe, and, everything else being equal, leave non-serious conditions to private clinics. This proposal resembles one of the many ways in which public hospitals set priorities, for instance, in cosmetic plastic surgery.

### Prediction 2

Let us now turn to the second prediction of the argument. Even if it were true that PGD would lead to "misuse", and to disrespect for reproductive choices, the strength of the argument would also rest on the prediction that PGD misuse *could* lead to eugenics and erode our respect for the interests of disabled people as a result. However, it seems neither

balanced nor fair to abandon the use of PGD (or any kind of technology) in response to the *possibility* of bad consequences. Every kind of technology *can* lead to bad consequences—and indeed in some situations will lead to bad consequences through misuse by evil or morally insensible people or states. Some Nazis misused surgery and diagnosis in psychiatry in concentration camps during the second world war. Obviously, they might be misused again in totalitarian or intolerant societies that exist now or will exist in the future. But this is not a convincing argument for abandoning surgery or psychiatric diagnoses in today's democratic countries. These kinds of practice have been used, and continue to be used, to save the lives of many people all around the world.

To fortify her argument, Freeman needs to show that the alleged “misuse” of PGD will generate a higher probability of bad consequences than current use of other technologies that we already find morally acceptable. As she does not supply evidence for this claim, we cannot tell, merely by examining the argument she presents, whether she is right or wrong.

In democratic and tolerant societies, it seems realistic to suppose that the use of these medical technologies will be properly managed and controlled. For instance, the chances of misuse will be reduced if PGD is only carried out in hospitals that are authorised to do PGD and carry out research in the field of PGD. This can be taken as evidence for the view that such societies are able to control potential misuse of PGD and the bad consequences that may follow from such misuse. The fact that, in parallel with the employment of prenatal diagnosis, many countries (for example, Australia, Sweden, and Denmark) have witnessed expanding recognition of the interests and rights of disabled people supports this conclusion. Regulations and legislation ensure that people use PGD appropriately only to test for severe genetic diseases and that people themselves decide whether or not to use PGD and how to act on the information revealed by the technique.

Finally, it should be noted that Freeman's argument seems to exaggerate the adverse effects of PGD. Even if it is true that in some cases PGD supports the development of outcome Z, there seem to be other more significant causes of discrimination against disabled people: ignorance, intolerance, and egoism, to name just three. Of course, “ablist” discrimination existed long before PGD came into use. In fighting it, one should not fight the use of PGD, but the harmful ignorance, intolerance, and egoism. An analogy is as follows: in our attempt to stop the violence among fans at big football matches we should not necessarily abandon big football matches but instead ensure that the fans of opposing teams are separated from each other as fully as possible.

To sum up, it seems realistic to conclude that the use of PGD can be regulated so that misuse and its bad consequences are excluded.

### A CRITICAL DISCUSSION OF FREEMAN'S ARGUMENT: THE MORAL EVALUATION

Let us suppose that good empirical evidence is available to show that it is very likely that PGD will lead to increased discrimination against disabled people. Do we now have a convincing argument? Not necessarily. Some have claimed that if a slippery slope argument were based on empirically sound facts, it would be convincing.<sup>15</sup> But this is doubtful since there is still plenty of room for the argument to fail. It can fail if it is shown that even though PGD will cause an increase in the number of discriminatory acts towards disabled people, it is morally preferable (all things considered, of course) to have such an increase.

Thus when evaluating a slippery slope argument such as Freeman's, it is important not only to estimate *what the*

*probability* is that A will cause Z but also to ask *how morally bad* outcome Z is relative to alternative outcomes (centrally, the alternative of not doing A). Indeed the strength of Freeman's argument can be formulated as follows: the higher the *probability* that outcome Z will be realised if we allow A, and the *worse* outcome Z is compared with the alternative outcomes, the more convincing the argument will be in favour of rejecting A. It is to the moral claim of Freeman's argument that I shall now turn.

Generally, slippery slope arguments against PGD tend to focus only on possible harms to disabled people. Such opposition ignores, or vastly underestimates, the increase in welfare of other individuals that might be gained from PGD.<sup>16</sup> Parents (or potential parents) may consider the possibility of PGD in the realisation of their reproductive choices to be paramount to their welfare. For instance, potential parents with a significant, known risk of having a severely disabled child might want to have a child only if they can at least try to have a child who is not born with a disability.

Thus it seems to be the case that PGD can satisfy some of the morally acceptable preferences of potential parents. When people want to have a child, they usually have a strong preference for a non-disabled child over a disabled child. The reasons behind this preference vary. Some parents prefer a non-disabled child because they fear that caring for a disabled child would take up much of their time and perhaps there would not be time enough to care properly for the other children in the family. Others believe that the child will not have a life worth living, or—balking at this—that a healthy child will at least have a life that is better than the life of a disabled child. These preferences can be invoked to explain why we think that it was right for a drug such as thalidomide (which was once taken by pregnant women and resulted in many children being born without arms or legs) to be taken off the market when it was found to have serious side effects. These preferences can also be invoked to explain why users of IVF would want to exclude embryos from implantation where PGD revealed severe genetic disease.

I think that these preferences are morally acceptable. Consider the denial of this—that is, the belief that any preferences parents have for non-disabled children are morally unacceptable. Such a denial certainly seems to have some problematic moral implications. It implies, for example, that it is *morally unacceptable* if a pregnant woman does *not* want to take a drug like thalidomide or if users of IVF want to exclude embryos *with* severe genetic diseases and instead implant embryos which are free of such diseases. If the preferences and choices in favour of having a healthy child are morally acceptable, this of course does not mean that such choices are legally required. In general, potential parents, at risk of having a disabled child but who do not want to use prenatal diagnosis should be free to do as they want.<sup>17</sup>

Be aware that the beneficiaries include not only the potential parents, but also the healthy child born instead of a disabled child. Imagine if following PGD, a couple can choose between having a child with cystic fibrosis or a child without cystic fibrosis. It seems to me that the potential parents should choose to have the latter child. With respect to the child they might have, the reason for this can be stated as follows: it is plausible to say that, where everything else is equal, having a healthy child without cystic fibrosis will benefit the healthy child *more* than having a child with cystic fibrosis would benefit (in that respect) the unhealthy child. One might here think it is controversial to claim that a child will benefit from coming into existence. But why? I believe I have a good life, and it does therefore seem quite reasonable to say that I have benefited from being brought into existence—in the sense that existence has given me the

opportunity to have a good life. This of course does not mean that I would have been harmed if I had not been brought into existence, since I was not there to be harmed.

Note that this estimate does not amount to saying, and nor does it imply, that the child with cystic fibrosis will have a life that is not worth living. Both children's lives may be equally worth living (for themselves and others), as it were, every day, week, or year. However, since the child without cystic fibrosis is expected to live for a longer period, his or her life will probably generate the largest sum of welfare. So the amount of welfare for the children we can bring into existence is likely to be higher if we accept PGD and the exclusion of embryos with severe genetic disease from implantation—assuming, of course, that a healthy child is born instead.<sup>18</sup> If the child born is not healthy, the benefits to the disabled child favour having that child.

The welfare and the autonomy of the parents and the future welfare of the child seem in most cases to speak in favour of using PGD. But, of course, this conclusion is only convincing if empirical studies support the claim that the total sum of welfare is greater in a society where PGD is used than it is in a society where it is not. Hence we should not always respect the autonomy of parents.

If sound empirical studies were to show that many disabled people were being harmed by PGD (for example, by serious employment discrimination; barriers to obtaining health insurance; cutbacks in public support programmes; or a rising suicide rate because of demoralisation or hostile attitudes), then we will have a strong reason to abandon the use of PGD. However, if studies showed that the use of PGD would have no, or only limited, harmful effect on disabled people, then we will have a weak reason not to use PGD.

## CONCLUSION

I have argued that:

- Freeman's slippery slope argument lacks empirical support and this makes it difficult to assess the conclusion of her argument
- history of medicine has taught us that the use of technology can be regulated (especially in democratic countries) in a way which prevents adverse outcomes and PGD seems to be no exception to this
- it seems more effective to fight the obvious causes of discrimination, such as intolerance and egoism, to reduce discrimination than to abandon PGD.

I have also claimed that:

- even if we accept that PGD will generate discrimination against disabled people, it is far from obvious that this is sufficient to warrant its moral condemnation.

Freeman's argument against PGD therefore is not convincing enough that we should cease to use PGD to select for embryos with severe genetic diseases.

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- 6 Cf. **King DS.** Preimplantation genetic diagnosis and the "new" eugenics. *J Med Ethics* 1999;25:176–82; and **Testart J.** The new eugenics and medicalized reproduction. *Camb Q Health Ethics* 1996;4:304–12.
- 7 **Freeman JS.** Arguing along the slippery slope of human embryo research. *J Med Philos* 1996;21:1, 79.
- 8 In fact Freeman does not argue specifically against the use of PGD, but against some of the preconditions for PGD being part of public healthcare, namely federal funding of embryo research. See reference 7: 61, 73.
- 9 **Wertz DC.** Eugenics is alive and well. *Sci Context* 1998;3–4:493–510.
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- 14 Thanks to an anonymous reviewer for directing my attention to these important worries.
- 15 **Walton D.** *Slippery Slope Argument*. Oxford: Oxford University Press, 1992:74.
- 16 For views like this, see **Buchanan A 1996: 22**; and **Kuhse H 1999: 23–5** (see reference 2).
- 17 Furthermore, if potential parents only want to have a disabled child and will not have a healthy child, say they want a deaf child, I believe they should be allowed to use PGD to choose for a child that is deaf. The parents' autonomy is satisfied and we can expect that the life of the child will be well worth living. Note that the alternative, as the case is described, is no child at all.
- 18 For reasoning very similar to this, see **Parfit D.** *Reasons and Persons*. Oxford: Oxford University Press, 1984, Chapter 16.