

Using Pre-Implantation Genetic Diagnosis to prevent genetic disorders – 3 possible responses

1. Using PGD to prevent genetic disorders is always wrong

Sanctity of Life

Many religions teach that human life begins at the moment of conception. They believe that science supports this view, showing that the embryo is genetically distinct from the very start. People who hold this view often disagree with experimenting on or destroying human embryos under any circumstances. PGD involves making a decision about embryos that would lead to the destruction of discarded embryos. For some, this is equivalent to murder.

Discrimination

PGD involves making a decision not to implant embryos because of a 'disorder' or 'defect'. In making such a decision, an assumption is made about the value of people with disabilities that applies to all disabilities, whether we screen for them or not. It is saying that a person with a disability is defective, inferior, incomplete. As well as going against the sanctity of life as outlined above, it also leads to discrimination. People with a specific genetic disorder are a minority. If PGD is used to reduce the number of people with that genetic disorder, they will be an even smaller minority. Also, if there is an element of choice about whether to have a child with a genetic disorder, parents may be held responsible for their child's disorder. Pressure may be put on people not to implant embryos with disorders. The funding and support for families of children with genetic disorders may dry up to discourage people from having children with disorders. Already people with disabilities feel that there are serious problems with discrimination in hospitals. Many hospitals refuse to perform transplants and other surgery on people with certain genetic disorders.

The central assumption behind the deployment of prenatal diagnosis is that life with a disability is not worthwhile and is primarily a source of suffering... From a disability-rights perspective, prenatal testing for foetal anomalies gives a powerful message that we seek to eliminate future persons with disabilities, fails to recognize the social value of future persons with disabilities, and conveys a devaluation of those now living with disability... By focusing so many resources on the elimination of potential persons with disability, we are drifting toward a eugenic resurgence that differs only superficially from earlier patterns. In the process we are seriously distorting the historical purpose of medicine as healing. We are creating a society in which disability is becoming increasingly stigmatized, with the result that human imperfection of all kinds is becoming less tolerated and less likely to be accepted as normal human variation.

Diane Beeson, "Social and ethical challenges of prenatal diagnosis",
Medical Ethics Newsletter (Lahey Clinic) Winter 2000, p. 2

Why should people who don't agree with religious views on the sanctity of embryonic life be dictated to by the minority who do? Isn't the issue of discrimination a different point – if we could remove a person's disability by surgery, would anyone argue that we shouldn't as this would increase discrimination on the smaller minority of people with this disability?

2. There are some circumstances under which it would be desirable to remove certain genetic disorders using PGD

Scientists claim that we each carry around 20 'faulty' genes. It is also widely held that the majority of diseases are at least partly affected by genetic factors. Our genes may not be directly responsible for the condition, but they give us a tendency towards the condition. Genetic disorders are caused by mutations in our genes. Mutations are sometimes completely harmless. Not all mutations are inherited – some happen during the ongoing process of cells dividing and reproducing. Mutations can also be influenced by lifestyle – smoking, unhealthy diets etc.

More than 10,000 genetic disorders have already been identified, affecting hundreds of millions of people around the world. Many of these are considered 'minor abnormalities' that don't seriously affect the quality of a person's life. There are hundreds of genetic disorders that are already screened for using PGD. Find out more about some of these in case studies on the BBC website:

- **Androgen Insensitivity Syndrome**
- **Congenital Adrenal Hyperplasia (CAH)**
- **Costello Syndrome**
- **Dyslexia**
- **Klinefelter's Syndrome**
- **Marfan Syndrome**
- **Noonan Syndrome**
- **Rett Syndrome**

A religious response based on love might ask us to put ourselves in the position of a person with a genetic disorder – would compassion lead us to decide to prevent people being born with this condition? Natural Law is usually used to support pro-life arguments. However, Natural Law arguments could be used to support PGD, arguing that we were not designed to have genetic disorders and therefore PGD helps select those embryos that are 'natural' or as God intended. The Catholic Church, whose official position is greatly influenced by Natural Law thinking, states that life begins at conception, and therefore considers PGD a grave violation of God's law. However, there are many Christians who believe that an embryo has not yet been ensouled, and they may therefore support PGD in some cases.

Which of these is it acceptable to screen for? Whose choice should it be? Is it okay to make germ-line changes?

3. There should be no restrictions on the removal of genetic disorders using PGD

Some people believe that using PGD is up to prospective parents. In a free society, they might argue, the individual should be allowed to choose whether to continue with a pregnancy, and should be given all of the information that science can provide. A utilitarian response might be to look at the potential pain and suffering that genetic disorders can lead to.

...in selecting against having disabled children, parents show that they value having a child without a disability more highly than having a child with a disability, and ... this judgment can, in principle, be a sound one.

Peter Singer, 'Shopping at the Genetic Supermarket'

What counts as a disorder? What point was the writer of Gattaca trying to make? What effect might PGD have on our society?