

Designer Babies

Introduction

This activity explores the meanings of the term ‘designer baby’. It provides a review of the techniques and the issues associated with the application of genetics to human reproduction. Students discuss their personal views and then go on to prepare and perform a short scripted debate about the ethical issues involved in the Hashmi case.

This topic will be more effective if students have already learned something about inheritance and genetic diseases and covered the reproduction aspects of 9.3 Medical Ethics. It will probably work best as the conclusion to 9.5 Genetic Diseases though some may wish to use it as an introduction to this section. The issue provides a good mixture of science and ethics.

This activity is in three parts;

- an introduction, in the form of a questionnaire, to find out what the class think they might want to do themselves as potential parents.
- a revision of all the techniques available leading to personal decisions on which of these are acceptable.
- writing a short play to stimulate a more detailed look at one case which has been popularly described as leading to a ‘designer baby’ and is the highest level of intervention currently possible.

Activity 1 A questionnaire

This activity is a simple survey of the class to answer the questions “If you could design your baby what would you choose?” Collect results on the board. It is likely that there will be considerable variety. The question on colouring may be problematic in many groups though it is a cultural issue as the title of the book ‘How to clone a blond’ indicates.

Activity 2 The line

The line itself is a useful revision of reproduction and genetic screening science. It also challenges students to decide what is actually meant by designer babies and to develop their own opinions on what should be allowed.

Students should be given the sheet, and the glossary if you think they need it. Give them a few minutes to read and to think about their own position. In some classes there will be questions and clarifications needed at this stage. Then, making sure there is enough space, draw an imaginary line from A to L across the room and get all students to take up a position corresponding to the letter corresponding to the furthest intervention in human reproduction that they think is acceptable.

You may well find that there is dispute about the ordering of the interventions. My class debated the relative positions of E & F and of G & H and decided to reverse my original ranking.

References

Textbook
Chapter 6

Specification
9.3 Medical Ethics
9.5 Genetic Diseases

When everyone is in position there will probably be quite a lot of bunching. Record how many people there are at each letter. Get each student to pair up with someone who is one letter higher or lower than themselves and give them 5 minutes to try to change each other's mind. Then let them locate themselves on the line again and see if there are any changes. In my class those who moved went one letter further down the alphabet not up. This may be an opportunity to talk about the role of debate for decision making.

Have a general discussion in which some students feed back their reasons for choosing a particular limit to intervention. Total time 30 - 45 minutes.

Activity 3 The Hashmi case. Write a play

The aim of this activity is to get students to develop a debate without the personal commitment to their own point of view. It should help them think about developing a reasoned argument in response to a point of view.

It is worth spending about 15 minutes in preparation. Two issues need covering: why we need regulation at all; and one or two examples of how to conduct an argument. I started with the Vivienne Nathanson statement and got them to realise that one could counter 'without risk to others' from the point of view of the unborn child. The Daily Mail quote provides the argument. With some groups it will be helpful to summarise the main argument in each quote or perhaps to reduce the number of quotes provided.

4 or 5 students could be in each group to write the play, with four of these prepared to actually perform in front of the class. In a small class the role of the Chair could be omitted from the play.

Students will need about 30 minutes to write the play. Each performance will take 5 -10 minutes. Remind the students that this is a play. They do not have to agree with the opinions they are expressing. The class should be invited to comment on the performances when all groups have performed.

A questionnaire

What would you choose?

- If it were possible would you want to ‘design’ your baby?
- If you could design your baby what would you choose? You can’t, but many people think that one day it will be possible. Would we all choose the same features or would people be as varied as ever?

This exercise is designed to find the answer to these questions in your class.

Choice 1

Do you want to choose at all; such choice means that conception becomes a medical procedure; would you rather conceive your child in the normal more pleasurable and less intrusive and love whoever you get?

Choice 2

Assuming you do decide to go ahead and choose your child’s features what would you choose?

sex	male	female	
height	tall	average	short
colouring	fair	dark	
attractiveness	very beautiful	average	
intelligence	very intelligent	intelligent	average
personality	lively	generous	calm

Choice 3

Is it worth the risk? Your carefully ‘designed’ child might not turn out the way you had planned. Might you then love them less?

Designer babies

There is an element of design in all babies. The list below shows all the techniques which have been, or might one day be used.

How far down the list do you think the term “**designer babies**” starts to apply? If you do not understand all the terms used see the glossary below.

Consider the list as a line representing us interfering more and more in what sort of baby is born. Decide how far down the line you think interference is acceptable. Walk down the line until you get to the procedure that is the limit for you. Stop there.

When the whole class is lined up talk to the person who has gone one stage further or less far than you. Explain to each other why you have stopped where you are. Can you persuade them to move one position?

Techniques	Comments
A Choose a partner “you would want to have children with”.	The normal procedure.
B IVF for infertility, the “best” embryo, the one most likely to develop, is implanted	A subjective choice by the technician based on experience
C Genetic screening of potential parents. If both are found to carry a defective gene they may be advised not to have children together.	Used to prevent birth of babies with Tay Sachs disease and other recessive genetic conditions.
D Sex selection by PGD on an IVF embryo. If the foetus is at risk from an X-chromosome linked genetic disease only female embryos are implanted the male ones are destroyed.	Duchenne muscular dystrophy is an example of an X-linked genetic which therefore only affects boys
E PGD on an IVF embryo for couples who carry a genetic disease. Only embryos without genetic are implanted the rest are destroyed.	A single cell removed from each embryo disease is carefully genetic tested f or a specific disease known to be carried by the parents.
F Amniocentesis or CVS on a developing foetus at about 3 - 4 months. Abortion if the foetus is found to suffer from a genetic disease.	The most widely used technique for prevention of the birth of babies with genetic diseases.
G Use of PGD on an IVF embryo to select an embryo a few of whose cells will, at birth, be able to be used to cure a seriously ill brother or sister.	This has been used several times in families where one child needs a matched transplant to survive.
H Abortion of a developing foetus found to be the “wrong” sex.	Widely practiced in some cultures, though not normally legal.
This is as far as we have gone so far. But the ideas below are all likely to happen in the future.	
I Use of PGD on an IVF embryo to select an embryo with ‘normal’ genes, not those that increase the risk of heart disease or mental illness.	More and more genes are being found which may increase the risk of disease, though none cause directly it unless other factors are also present
J Use of PGD on an IVF embryo to select an embryo that carries genes known to be linked to intelligence, beauty or sporting prowess.	Such genes have not been found yet but research continues.
K Genetic manipulation of the developing foetus in vitro to introduce genes for particular characteristics.	Has been done on animals although the success rate is low and many others die early or are deformed. But techniques are getting better.
L Clone a human from the cell of someone you want your child to be like.	Has been done on animals with very low success rate and many deaths and deformities. But techniques are getting better. Idea appeals to those wishing to recreate a loved one or for infertility

Definitions

Amniocentesis	The amniotic fluid which surrounds the developing foetus in the uterus always contains a few cells shed by the foetus. If a little of this fluid is withdrawn from the uterus the cells can be screened for gene or chromosomal defects.
Clone	To create another person with exactly the same genetic material. Identical twins are clones, as are plants taken from cuttings. The nucleus is taken from a cell and inserted into a human egg, from which the nucleus has been removed. Sometimes this egg can be shocked into dividing as it would after fertilisation.
Embryo	The early stage of development of a baby before the cells have differentiated into different functions..
Foetus	The developing baby in the uterus until it is born
Genetic Manipulation	It is now possible to introduce genes into a cell nucleus. Sometimes these genes become part of the cell's chromosomes and function normally. Normal genes can be introduced to take over the function of a defective gene such as the CF gene which causes cystic fibrosis.
Genetic Screening	DNA is extracted from the cell, usually it is then copied by special enzymes. The DNA can then be matched to standard DNA samples to see whether it is normal or not.
IVF	In Vitro Fertilisation; literally means fertilisation in glass and is often popularly known as "test-tube babies". The woman is given hormones to make her ovulate with several eggs at once. These are removed by micro-surgery and each egg is fertilised by sperm in a petri dish. After a few cell divisions the "best" embryo is implanted in the uterus. Sometimes the embryo implants in the uterus lining and a normal pregnancy continues. IVF has a success rate of about 20%.
PGD	Preimplantation Genetic Diagnosis; when the fertilised egg has divided to an embryo of about 8 cells one of these can be removed without harming development. The DNA in this cell can then be replicated and tested for defects. If a defect is found the embryo is discarded, if not the embryo may be implanted in the uterus as with any IVF treatment.
X-chromosome	Females have two X-chromosomes so any defect on one will not be expressed. Because males have only one X-chromosome, and one Y-chromosome, they will be harmed by a defect on their X-chromosome.

A real case; Write a short play

This case has been described in the media as being about designer babies

The Hashmi family had four children. The youngest Zain was found to have α -thalassaemia. He requires frequent blood transfusions and other treatments, which seriously affect his quality of life. He is unlikely to live beyond his thirties.

α -thalassaemia is caused by a defect in one of the genes responsible for the red blood cells. Inheritance is recessive, Zain must have two defective genes, one from each parent; the other children in the family do not have the disease.

The condition can be cured with a transplant of bone marrow cells, however these cells must match the recipient if they are not to be rejected. No one in Zain's family is a good enough match. It is also possible to transplant stem cells from the umbilical cord of a new-born baby, if the baby is an exact match. When they discovered the problem the family had another child in the hope that its cord stem cells could be donated to Zain. Unfortunately it did not match.

The Hashmis then applied for permission to use IVF and PGD to select, from several fertilised embryos, one that would match Zain. As well as knowing that the new baby would not have α -thalassaemia, they would be sure that it would be able to act as a donor, because they had selected it specifically to serve this purpose. Many people support the family in their wish to do everything possible to save the life of their child and believe that they will also love the new baby for its own sake. Others see serious ethical objections, describing the process as creating a 'designer baby'. The legal process has been uncertain too and permission was first granted then overturned then granted again by higher and higher legal authorities.

Parents' arguments

Providing sufficient ethical guidelines are in place - and I believe they now are - fear of public harm from such techniques will be avoided. How will the public be hurt by saving Zain's life with the help of a new sibling who will be a cherished member of a loving family? Nature shall determine what embryos are produced and we will select only the embryo that is the right tissue match.

Dr Simon Fishel

"Where technology exists that could help a dying child without risk to others, it can only be right that it should be used for treatment."

Vivienne Nathanson, head of ethics at the British Medical Association

"As far as the Hashmis are concerned, this is their only chance. Neither parent nor any of their other five children is a match."

HFEA arguments

If future licenses are issued, strict criteria will have to be met. For example all other possibilities of treatment and sources of tissue for the affected child must have been explored, embryos created should themselves be at risk from the condition affecting the existing child, the child's condition must be severe or life-threatening, embryos must not be genetically modified to provide a match, couples must receive appropriate implications counselling, the parent cannot be the intended recipient.

HFEA

IVF treatment to select an embryo that was a tissue match was allowed because Zain suffers from an inherited condition and any future baby would be at risk of the same disease. The HFEA reasoned that there was a benefit to the future child in ensuring it would not develop thalassaemia, which outweighed

the risks involved in removing a cell from the embryo for genetic testing. Tissue typing - to ensure the new baby's stem cells would be a perfect match for Zain - could be carried out at the same time without any extra risks.

Newspaper report on the case

If the decision of the HFEA is upheld in the present case it does not mean that parents have a right to in vitro fertilisation for social selection purposes. Parliament was "not opposed in principle to doing to an embryo any of the things which are likely to happen to it." On the other hand Parliament did not sanction a free-for-all."

One of the Law Lords who agreed to the treatment.

"I am relieved that this judgement, once and for all, supports the HFEA as the proper regulatory body for licensing these technologies." He added: "From the public's point of view they should have no fear because cases such as the Hashmis and the procedures involved will remain highly regulated by the HFEA and strict conditions will apply to all couples seeking this treatment on a case by case basis."

HFEA spokesperson

Arguments used to oppose the treatment

Of course it would be legitimate to produce a child for whatever reason, including such a noble one. But the motivation for producing offspring is actually NOT the problem here. Rather, the nasty issue is hidden in the phrase "selecting an embryo": selecting here means picking one and killing all other embryos whose tissue does NOT match. And since intentional killing of human life is murder, it would not be appropriate to select. If a method is found that does not kill embryos, there could hardly be an objection to the treatment, but all embryos are living human beings, and as such basic human rights apply.

An opinion expressed on the BBC website

The whole life of the new child is like an experiment and that child cannot withdraw from that experiment nor give consent.

Homerton Baptist Church

The HFEA's distinction fails to address the central issue of using one child to benefit another. The danger is that any such 'designer' children will think they have been chosen and others discarded principally to save a sibling's life. What if the attempt fails and the older child dies or remains seriously ill? And might the parents feel differently towards the child that needs to be saved and the baby they have brought into the world to provide that help? Children need to be valued for themselves. They should never be used as commodities.

Daily Mail

The Hashmi ruling has opened the door for human beings to be manufactured for the prime purpose of providing tissue for someone else.

Christian Medical Fellowship

Write a script

Before the decision is made on such cases a hearing may take place to consider different opinions. The debate is to consider the **ethical issues**, not the science. It is known that the PGD technique can ensure both that the unborn child will be free of thalassaemia and that it will be a perfect match to serve as a suitable donor.

The task

Write a script for a short play showing the debate taking place at such a hearing. Your group should work together as a team to consider the arguments that might be used and to put these together as a lively debate. Some arguments that have been used are included here to help you but you can use others.

Write the script for three or four characters, depending on whether you include a chairperson.

The characters

- **The parents or their representative:** You are interested in trying to save Zain's life.
- **A representative of a bioethics group with a strongly Christian background:** It is such a group which challenged the original permission granted by the HFEA leading to the refusal. (This refusal was then challenged by the HFEA). You feel that you are standing up for the rights of the unborn child and for the unwanted embryos.
- **A representative of the HFEA:** the organisation that has overall responsibility for giving permission for any treatment involving human fertilisation, including this case. You are interested in general principles and also want to defend your right to make decisions.
- **The chair:** the Chair has to intervene to ensure that the arguments are reasoned and non-abusive and that participants do not interrupt each other. In a small group you can leave this role out.

Some hints

You might choose to start with one of the arguments given above and then get someone else to respond.

Remember each speaker should directly refer to the previous contributions and seek to explain why they disagree with the other's position, as well as explaining their own position. Because it is a formal setting there will not be any actual rudeness but there will be very strong feelings expressed, as well as logical arguments.

Your script should take about 5 minutes to perform.

You will perform your playlet to the rest of the class. Because you will be acting when you perform it does not matter whether or not you agree with the role you take.

Your own opinion

When you have written your own script and possibly also heard others read their scripts you should be prepared to discuss whether you would allow this procedure to go ahead.

Do you think this is the beginning of a 'slippery slope' to allowing designer babies for any reason. Is the use of the term 'designer baby' one that is used deliberately to make the technology sound negative?

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