

A
Research Paper
from
No Less Human

QUESTIONS AND ANSWERS
ON PRE-IMPLANTATION
GENETIC DIAGNOSIS

Published by No Less Human
A GROUP WITHIN THE SOCIETY FOR THE PROTECTION OF UNBORN CHILDREN

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1. What is Preimplantation Genetic Diagnosis? (PGD)

PGD is a way of examining in the laboratory human embryos produced by “*in-vitro fertilisation*” (IVF) technology (i.e. in a test-tube.)

- ♦ If a genetic disabling condition is detected, the embryo is thrown away.
- ♦ If not, the embryo is implanted in a woman, and allowed to grow and develop and, eventually, be born.
- ♦ “*Preimplantation*” diagnosis means that the embryo is examined before implantation in a woman’s womb.
- ♦ PGD has also been used to identify an embryo that can serve as a tissue match for a sick child.
- ♦ In some IVF programmes in other countries, PGD has been used to select the sex of an embryo for the purposes of ‘family balancing’ i.e. where parents already have children of one sex and want a baby of the opposite sex.

2. How is PGD performed?

- After being created by IVF technology, a biopsy is carried out to remove a cell from the developing embryo.
- The biopsy is usually performed 2-5 days after fertilisation, when the embryo consists of 6-10 cells¹.
- The cell that has been removed is then tested to see whether the embryo carries a genetic disabling condition.

¹ Human Fertilisation and Embryology Authority Eighth Annual Report and Accounts 1999

3. Which disabling conditions can PGD detect?

PGD is most frequently used for people who have a family history of genetic disabilities, including cystic fibrosis, Huntington's disease and Tay-Sachs disease.

Such people can opt to use IVF and PGD technology to ensure that any embryo that is implanted does not have the condition in question.

4. Do parents have a right to a non-disabled baby?

It is, of course, both natural and right that parents should hope that their children will not have to contend with illness or disability, and that they should take ethical steps to try to give their children the best possible start in life.

There are ways of protecting unborn children from disability which are not destructive - for instance,

- * refraining from smoking
- * abstaining from alcohol,
- * taking supplements of folic acid, which can prevent the disability spina bifida occurring.

These positive measures are entirely consistent with pro-life thinking.

It is true that they cannot prevent every disabling condition, but it must be recognised that **life is a gift, not a right**, and that parents do not have a “*right*” to have a child, or to have a particular sort of child.

Children are not commodities to be accepted or rejected according to whether or not they meet someone else's particular “*specifications*.”

5. Is PGD acceptable to prevent serious disability?

It is often suggested that both PGD and pre-natal diagnosis “prevent” disability, but this is true only in the sense that it aims to facilitate the destruction of human individuals found to have a disability.

- This is a form of fatal discrimination, and a denial of the fundamental right to life all human beings share.
- It is also highly offensive to people living with a disability, who realise that had this technology been available before their birth, they too would have been destroyed in the name of “preventing disability.”
- Of course, funding both PGD and screening is seen as having economic benefits for the community because it is cheaper than providing adequate services for people with disabilities

6. Is PGD preferable to pre-natal screening leading to abortion of disabled babies?

Both PGD and pre-natal screening aim to detect disabled individuals so that they can be destroyed - by being thrown away at the embryonic stage, or by being aborted if they are older.

The two kinds of diagnosis are essentially the same, the only difference being the age at which the disability is detected and the disabled individual destroyed.

Killing a human being because s/he has a disability is wrong, whatever the age of the victim.

7. Will PGD lead to “designer babies”?

The Human Fertilisation and Embryology Authority and the Advisory Committee on Genetic Testing suggested in 1999 that they believed it unacceptable to test human embryos for “*social or psychological characteristics, normal physical variations, or any other conditions which are not associated with disability or a serious medical condition.*”²”

However, in June 2004, the HFEA

There is no logical reason for making a distinction between testing for disability and testing for social, physical or psychological characteristics.

If parents are allowed to choose to destroy a child on the grounds that s/he has a disability, there is no logical reason for not allowing them to treat in the same way a child considered “*undesirable*” for any other reason.

In truth, in permitting PGD to be used to detect embryos with a disability, the concept of “*designer babies*” has already been approved.

An attempt to “design” babies to *any* particular specification is morally repugnant.

² HFEA & ACGT Consultation Document on Preimplantation Genetic Diagnosis para. 22. 1999

8. Is counselling before PGD a sufficient safeguard against abuse?

PGD is unethical, because it involves facilitating the destruction of human beings, whether or not counselling has been given first to the parents.

Killing and caring cannot be presented as two equally acceptable alternatives.

Human beings have an intrinsic dignity and an absolute right to life which cannot be ethically ever be denied to them.

If destruction is presented as an ethical option, the possibility of recognising that intrinsic right to life is lost.

9. Does PGD respect the value and status of the human embryo?

Normally each individual human life begins at the moment of fertilisation, the only exception being when technology is used to create an embryo as a clone of another person.

From that point on, human beings are entitled to the respect proper to their human nature, to protection from harm, and to rights appropriate to their stage of development.

The right to life is the most fundamental human right of all, and is applicable to all human beings, whatever their age.

People with disabilities, whatever their age and however severe the disabling condition, have an equal and unequivocal right to life and to protection from harm.

PGD fails to respect the human value of the embryos examined in the laboratory, because the aim in doing so is to destroy those found to have disabilities.

PGD is completely incompatible with a respect for the right to life, because it entails destroying those human beings who do not measure up to an arbitrary measure of “*desirability*.”

The Consultation Document on PGD prepared by the Human Fertilisation and Embryology Authority and the Advisory Committee on Genetic Testing stated that:

“The Human Fertilisation and Embryology Act was designed to ensure that human embryos are not used frivolously or unnecessarily, and was guided by the principle that respect is due to human life at all stages of its development” (para 51.)

It is not possible to have “*respect*” for a human individual whom one is prepared to destroy if s/he does not measure up to a particular specification.

Real respect means recognising the value of the individual and taking steps to protect him or her from harm.

No safeguards could be adequate, because PGD depends on the concept that it is acceptable to destroy certain human beings.

10. What is the judgement of No Less Human on PGD?

- It is never acceptable to reject - indeed, deliberately to seek out and destroy - those human beings who have disabling conditions.
- **IT IS IMPOSSIBLE FOR A SOCIETY TO “value” A GROUP OF INDIVIDUALS WHOSE SYSTEMATIC DESTRUCTION IT IS SIMULTANEOUSLY ADVOCATING.**
- We can only acknowledge and demonstrate the equal value and dignity of every human being by wholeheartedly welcoming into our society every child, disabled or not.
- PGD denies the human value of the embryos who are sought out for destruction.
- thus PGD is never ethically acceptable.

Alison Davis 9/03 revised Aug 2005

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