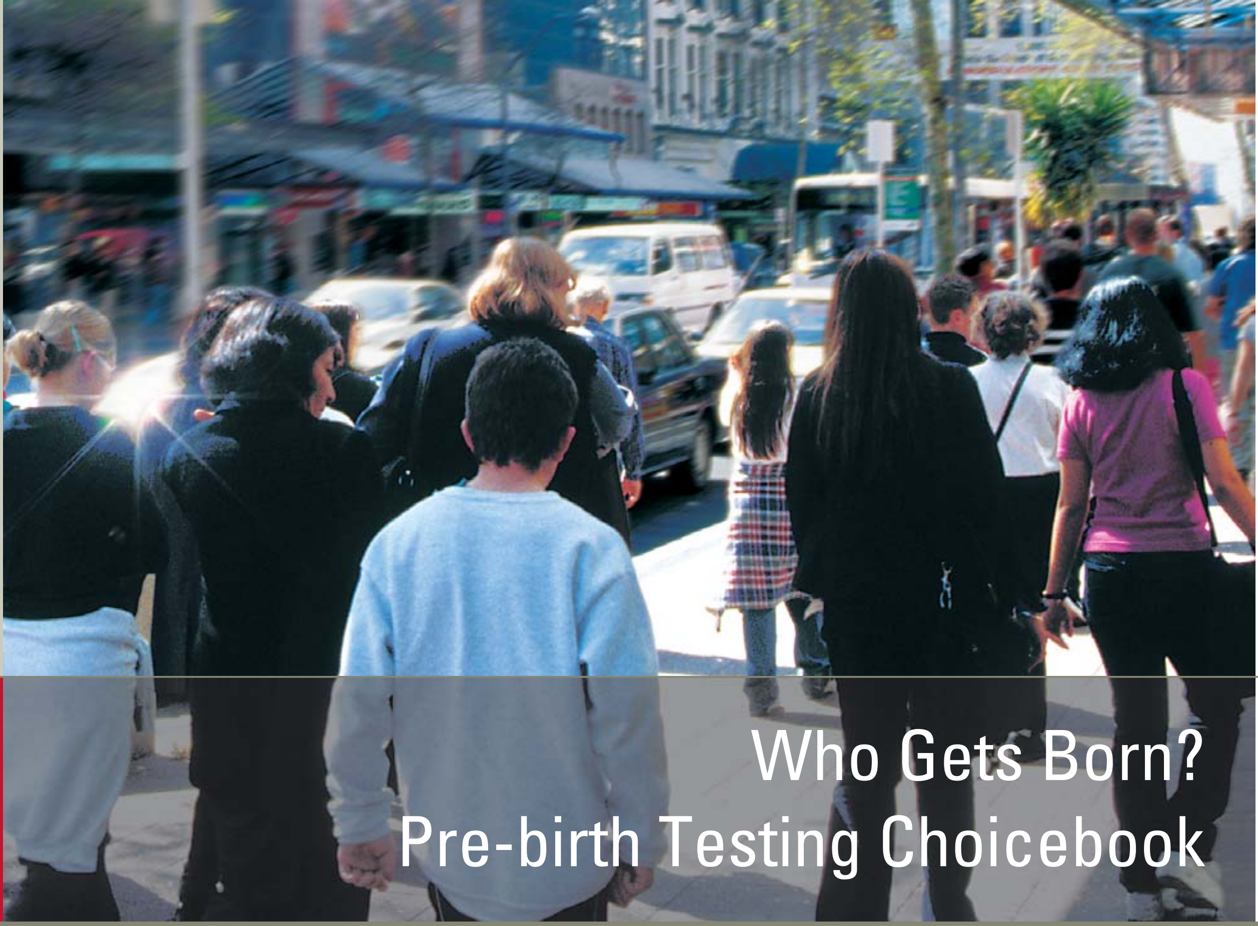

Who Gets Born?
Pre-birth Testing Choicebook

toi te taiao
the BIOETHICS COUNCIL

WWW
bioethics.org.nz

This Choicebook aims to encourage deliberative dialogue

> **This Choicebook aims to encourage deliberative dialogue about pre-birth testing. Pre-birth testing, together with ante natal care, have become a routine part of helping ensure the health of the baby and the mother.**

However, the outcomes are not always straightforward. Pre-birth tests such as blood tests, scans, amniocentesis or pre-implantation genetic diagnoses can detect conditions such as Down syndrome, cystic fibrosis and spina bifida. These conditions can have a devastating effect on the child and the parents.

People have very different views about pre-birth testing and whether or not there should be any limits to what people should be allowed to do; or even if we should have the right to destroy an embryo or terminate a pregnancy if the results of a test show there is some abnormality.

Deliberating on an issue means people coming together as informed citizens and taking responsibility for making choices about how they want to live, how they want to act together, and how they want their government to function. People come together and carefully weigh up each perspective, looking for what is positive about that point of view, its drawbacks, the trade-offs they are prepared to make in taking particular action(s), and what the consequences might be of taking such action(s).

Thanks to Valerie Bos for the use of her paintings on pages 10, 11, 15, 17, 21, 23 and 25

The Bioethics Council wishes to thank all those people who took part in the framing exercises in August 2007. This Choicebook reflects their hard work and commitment.

More information about pre-birth testing is available through our web site at www.bioethics.org.nz

A web-based deliberative dialogue is to be held from late October 2007 at http://nzbioethics.dialoguecircles.com

We invite you to join this discussion and let your voice be heard.

Dr Martin Wilkinson
Chair
Toi te Taiao: the Bioethics Council

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Who Gets Born? Pre-birth Testing Choicebook

PRE-BIRTH TESTING

Pre-birth testing is part of a broad set of issues to do with human reproduction. Reproductive technologies are being used more and more; with increased use come certain moral, ethical and social questions. These might have profound implications for the way we think about reproduction and the family.

Toi te Taiao: the Bioethics Council has produced this document with the intention of stimulating deliberation and discussion on these important issues. The approaches in this document reflect the interests, concerns and values that the Council heard from 56 members of the public at preliminary workshops.

You are participating in one of 18 deliberative dialogue events that are being held throughout the country. The results of these events will be reflected in a report to Government; it is expected that policy and decision makers will take the recommendations seriously when they address issues about pre-birth testing.

Pre-birth testing

Includes:

Before pregnancy
Pre-implantation genetic diagnosis (PGD)

During pregnancy
Pregnancy test
Blood pressure
Urine test
Foetal heartbeat
Blood tests
Triple screening test
Ultrasound
Amniocentesis
Chorionic villus sampling

DEVELOPMENT OF PRE-BIRTH TESTING

If you ask people who are about to have a baby what they want for their child, they will often say ‘a healthy baby’. Others might want to know the sex of the baby. These wishes are not new.

1350 before Christian era (BCE)

One of the earliest written records of a urine-based pregnancy test can be found in an ancient Egyptian document. A papyrus describes a test in which a woman who might be pregnant could urinate on wheat and barley seeds over the course of several days: “If the barley grows, it means a male child. If the wheat grows, it means a female child. If both do not grow, she will not bear at all.” Testing of this theory in 1963 found that 70 percent of the time, the urine of pregnant women did promote growth, while the urine of non-pregnant women (and men) did not.

By the 1890s public health advocates started to encourage women to see their doctors as soon as possible after pregnancy was suspected. Prenatal care was found to improve the health of both infants and mothers, even though most women did not see a doctor or midwife until well into the pregnancy.

In 1959 it was discovered that people with Down syndrome[1] have an extra chromosome 21. This was the first time that a disability and a chromosome disorder had been linked.

By 1968 it was possible to test some cells from the fluid surrounding the foetus to detect some genetic disorders, although this process (called amniocentesis) has some risks for the pregnancy. From the 1970s, amniocentesis was frequently offered to older women because it was known that Down syndrome is more common if the mother is older.

By the 1980s, ultrasound tests became available and it was possible to see whether the foetus appeared to be developing well or whether there were certain foetal abnormalities. It was also possible to measure the fluid-filled area at the back of the foetus's neck: an increase between 11 and 14 weeks into the pregnancy is associated with Down syndrome. It can be detected by a nuchal translucency measurement (NT screening).

NT screening is more reliable if combined with testing blood from the pregnant woman, as well as taking into account the age of the mother. If the screening indicates a possible problem, the woman is offered an invasive diagnostic test using cells taken by amniocentesis or chorionic villus sampling (CVS). These tests can identify a number of other conditions in addition to Down syndrome.

> **Screening:** A positive result from screening shows there is an increased chance of a particular condition being present.
>
> **Diagnostic tests:** These can show more reliably whether or not the condition is present.

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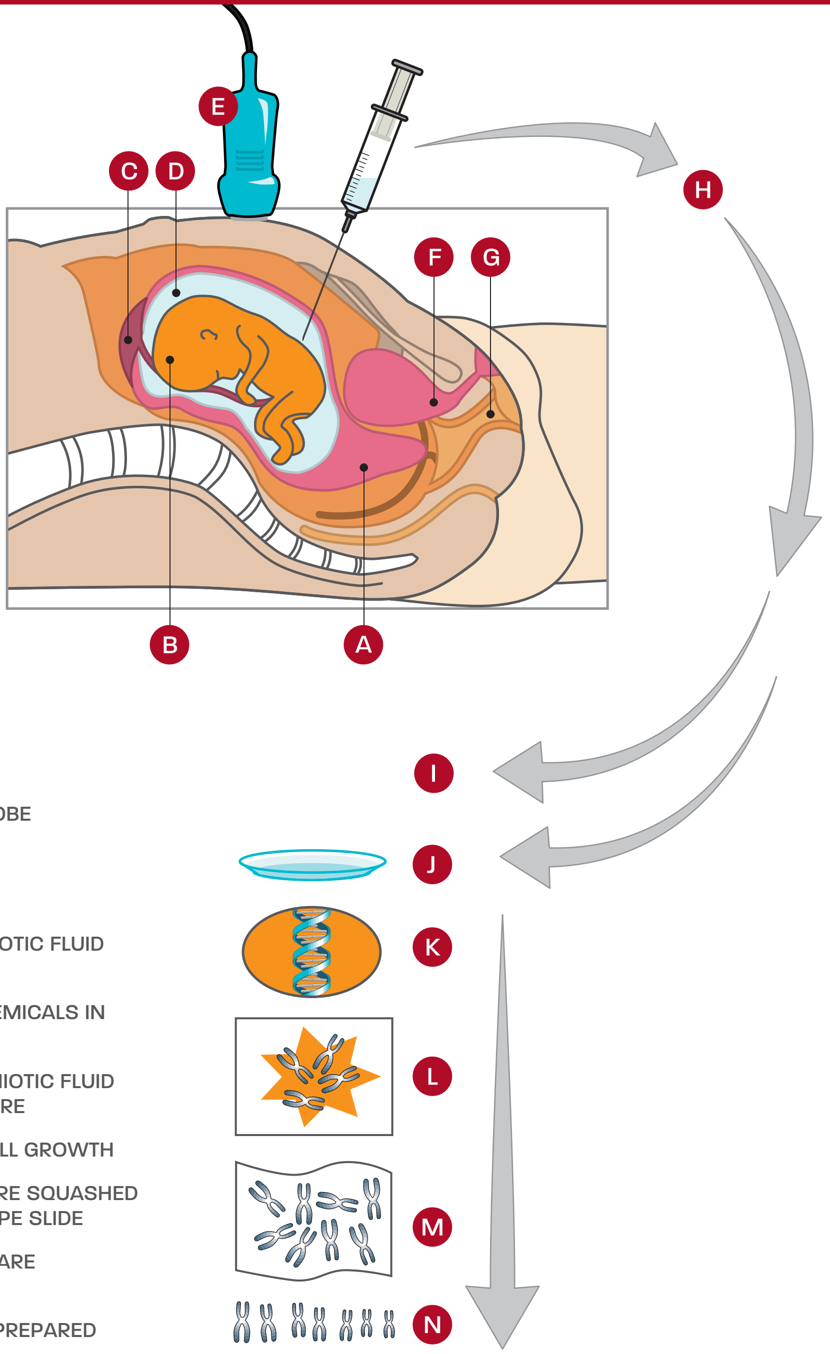
[1] Called Down's syndrome in British English.

AMNIOCENTESIS DIAGRAM



A	UTERUS
B	FOETUS
C	PLACENTA
D	AMNIOTIC SAC
E	ULTRASOUND PROBE
F	BLADDER
G	VAGINA
H	SAMPLE OF AMNIOTIC FLUID REMOVED
I	ANALYSIS OF CHEMICALS IN AMNIOTIC FLUID
J	CELLS FROM AMNIOTIC FLUID GROWN IN CULTURE
K	2-3 WEEKS OF CELL GROWTH
L	TREATED CELLS ARE SQUASHED ON A MICROSCOPE SLIDE
M	CHROMOSOMES ARE PHOTOGRAPHED
N	A KARYOTYPE IS PREPARED

Adapted from How Stuff Works

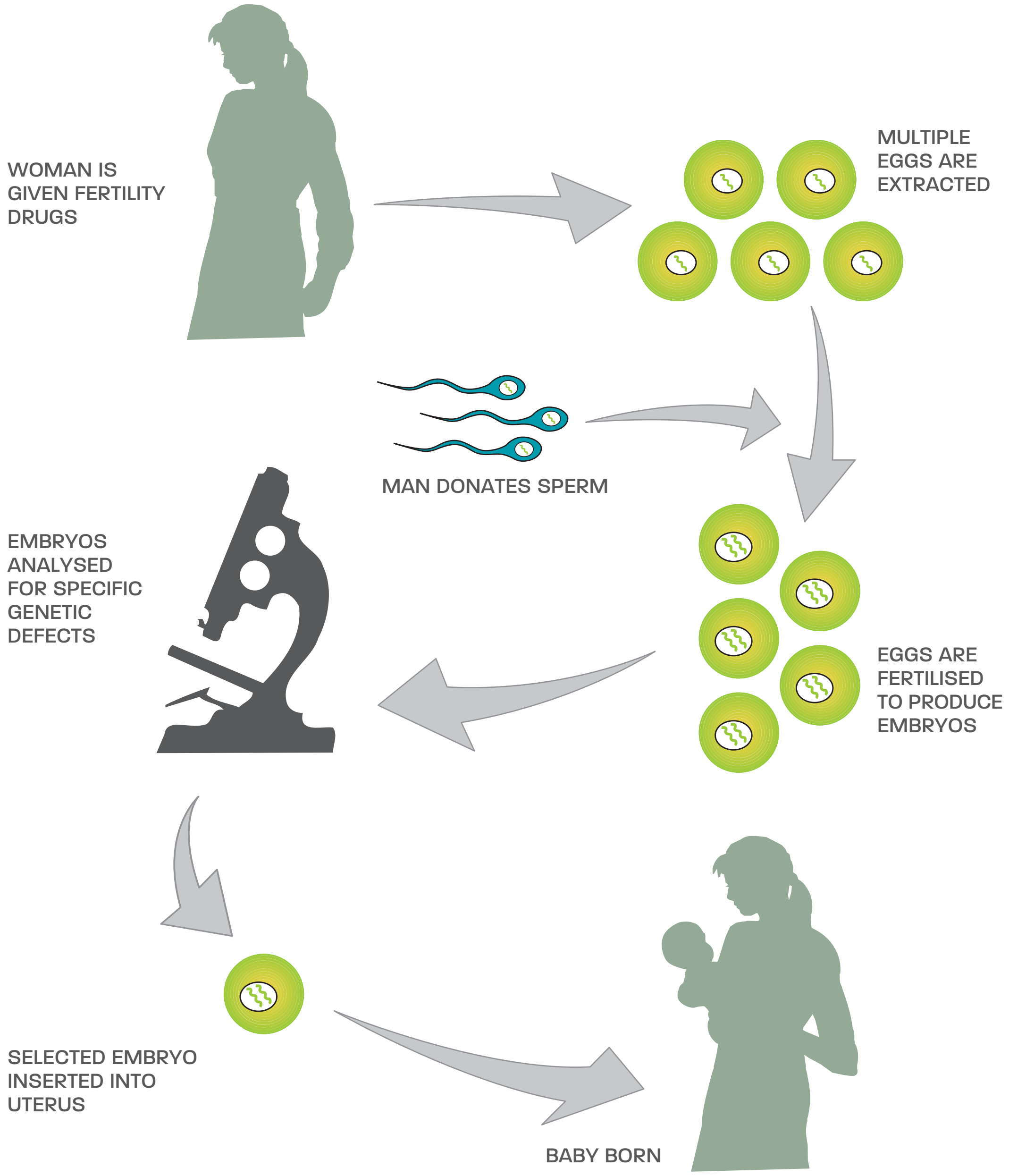
PREIMPLANTATION GENETIC DIAGNOSIS (PGD)

Before the 1970s, if people knew there was a genetic condition in their families which they did not want to pass on to their children, they had two choices: either not to have children or the woman would become pregnant then test for the condition. If the result was positive the woman or couple would choose whether or not to continue the pregnancy.

In 1978, Louise Brown was born, the first baby from an embryo created outside the mother using in vitro fertilisation (IVF). From then on, many more choices became possible. In the mid-1980s, research began in the United Kingdom to find out whether an embryo created through IVF could be tested using preimplantation genetic diagnosis (PGD) to diagnose genetic conditions. PGD involves removing one or two cells from a number of embryos and testing the cells for a genetic condition. Embryos free of the condition are chosen to be transferred to the mother.

As we understand more about genetics, more testing will become possible. Some tests will relate to medical conditions, while others might relate to other characteristics, such as height or eye colour.

PGD DIAGRAM



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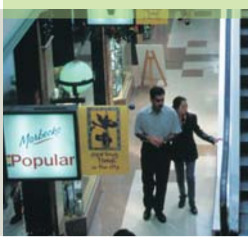

'SAVIOUR SIBLINGS'

Sometimes a sick child with a serious medical condition, such as certain blood conditions[2] can only be treated by using tissue which is matched to that child. If there is no matching donor available, parents might choose to use PGD for tissue typing to ensure that the new baby will be a genetic match to the sick child. The new child is sometimes called a 'saviour sibling'. Generally, the umbilical cord blood from the baby is used to treat the sick child.

Using PGD to have a 'saviour sibling' must be approved by an ethics committee on a case-by-case basis. The current guidelines state that:

- the sick child must suffer from a single-gene disorder or familial sex-linked disorder[3]
- the parents must only intend to use the cord blood of the saviour sibling
- there must be no other treatment available
- the embryo must be a sibling of the affected child.

At present in New Zealand PGO for tissue typing is only allowed if the sick child has a condition that the new baby might also inherit. Therefore there must be two purposes: to ensure that the new baby's cord blood will be suitable to treat the sick child; and to prevent the baby from inheriting the condition. It cannot be used to produce a 'saviour sibling' for a child with a condition that is not inherited, such as leukaemia. The New Zealand guidelines for the use of PGD are currently being reviewed by the Advisory Committee on Assisted Reproductive Technology (ACART).

WHAT ARE THE LEGAL LIMITS?

In New Zealand, the legal position relating to pre-birth testing is:

- testing may be carried out during pregnancy
- abortion is legal up to 20 weeks gestation if there is a serious danger to the mental or physical health of the mother or a substantial risk that the child would be seriously handicapped
- abortion is only permitted beyond 20 weeks gestation if it is necessary to save the life of the woman or prevent serious permanent injury to her physical or mental health
- PGD may not be used[4]:
    - for non-medical sex selection (such as parents who want to balance their families, by having boy/s and girl/s)
    - to alter the genetic constitution of an embryo
    - to select embryos with a genetic impairment seen in a parent
- PGD may be used in the following situations without ethics committee oversight:
    - a single-gene disorder has been identified in the family and there is a 25% or greater risk of an affected pregnancy
    - for sex determination if familial sex-linked disorders have been identified in the family and no test is available for the specific mutation
    - for familial chromosomal disorders if the disorder has been identified in the family
    - for non-familial chromosomal disorders if the woman is of advanced reproductive age, or has had recurrent implantation failure or miscarriage.

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[2] An example is Diamond Blackfan Anaemia (DBA), a blood condition caused by a failure within the bone marrow.

[3] A genetic disease is sex-linked, if a mutant gene is part of the X chromosome (females have two X chromosomes per pair of such sex chromosomes, males have an X chromosome and a Y chromosome). All male offspring are affected because the Y chromosome of the XY pair does not have a compensating normal gene. Because the mutation is on the X chromosome, however, and males transmit only the Y chromosome to their sons during fertilisation, males do not transmit the disease to male offspring but only to female offspring.

[4] Human Assisted Reproductive Technology Act 2004, s11.

As well, the disorder must be going to cause the child to be ‘seriously impaired’. The fertility clinic and a clinical geneticist must decide whether the disorder is likely to be serious.

- Any other uses of PGD must have ethics committee approval.

LET’S DELIBERATE!

Many families have been able to avoid having children who would suffer from painful, disabling or fatal conditions by using pre-birth testing. Some people have concerns about testing and there is significant disagreement about the best response to these concerns. This choicebook presents four main perspectives (called approaches), about how we, as a society, should deal with pre-birth testing.

Each perspective presents arguments supporting that approach and recommendations for specific actions. Each approach has advantages and disadvantages which are outlined in the ‘in support / in opposition’ boxes at the end of each section.

> At the end of this choicebook the approaches are presented to you side by side, so that you can compare the main points of each approach and consider how these views correspond to your own.

You do not have to select just one approach. In fact it is very likely that during discussions with other participants, you will find that there are aspects of other approaches that appeal to you. Using insights from a range of approaches is what deliberation is all about.

This choicebook is intended to encourage rewarding discussions between people about the issue of pre-birth testing. When we know what others believe about the issue, we can have reasoned respectful dialogue about how to best respond to the challenges and opportunities posed by pre-birth testing.

Approach one:
‘MY CHOICE MY RIGHT’

Deciding whether or not to have pre-birth testing and then deciding what to do in response to the results is regarded as a matter for the mother / parents. Nobody else should be able to interfere with these decisions. This approach promotes personal responsibility and the freedom to make our own choices.

Approach two:
‘LIFE IS A GIFT’

People who support this position would not allow any decision to destroy an embryo or terminate a pregnancy, because every embryo or foetus has a right to life. This approach suggests that when it comes to unborn children, we should interfere with nature as little as possible.

Approach three:
‘TANGATA WHENUA’

This approach holds that it is important that Māori values and the Treaty of Waitangi are taken into account appropriately. Efforts are needed to inform and empower Māori, to enable them to develop tikanga[5] about pre-birth testing and have these tikanga respected by health providers and scientists.

Approach four:
‘IT’S ABOUT INFORMATION, KNOWLEDGE AND THE PUBLIC’S INVOLVEMENT’

This means that better information about pre-birth testing needs to be widely available and in more accessible forms. The development of these resources needs to include people’s perspectives, interests and knowledge as well as medical facts.

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[5] For an approximation of the meaning of Māori terms, see the glossary on page 26.

LET'S NOW LOOK AT THESE APPROACHES IN MORE DETAIL

Approach one:
'MY CHOICE MY RIGHT'

Mothers / parents should have the right to decide:

- whether or not to use IVF with PGD in order to choose a particular embryo
- to select any embryo they wish to transfer to become pregnant
- whether or not to have screening and testing during pregnancy
- whether to continue or terminate a pregnancy.

Decisions whether to begin or continue a pregnancy involve the woman's right to control her own body, the father's interests, and the rights of the whānau / family. Mothers / parents are in the best position to know whether a decision is right for them and their whānau / family.

REPRODUCTIVE AUTONOMY

Current law and practice allows women / parents considerable freedom to make their own choices with regard to pregnancy.

Women / parents can generally choose whether or not to have screening, diagnostic tests or both, and decide whether or not to continue the pregnancy based on the results.

However, currently there are some limits on reproductive freedom:

- Using PGD for sex selection (choosing to have a boy or a girl by selecting a particular embryo) is prohibited unless it is done to prevent or treat a genetic disease. Supporters of approach one think that mothers / parents should be able to choose either a girl or a boy. Supporters argue that there is no noticeable preference for a particular sex in New Zealand, so allowing sex selection would make little difference to the overall number of boys and girls
- Women / parents can only use PGD to avoid a genetic condition if the fertility clinic, together with a clinical geneticist, decides that the child is likely to be seriously impaired. Supporters of approach one say that women / parents should be able to use PGD for whatever purpose they wish, as they are best equipped to decide what will be serious in their particular circumstances
- Use of PGD to create a 'saviour sibling' needs the approval of an ethics committee. Supporters of approach one say it is a private matter for them to decide, if they had a sick child and wanted to use PGD to select an embryo. They do not believe that an ethics committee should have the power to interfere in what is an intensely personal matter
- Another limit at present is that PGD may not be used to select embryos with a genetic impairment seen in a parent, for example, deaf parents who want a deaf child. Supporters of approach one say that if parents are using PGD they should be free to select whatever embryo they wish to transfer to the mother, even if the embryo carries some genetic condition. They point out that most embryos have some genetic differences and it is not always clear whether these will affect the child. They consider this is a choice that should be left to the women / parents.

Supporters of approach one: 'my choice my right' say that testing regimes cannot give us definite answers. There is always some level of uncertainty. Mothers / parents who support approach one say that they and their families are most affected and so they are in the best position to make these complex decisions. They do not accept that these are matters that should be controlled by the government or overseen by ethics committees.

HEALTHY CHILD

People supporting approach one: ‘my choice my right’ argue that most parents want a healthy child. They point out that it distresses parents if their child suffers pain, needs to undergo invasive medical treatments or may die. They say that parents are in the best position to assess whether they would have the financial and emotional resources to raise a disabled child. The considerable costs involved in supporting a child with a chronic illness or disability might include harm to parental well-being, employment, career, earnings, savings and relationships, including relationships with their other children.

LESS GOVERNMENT INTERFERENCE

Supporters of approach one: ‘my choice my right’ believe in the protection of individual rights. They believe that regulating reproductive decisions means that the government is eroding personal freedoms, allowing the government to increase its control over individuals. If the government regulates reproductive decisions, it disregards personal choice and personal responsibility by making the decisions for women / parents.

Supporters argue that if women / parents are able to pay for tests they should be able to have them. They point out that they would, in any event, be able to get any tests they want overseas. Some say that with unlimited choice mothers / parents should be personally responsible for funding the costs of the tests.

Public funding for the full cost of up to two cycles of IVF / PGD is available to people who use PGD to test for serious inherited genetic disorders. This funding includes the costs of the IVF treatment that must accompany PGD. Government funding will be around $500,000 per year in total.

PGD may also be used to detect chromosome disorders associated with advanced maternal age or infertility, although this use of the screening is not publicly funded. The Ministry of Health expects nearly 150 cycles of IVF / PGD to be carried out in New Zealand each year, of which 40 will be to detect serious inheritable genetic disorders.

WHAT CAN BE DONE?

- remove all restrictions on PGD, pre-birth testing and abortion.

For and against the approach 'my choice my right'

In support:

- this approach places all decision making in the hands of mothers / parents
- it allows parents to engage in collective decision making with family / whānau if they wish
- it acknowledges that parents are the best people to decide whether they can cope with a child (or further children) with a disability
- it ensures that no one set of values is dominant
- it reduces state involvement in people's personal lives
- it allows people to make their own personal and financial decisions.

In opposition:

- parents' reproductive autonomy should not be unrestricted
- every embryo and foetus has a right to life
- decisions about pre-birth testing / screening do not only affect the mother / parents. Many individual choices can have a cumulative effect on society
- if the condition is not serious or would not develop until after childhood, the right to use PGD or to terminate pregnancy should be restricted
- people should not be able to select against embryos or terminate pregnancies if the condition is likely to be able to be successfully treated
- individuals don't always have the wisdom to make good decisions
- this approach is not fair or equitable as many families do not have the resources to meet the full costs of these forms of testing.

Approach two: 'LIFE IS A GIFT'

For people who support approach two: 'life is a gift', life is not something we should be trying to control. Trying to control the sort of babies we have interferes with what is natural and could have unintended and unwanted consequences.

The 'life is a gift' approach says we should be developing ways to make sure all children have the best chance to reach their potential. This can be achieved by supporting parents and caregivers. This approach would embody our most important values: love, respect for all human life, and care of our most vulnerable people.

Supporters of approach two: 'life is a gift' say that pre-birth testing is based on an assumption that the life of a person with a disability has less value than the life of a person who does not. They are concerned that screening and testing will reduce the overall numbers of people with disabilities.

People who support approach two may think it immoral to discard embryos or abort foetuses on the basis of pre-birth tests. This might be because they believe embryos and foetuses have souls.

It could also be based on what they say is a 'biological fact' – that at conception, when the two halves of the human genetic material combine, a new individual is formed with its own unique DNA, and organised development begins.

Some think it's wrong to destroy embryos and foetuses because they have a right to life, the same rights as any person. From this perspective, destroying an unborn child is the same as murder.

Some view pre-birth testing in terms of the context that God made us and the world around us. For people who believe this, pre-birth testing goes against what is God-given.

Supporters of approach two: 'life is a gift', sometimes describe pre-birth testing as a 'search and destroy mission' because the underlying assumption of testing is that affected embryos or foetuses will be destroyed.

Some people say this bias is built into our medical systems and is reflected in the fact that in New Zealand today mothers / parents choose to abort over 90% of the foetuses that test positively for Down syndrome.

Some people fear that testing foetuses for conditions such as Down syndrome in national screening programmes would be a form of eugenics. These sorts of programmes are likely to significantly reduce the number of people in our society with conditions such as Down syndrome.

Another concern is that pre-birth testing interferes with Nature and could result in unintended and unwanted consequences. For example, pre-birth testing could reduce the genetic diversity of the human species.

Not all pre-birth tests are completely safe. For example, amniocentesis can cause infections and miscarriages. Some people question whether removing 1 or 2 cells for PGD from a 6- or 8-cell embryo might harm it.

Recent research indicates that embryos might not implant as well in a woman after PGD. It is not yet known whether there will be longer-term impacts, so the results of this 'experiment' won't be known for a generation or two.

For many people, there is more to human 'health' than medical conditions. More broadly, 'health' includes factors such as society's attitudes to disabled people and about how we think about bringing children into the world.

WHAT CAN BE DONE?

Supporters of the 'life is a gift' approach generally favour the following actions:

- allow testing that benefits the mother or helps parents prepare for a child, as long as embryos are not discarded and foetuses are not aborted
- require that every IVF embryo be transferred into a women's uterus at some stage, with the intention that it will implant and develop into a baby
- review the capacity of the support services for people with illnesses, diseases and physical disorders
- provide adequate government support and funding to people who care for disabled persons
- provide adequate levels of government-funded respite care to family members who care for disabled relatives
- provide the infrastructure so that disabled people can participate fully in our society.
- provide opportunities for people to develop the ability to make moral judgements about complex issues.

For and against the approach 'life is a gift'

In support:	In opposition:
• this approach emphasises the need to promote and preserve the most positive human values of love, respect for all human life, and care of our most vulnerable people • this approach recognises that embryos and foetuses have a right to life • it prevents pre-birth testing being used for eugenic purposes • it would maintain the diversity of our community • diversity is more important than financial considerations • this approach recognises the worth of people with disabilities.	• why wouldn't we try to prevent children being born if they are going to suffer or die young? • caring for disabled children can be stressful for parents and has caused relationships to break up • if more severely disabled people are born, more care will be needed • we can't ignore the financial cost of caring for more disabled people • pre-birth testing is routinely available overseas: why shouldn't New Zealand parents be able to make the same choices? • more restrictive grounds for abortion may increase the number of 'back street' abortions.

Approach three: 'TANGATA WHENUA'

This approach requires that the government work with Māori to ensure that the Treaty of Waitangi principles are applied to pre-birth testing.

The principles of partnership, protection and participation require that the specific needs of Māori are met and that Māori values are taken into account. Adequate resources must be available to inform and empower Māori, so they can develop tikanga and matauranga about infertility and pre-birth testing.

> Core values for Māori are whānaungatanga, hapūtanga, iwitanga and tino rangitiratanga[6].

TIKANGA

- many Māori believe that social pressures and expectation are slowly breaking down cultural values
- tikanga relevant to pre-birth testing include whakapapa, tikanga mauri, whenua, hapū.

More needs to be done to engage Māori at iwi level, with more time and assistance made available, so that iwi can develop tikanga about pre-birth testing. This would require the development of a resource, using language and concepts that are meaningful to Māori, and having it delivered in a culturally appropriate manner. Then kōrero over time would lead to the development of tikanga.

Ma te tika te pono me te aroha

IT'S ABOUT WHĀNAU

Māori people have many different views on pre-birth testing. Some people do not wish to undergo any testing at all. In whānau with serious genetic conditions, some people have chosen to use testing to avoid the birth of children with the condition, while others have decided to continue the pregnancy even though they know the child will have the condition. Mana whānau reflects the importance of pre-birth testing for some whānau.

Many Māori see these decisions as being matters for the whānau to decide rather than individual decisions being made by the mother / parents, because the decisions may affect future generations.

Even if an individual makes a decision which is different from what the whānau wanted, the whānau will usually accept the decision and support the whānau member. Māori value the support that the whānau can provide. Manaakitanga has been described as nurturing relationships, looking after people, and being very careful about how others are treated. This is consistent with respect for their mana, personal authority or dignity.

Support for whānau includes ensuring provision of sufficient support for whānau with disabled children and the need to have access to affordable services.

Naku te rourou nou te rourou ka ora ai te iwi

RISKS

Pre-birth testing is more than just a medical matter and the effects may be different from those intended. There is a need to consider the risks from pre-birth testing. This includes risks to whakapapa and the risk of discrimination against others, particularly people with disabilities.

Some people say that tests should not be used to reinforce stereotypes and prejudices. For example, although there is not yet a known genetic basis for homosexuality, there is concern that, in the future, testing may be used to discriminate against homosexual people.

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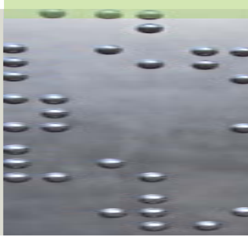
[6] For an approximation of the meaning of Māori terms, see the glossary on page 26.



‘Warrior gene’ research

In 2006, the monoamine oxidase-A gene was widely reported in the media as being associated with risk-taking and aggressive behaviour in Māori. Commentators expressed concerns about whether the participants in the research, and the research ethics committee, were aware that the research included the exploration of hypotheses linking the ‘warrior gene’ with violent and antisocial behaviour, and that generalisations were to be made from the research participants to the entire Māori population.

There are risks that tissue or blood might be misused. In traditional Māori culture, body parts separated from the body were accorded a ceremony similar to a tangi. Māori need to know that they have the right to have their tissue / blood returned to them or destroyed after testing. It is important the tissue / blood is stored or used for research only with appropriate consent.

He tapu te tangata ahakoa ko wai

BETTER INFORMATION

Whānau with known genetic conditions must have access to culturally appropriate genetic counselling and information. This will allow them to talk about and decide whether they wish to use PGD and/or testing during pregnancy.

Māori women and communities need to know why it is good for them to see a health practitioner early in pregnancy for general health care as well as having options about pre-birth testing. This information needs to come from health professionals, community leaders, churches and Māori agencies, as knowledge will help dispel fear.

Te manu i kai te matauranga nona to ao

Information given before screening and testing should be supportive, relevant to the needs of the woman / whānau, easily understood and available in te reo Māori.

It’s not just the information that is important, but also who gives it and how it is given. Information should be given at the right moment when the women / whānau are ready to hear it. There should be enough time to understand and think about the information and the choices that might have to be made.

Te kai o te rangatira he korero

RESEARCH

Māori want the opportunity to shape the direction of research which uses their genetic material. This could be achieved by Māori having leadership roles in research teams, backed up by genuine kōrero between researchers, funders and Māori research subjects.

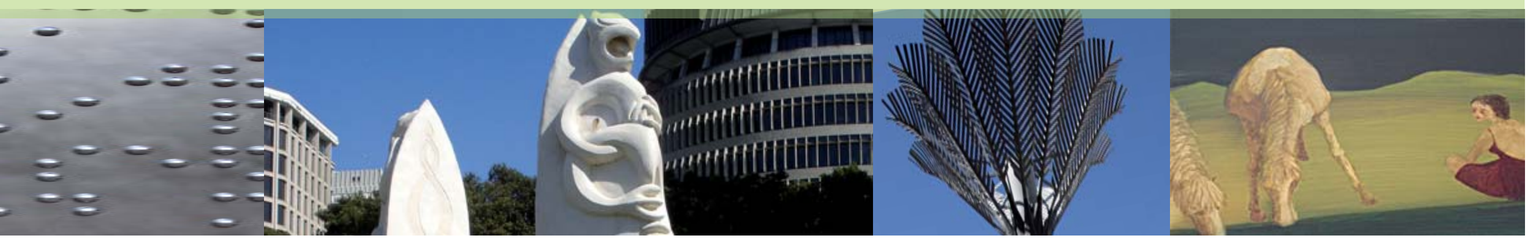
Māori must be able to protect their cultural practices and their tikanga *and* participate fully in New Zealand society *as Māori*. This can only occur if they are able to exercise tino rangatiratanga in relation to their values and cultural practices. With regard to proposed research this means, that there must be dialogue about what problems we are trying to solve and what sort of world we are trying to create.

There is also concern that some research into genetic conditions affecting Māori might not benefit them. For example, the commercialisation of genetic tests might make them unaffordable for some whānau.

ACCESS

Many Māori women miss out on the first trimester screening tests, because they begin their antenatal care after the 14th week of pregnancy. There are many reasons for this, such as:

- Lead Maternity Carers are not funded to provide care for pregnant women until the second trimester, and many do not sign a care plan until the 14th week of pregnancy. This does not stop a woman from visiting her GP or receiving advice from her midwife, but the system might discourage some women from early care
- if their Lead Maternity Carer of choice is fully booked there might be delays in finding another



- women who have had a child may feel that they do not need to attend as early because they already know what to expect during pregnancy and childbirth. They might also have difficulty arranging childcare in order to attend antenatal care
- women are more likely to begin antenatal care late and attend less often, if their pregnancies were unplanned, they had a negative reaction to the pregnancy, or they were not employed prior to pregnancy.

In addition, many Māori women who receive a positive result from a pre-birth test might not be referred for suitable counselling and support services. This is because there might be limited availability of clinical genetic services or because some medical professionals and Māori families do not know about the existence of these services.

WHAT CAN BE DONE?

- involve iwi, hapū and Māori organisations when developing policy and setting priorities with respect to pre-birth testing
- produce relevant, appropriate information about pre-birth testing, genetic counselling and care during pregnancy
- provide fully funded pre-birth testing which is available to all women / whānau who choose to have testing
- provide adequate support for Māori women / whānau whatever choices they make in response to the results from pre-birth testing. This includes adequate support for families with disabled children
- ensure that tissue and blood may not be retained or used for research without specific informed consent
- if research uses Māori genetic materials, iwi, hapu and individuals must be made fully aware of the purpose of the research and its potential harms and benefits before the research begins. Ethics committees must be satisfied that this will happen before they approve the research project.

For and against the approach: 'tangata whenua'

In support:

- the Crown will comply with its obligations under the Treaty of Waitangi to actively protect the social, economic and cultural well being of Māori
- Māori women / whānau will be able to make more informed choices
- access to all antenatal care by Māori women would be improved
- whānau with genetic diseases will have choices and be supported whatever choice is made
- there will be less chance that Māori will be the subjects of research and yet be denied the benefits of that research.

In opposition:

- Māori might benefit from more than a fair share of the limited resources available
- who speaks for the unborn child / foetus?
- the money used for new technologies such as PGD might be diverted from more common healthcare needs, such as treatment of diabetes which particularly affects Māori.

Approach four:

'IT'S ABOUT INFORMATION, KNOWLEDGE AND THE PUBLIC'S INVOLVEMENT'

WHO SHOULD HAVE A SAY?

Most mothers in New Zealand undergo some pre-birth tests. These, together with ante natal care, have become a routine part of helping ensure the health of the baby and the mother. Most pregnancies progress without any problems being detected and the use of pre-birth testing has provided millions of women / parents with a sense of security concerning the future health of their children.

However, the outcomes are not always so straightforward. Pre-birth tests like blood tests, scans, amniocentesis or pre-implantation genetic diagnosis do sometimes detect conditions such as Down syndrome, cystic fibrosis and spina bifida. These conditions could have a devastating effect on the child and the parent(s).

Not everyone who finds out that there is a problem will choose to terminate the pregnancy. Supporters of approach four: "it's about information, knowledge and the public's involvement" believe that it is very important, whatever the outcomes of the test might be, that there is no pressure, intended or not, for women or parents to follow a particular course of action. For example, some people who find out that their baby will have Down syndrome choose to have the child; pre-birth testing gives them the opportunity to prepare for that child.

However, they also say more needs to be done to inform parents about pre-birth testing and this information needs input not just from health professionals but from women, parents and communities.

We all expect when we have a medical test, even a routine one, that the medical professional will get our consent. We also expect that we will be given information about any possible side effects, the accuracy of the test and what the possible courses of action might be if the test shows there is something wrong. In other words, knowing about the test helps us to make an informed choice whether or not to have it and what the implications might be. As the saying goes "knowledge is power".

In order to make a choice once you have the results, you need more than just medical information. For example, most people have limited experience of what might be involved in caring for a person with a disability.

People need to know what is involved in looking after a child with a disability and what is available to support the family. Before making their decision they should have the opportunity to discuss all the implications with experts and also with parents who have cared for children with similar disabilities.

Supporters of approach four: 'it's about information, knowledge and the public's involvement' acknowledge that information regarding pre-birth testing is available from a variety of different sources. However, they think that not everyone gets the information they need.

Many women might have early tests, such as blood tests, without realising that the information from these might lead to decisions about further tests. Ultimately, they might have to decide whether or not to terminate a pregnancy. So it's important that people are aware of the implications of routine tests.

As we discover more about genetics and are able to develop more tests, the range of decisions that parents have to make will increase.

PRE-BIRTH TESTING IS MORE THAN JUST SCIENCE AND TECHNOLOGY

This approach involves more than just providing good medical information consistently throughout the country, although this is very important. Approach four maintains that information and knowledge about pre-birth testing can lead to complex, difficult and

emotionally painful decisions. It's important therefore to be in a position to take all the factors into account. The medical facts alone are not enough.

> GP and mum Sarah Buckley explains: "Some women are definitely grateful for the opportunity to terminate an affected pregnancy, but for other women the pain of choosing to terminate a pregnancy can take years to resolve."

People favouring approach four want the government to ensure there is adequate funding to ensure that all women / parents have access to consistent, high-quality information and that there are enough well trained, experienced people available to answer any questions and concerns women / parents might have. These concerns may well go beyond medical issues.

CULTURAL ISSUES

Too often ordinary people's experience, knowledge and wisdom aren't taken into account. Information may be written and delivered in a way that doesn't take into consideration different cultures, languages and levels of understanding. For example, Māori, Pacific and Asian peoples have particular information needs and their communication needs may require specific knowledge.

From the perspective of approach four: "it's about information, knowledge and the public's involvement" important aspects that must be taken into account when thinking about pre-birth testing are:

- who is involved in developing the information
- how it is presented
- who presents it
- when the information is given.

Some people are concerned that current knowledge about pre-birth testing is dominated by the medical profession, fertility clinics and drug companies. This needs to be addressed by providing much greater public input into developing resources and information that meets people's needs.

TRUST

Some people question whether the advances in pre-birth testing are primarily intended to benefit families, or whether profit is the dominant motive.

They say pre-birth testing is big business involving multi-national companies, the medical profession, fertility clinics and the research industry. They say that people developing tests must work with members of the community to build trust so that the public is confident that the interests of families come first.

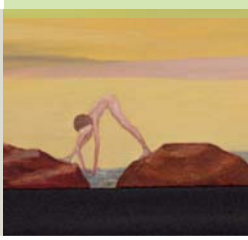
MORE TESTS, BUT NO EASY ANSWERS

Many more tests are being developed for detecting illnesses, diseases and disorders and as our knowledge of genetics is improving we can test for more genetic conditions.

Also improvements in ultrasound technology mean that we can detect more abnormalities. Despite these advances in testing, we cannot yet treat or cure many of these conditions.

The results from the tests are not always conclusive. Just because people carry a particular gene does not always mean that they will suffer from the condition. Even if they do suffer from the condition you cannot tell how severe the condition will be or when it will develop.

Some conditions, such as cancers, might be able to be treated, but the treatment is unpleasant and there is no guarantee of a cure. This uncertainty might put people in a very difficult situation when they are faced with deciding whether or not to continue with the pregnancy.



It is possible to use genetic tests to detect conditions that develop after infancy. These are called **late-onset** conditions. Some people are concerned about this because the person might have a good life until the disease occurs and by then a treatment may be available.

Tests for genetic susceptibility to diseases like hereditary breast cancer also cause concern because there is no guarantee that the disease will develop. This is called **low penetrance**.

INTO THE FUTURE

More information might be available from testing in the future, and people might have to make even more difficult decisions. Many of us have heard the phrase ‘designer babies’, the idea that we might be able to ‘dial-up’ whatever kind of child we want. At present this isn’t scientifically or technically possible; you are stuck with the genes you inherit from your parents. However, in the future we might be able to modify embryos to choose certain features or characteristics, for example a child with blue eyes and dark hair who would be a world-class high jumper.

Should this ever be possible it might change our way of thinking about what it means to be human and have serious societal effects. Questions that affect all of us include who should make the decisions and whether or not we should move in this direction. Therefore, we all need to be fully informed about developments in this area. The concerns, interests and values of ordinary citizens need to be at the forefront of decision making.

WHAT CAN BE DONE?

- provide the same level of information and make it available throughout the country
- information about pre-birth testing needs to include the cultural, ethical and spiritual aspects of testing and its implications, as well as medical facts
- families and communities need to be involved in the development of information about pre-birth testing
- provide suitably trained people who are able to answer any questions and concerns about pre-birth testing
- ensure the public is involved early in the process of decision making and policy formation about future developments.

For and against the approach ‘information, knowledge and public involvement’

In support:

- it’s not possible to make informed decisions unless you have access to the information you need
- decisions about whether to test and what to do about the results involve more than just medical matters. Consideration of the emotional, cultural, spiritual, ethical and moral issues are just as important
- the implication of these technologies affect us all so it’s important that different members of the public are involved in developing the types of information to be made available
- citizens must be involved in decisions about how far these developments should go in light of future possibilities
- if a range of different people are involved in developing information resources on pre-birth testing, this will ensure that the information reflects the needs, interests and values of communities.

In opposition:

- plenty of information on pre-birth testing is already available
- people have access to this information so there is no need to use resources which could be better spent in other parts of the health system where the needs are greater
- there aren’t enough interested people available who would be willing to get involved in developing the information
- anyway, who would decide which members of the public would be involved? You could never include everyone
- more information would not necessarily make it easier to make decisions. The results may only say that there is a possibility of a problem – in which case some people would rather not know
- if pre-birth testing is more widely discussed this could lead to conflict within some cultural and ethnic groups.

So what's the issue,

what can be done, and what are the arguments against each approach?

Pre-birth testing has become a routine part of a woman's pregnancy, while the use of PGD (although much less common) is increasing. Depending on where developments lead to, PGD could, in the future, be as much in demand and as routine as scans, blood tests and amniocentesis are today.

To help citizens consider the issues concerning pre-birth testing, this choicebook considers the issues from four different perspectives, and suggests approaches by which the issues might be resolved.

Each approach offers a different diagnosis of what's important. Each provides a direction for public action. This section of the choicebook places the approaches side by side to help you compare and consider them.

APPROACH ONE:
'My Choice My Right'

Mothers / parents should be able to make their own decisions about reproduction. We will all benefit if individuals are left to make up their own minds about very personal and private issues such as pre-birth testing. Mothers / parents are in the best position to know what their best interests are and what is best for their child. If we allow the government to regulate reproductive decisions, this will lead to erosion of our personal freedoms and will allow the government to increase its control over individuals.

WHAT CAN BE DONE?

- remove all restrictions on PGD, pre-birth testing and abortion.

IN OPPOSITION:

- parents' reproductive autonomy should be limited
- every embryo and foetus has a right to life
- decisions about pre-birth testing / screening do not only affect the mother / parents. Many individual choices can have a cumulative effect on society
- if the condition is not serious or would not develop until after childhood, the right to use PGD or to terminate pregnancy should be restricted
- people should not be able to select against embryos or terminate pregnancies if the condition is likely to be able to be successfully treated
- individuals don't always have the wisdom to make good decisions
- this approach would not be fair or equitable.

APPROACH TWO:
'Life Is a Gift'

People shouldn't have the right to discard embryos or abort foetuses on the basis of pre-birth tests. Instead, we should focus on ways to make sure all children have the best chance to reach their potential. Doing this would mean paying serious attention to our most important values: love, respect for all human life and care of our most vulnerable people. Trying to control our babies' characteristics interferes with what is natural and could have unintended and unwanted consequences.

WHAT CAN BE DONE?

- allow testing that benefits the mother or helps parents prepare for a child, as long as embryos are not discarded and foetuses are not aborted
- require that every IVF embryo be transferred into a women's uterus at some stage with the intention that it will implant and develop into a baby
- review the capacity of the support services for people with illnesses, diseases and physical disorders
- provide adequate government support and funding to family members who choose to care for disabled relatives
- provide adequate levels of government-funded respite care to family members who choose to care for disabled relatives
- provide the infrastructure so that disabled people can participate fully in our society
- provide opportunities for people to develop the ability to make moral judgements about complex issues.

IN OPPOSITION:

- why wouldn't we try to prevent children being born if they are going to suffer or die young?
- caring for disabled children can be stressful for parents and has caused relationships to break up
- if more severely disabled people are born, more care will be needed
- we can't ignore the financial cost of caring for more disabled people
- pre-birth testing is routinely available overseas: why shouldn't New Zealand parents be able to make the same choices?
- more restrictive grounds for abortion may increase the number of 'back-street' abortions.

APPROACH THREE:
'Tangata Whenua'

It is crucial that when it comes to pre-birth testing, the needs of Māori are met and Māori values are taken into account. This means that the government must work with Māori to ensure that the Treaty of Waitangi principles of partnership, protection and participation are applied to pre-birth testing. Māori must have access to adequate resources to inform and empower them, so they can develop tikanga and matauranga about infertility and pre-birth testing.

WHAT CAN BE DONE?

- involve iwi, hapū and Māori organisations when developing policy and setting priorities with respect to pre-birth testing
- produce relevant, appropriate information about pre-birth testing, genetic counselling and care during pregnancy
- provide fully funded pre-birth testing which is available to all women / whānau who choose to have testing
- provide adequate support for Māori women / whānau whatever choices they make in response to the results from pre-birth testing. This includes adequate support for families with disabled children
- ensure that tissue and blood is not retained or used for research without specific informed consent
- iwi, hapū and individuals must be made fully aware of the purpose of research and its potential harms and benefits
- ethics committees must ensure this before approving research proposals for research using Māori genetic materials.

IN OPPOSITION:

- Māori may benefit from more than a fair share of the limited resources available
- who speaks for the unborn child or foetus?
- the money used for new technologies, such as PGD, may be diverted from more common healthcare needs which particularly affect Māori, such as treatment of diabetes.

APPROACH FOUR:
‘Who Should Have a Say?’

For most mothers / parents pre-birth testing is just a routine part of pregnancy. However, the reason for screening and testing is to find out whether there are any abnormalities in the foetus or embryo. If there are, parents might suffer anxiety and will need to make informed decisions about what to do. In other words, pre-birth testing always has potential implications. This being the case, the government needs to provide people with clear and relevant information about pre-birth testing. The information needs to reflect not only ‘facts’ but also the kinds of cultural, ethical and spiritual issues which might help people come to terms with such potentially difficult decisions. It is equally important to make sure that a wide range of people have input into any information so that it reflects their experiences, needs and knowledge.

WHAT CAN BE DONE?

- provide consistent information about pre-birth testing, which must be made available throughout the country
- information about pre-birth testing needs to include cultural, ethical and spiritual aspects as well as medical facts
- families and the public need to be involved in the development of information about pre-birth testing
- provide suitably trained people who are able to answer any questions and concerns about pre-birth testing
- ensure communities are involved early on in policy and decision making about future developments.

IN OPPOSITION:

- plenty of information on pre-birth testing is already available
- people can find all the information they need for themselves, so there is no need to use resources which could be better spent in other parts of the health system where the needs are greater
- there aren’t enough interested people available who would be willing to get involved in developing the information
- anyway, who would decide which members of the public would be involved?
- more information would not necessarily make it easier to make decisions
- if pre-birth testing is more widely discussed, this could lead to conflict within some cultural and ethnic groups.

Glossary

These are an approximation of the meaning of the Māori expressions used in this document – rather than a translation.

Hapū	Pregnant or subtribe
Hapūtanga	Pregnancy or subtribal
Iwi	Tribe
Iwitanga	Tribal
Kōrero	Discussion, debate
Mana	Status, dignity, pride
Matauranga	Knowledge
Mauri	Life force
Tangata whenua	People of the land (indigenous inhabitants/native people)
Tangi	Funeral, to cry
Te reo	Language
Tikanga	Custom, rule
Tino rangitiratanga	Independence
Whakapapa	Geneology
Whānau	Family
Whānaungatanga	Familial relationships
Whenua	Land

Toi te Taiao:
the Bioethics Council

Toi te Taiao: the Bioethics Council was established by the Government in 2002, following a recommendation of the Inquiry on Genetic Modification. Its purpose is to consider the cultural, ethical and spiritual issues raised by biotechnology. In this role Toi te Taiao: the Bioethics Council provides information, promotes and participates in public discussion and gives advice to government.

Join the discussion

Toi te Taiao: the Bioethics Council wants to hear from a wide range of New Zealanders. Your thoughts, feelings and questions are valuable.

Stay in touch with **Toi te Taiao: the Bioethics Council** - by visiting our website. Register your interest and we'll let you know about our activities and publications.

To have your say about pre-birth testing:

- **Visit the web site**
- **Join the pre-birth testing on-line deliberation**
  This runs from late October 2007. To register, log on to http://nzbioethics.dialoguecircles.com/
- **Check the newspapers and major magazines** for coverage of issues related to pre-birth testing.

For general information, web links, resources and the latest news, visit www.bioethics.org.nz the Bioethics Council's website

www.bioethics.org.nz

Pre-birth testing project
Toi te Taiao: the Bioethics Council,
PO Box 10362, Wellington 6036.

newzealand.govt.nz