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Who Gets Born?

A report on the cultural, ethical and spiritual aspects of pre-birth testing by Toi te Taiao: the Bioethics Council

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Letter from the Chair / He reta nā te Tiamana

It is with much pleasure that Toi te Taiao: the Bioethics Council presents the Associate Minister for the Environment with this report into the cultural, ethical and spiritual aspects of pre-birth testing.

Pre-birth testing includes common blood tests and scans, amniocentesis, and pre-implantation genetic diagnosis (PGD). The guidelines governing PGD are currently being considered by the Government, so it is timely for us to make recommendations in this area. But all forms of pre-birth testing, including tests that will in time be invented or become accessible, can raise difficult cultural, ethical and spiritual questions. That is why our focus in this report is broader than PGD alone.

The recommendations we present here are those of Council members, but they have been informed by the views of New Zealanders. As in our previous work, we have engaged in nationwide public deliberation. This time, we have pioneered methods, like the online choicebook and deliberative forums, that are new in this country. We wanted to encourage people to think through the consequences of their choices as well as to share their experiences and views with Council members and each other. We realise that this is not easy, and that we are privileged that so many New Zealanders were prepared to do so thoughtfully and passionately. We are most grateful to them. It is clear to us that policy-makers can learn a great deal from the public when it has the time and information to deliberate.

Toi te Taiao: the Bioethics Council has great satisfaction in presenting the Minister, and the people of New Zealand, with *Who Gets Born? A report on the cultural, ethical and spiritual aspects of pre-birth testing.*

Tēnei a Toi te Taiao: the Bioethics Council te tāpae atu i tēnei pūrongo mō ngā āhuatanga ā-ahurea, ā-matatika, a-wairua hoki mō te whakamātau i te kōhungahunga i te whare tangata, ki mua i te aroaro o te Minita Tuarua mō te Taiao, i runga i te ngākau hari.

Ko ētahi o ngā whakamātautau i te whare tangata ko ngā whakamātautau noa o te toto me ngā matawai, te wero i te kahu, me te whakamātau ira i mua i te whakatōkanga (PGD). Kei te whakahoutia ngā aratohu e pā ana ki te whakamātau i mua i te whakatōkanga e te Kāwanatanga, nā reira e tika ana kia whakaputaina e mātou ō mātou whakaaro mō tēnei kaupapa. Engari, ahakoa i tēhea whakamātautau i mua i te whānautanga, tae atu ki ngā whakamātau meake nei ka hangaia e hinengaro tangata, ka wātea ake rānei i roto i ngā tau, tērā tonu ōna pātai nunui mō te taha ki ngā āhuatanga ā-ahurea, ā-matatika, a-wairua hoki. Koia i whānui kē atu ai tā mātou titiro, i tēnei pūrongo, i te whakamātau i mua i te whakatōkanga anake.

Ko ngā kupu tohutohu ka horaina atu nei e mātou, nā mātou anō, engari nā ngā whakaaro o ngā tāngata takitini i Aotearoa i whai kiko ai. I runga anō i ngā tikanga o ō mua mahi, kua hoki anō ki te iwi ki te whakawhitiwhiti kōrero mō te kaupapa. I tēnei wā kua whakaurua mai ētahi tikanga hou, pēnei i te pukapuka-kōwhiri ā-ipurangi, ā, he mea hou tērā tonu i tēnei whenua. I te hiahia mātou kia whai whakaaro te tangata mō te hua o ō rātou whiringa, me te whakawhitiwhiti mō ō ratou wheako, tā rātou titiro hoki ki ēnei take, ki ngā mema o te Kaunihera, otirā ki a rātou anō. Ehara i te mahi māmā, engari me mihi anō ki a rātou mō rātou i māia ki kawe i te kaupapa, ki te whakaputa hoki i ō rātou whakaaro. E kore e mutu te whakamoemiti atu ki a rātou. He mārama tonu ki a mātou he nui te akoranga ka hua ake i te iwi whānui, mehemea ka tukuna kia āta kōrero mārire mō tētahi kaupapa, otirā ki te whakawhitiwhiti whakaaro.

Tēnei a Toi te Taiao: the Bioethics Council te tāpae atu i tēnei pūrongo Who Gets Born? mō ngā āhuatanga ā-ahurea, ā-matatika, a-wairua hoki mō te whakamātau i te kōhungahunga i te whare tangata, ki mua i te aroaro o te Minita Tuarua mō te Taiao, i runga i te ngākau tatū.

Dr Martin Wilkinson
Chair/Tiamana
Toi te Taiao: the Bioethics Council

Executive summary

During pregnancy, a woman and/or her unborn baby may undergo tests for various reasons. The term 'pre-birth testing' applies both to relatively common antenatal procedures, such as ultrasound examinations, and also to more specialised tests, such as those used to detect rare genetic conditions or illnesses. Another kind of pre-birth testing is preimplantation genetic diagnosis (PGD), where cells from embryos created outside a woman's body through *in vitro* fertilisation (IVF) are tested for certain conditions and illnesses.

Some forms of pre-birth testing are already commonly used in New Zealand. Certain emerging forms of pre-birth testing, particularly those involving PGD, are not yet permitted here. Others are permitted only with oversight by the government-appointed Ethics Committee on Assisted Reproductive Technology (ECART). New guidelines covering the use of PGD are currently being developed.

Meanwhile, the range of conditions and illnesses that can be tested for is expanding all the time. Overseas, the uses of PGD (potential and actual) are broadening as knowledge of genetics develops.

In light of these developments, important questions arise. How far might we go with pre-birth testing? What might the consequences be? Who decides whether to test a foetus, and in what circumstances? Who decides what to do once test results are known, and what choices are acceptable?

These questions are not only for the medical and scientific communities: they have significant cultural, ethical and spiritual dimensions that concern us all. During 2007 and early 2008, Toi te Taiao: the Bioethics Council talked with New Zealanders to find out what they thought about pre-birth testing. What we heard, together with the results of the Council's own research and deliberations, are presented in this report. It has two major components:

What the Bioethics Council heard (Sections 3 and 4)

These sections reflect the views of New Zealanders about pre-birth testing – its benefits, disadvantages, costs and consequences – and the administrative and legislative framework governing its use. The particular responses of Māori, and the world view which commonly underpins those responses, are reflected in *E kore au e ngaro he kākano i ruia mai i rangiātea: Māori deliberations on pre-birth testing* (Section 4).

The Bioethics Council's thinking (Section 5)

In this section, we reflect on what we heard and make recommendations to Government in key areas including:

- the challenges of decision-making about pre-birth testing
- the need for equitable access to testing for all New Zealanders
- the need for high-quality, appropriate and diverse information about pre-birth testing for parents and the wider community
- the need for people with disabling conditions (including those detected through pre-birth testing), and their families, to be supported
- the need for an administrative and legislative framework that can respond to new and challenging developments in PGD in ways that balance individual freedoms with wider cultural, ethical, spiritual and social concerns.

This report is the result of an innovative public deliberation process, outlined in Section 2. This was the first time Toi te Taiao: the Bioethics Council had used deliberation (rather than dialogue) to engage the public, and we found it extremely positive and productive. People came together face-to-face or online to identify the issues raised by pre-birth testing, to reflect deeply, to explore their own and others' thinking, and to develop common ground that could form the basis of future policy.

The rich, dynamic and thoughtful nature of these exchanges is reflected here in the many quotes and personal stories. We thank all those who participated, and whose views and experiences have helped shape this report.

The Bioethics Council's Working Group on pre-birth testing comprised Rosemary du Plessis (chair), Helen Bichan, Peggy Fairbairn-Dunlop, Waiora Port, Brett Stephenson and Huia Tomlins-Jahnke. They were assisted by John Pennington, Cordelia Thomas, Moana Sinclair and Simon Wright of the Bioethics Council's Secretariat, and by Margot Schwass, writer and editor.

1. Introduction

1.1 What is pre-birth testing?

The term 'pre-birth testing' covers a wide range of tests that are available to a woman and/or her unborn baby before and during pregnancy. Pre-birth tests extend from the simple urine test that is commonly used to confirm pregnancy, to ultrasound examinations that check foetal development, to sophisticated processes such as amniocentesis and chorionic villus sampling (diagnostic tests that can indicate whether an unborn baby has an abnormality or genetic condition, such as Down syndrome or cystic fibrosis).

One rapidly developing form of pre-birth testing associated with *in vitro* fertilisation (IVF) is preimplantation genetic diagnosis (PGD). This involves testing one or two cells from embryos that have been created outside the mother's body, with the aim of identifying certain medical conditions. An embryo without those conditions is selected and transferred to the mother, while affected embryos are discarded. Pregnancy then proceeds as normal. PGD only became possible with the development of *in vitro* fertilisation in the late 1970s, which allowed embryos to be successfully created outside a woman's body. It has since become one of the more challenging forms of pre-birth testing, raising many cultural, ethical and spiritual questions that will become more insistent as PGD grows increasingly common.

The regulatory framework

In New Zealand, it is legal to carry out pre-birth testing during pregnancy. If an impairment is detected as a result, the parent(s)[1] may decide to terminate the pregnancy. If so, the normal legal requirements for abortion must be met.[2]

The use of PGD is governed by the Human Assisted Reproductive Technology Act 2004 (the HART Act). Under the Act, certain reproductive technologies are prohibited. Some are permitted (known as 'Established Procedures'), while others require oversight by a government-appointed Ethics Committee (ECART).[3] Currently, PGD is not permitted:

- for non-medical sex selection (such as the parent(s) wanting to balance their families by having a boy or a girl)
- to alter the genetic constitution of an embryo
- for purposes that are not for the prevention or detection of a genetic disorder, such as to select embryos with a genetic impairment seen in a parent.[4]

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[1] In legal terms, this is ultimately a decision for the mother. However, in this report – while recognising that some women do not have a partner and so may make such decisions alone – we use the term 'parent(s)' to acknowledge the role of fathers when reproductive decisions (including those about pre-birth testing) are made.

[2] These requirements are set out in the Crimes Act 1961.

[3] Under the Act, policy decisions are developed by the Advisory Committee on Assisted Human Reproduction (ACART) while ECART considers applications to use technologies or undertake research on a case-by-case basis.

[4] From 'Guidelines on PGD', issued by the National Ethics Committee on Assisted Human Reproduction (NECAHR) in March 2005 and approved by the Minister of Health. These guidelines expired in November 2007, but were extended while ACART undertook further work.

The following uses of PGD are permitted without Ethics Committee oversight, providing the disorder is going to cause the child to be 'seriously impaired':

- where a single-gene disorder has been identified in the family and the risk of an affected pregnancy is 25 percent or greater
- 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.[5]

All other uses of PGD, such as its use to create a child who is genetically matched to a sick brother or sister, require approval by the ECART.

The uses of pre-birth testing: current trends

Ultrasound examinations are a very common form of pre-birth testing, and are carried out for many reasons such as confirming due dates, stage of development or abnormality. In 2004, around 91 percent of mothers in New Zealand had an average of 2.1 ultrasound examinations during their pregnancy.[6] However, 13.3 percent of Asian mothers and 13.1 percent of Pacific mothers had no ultrasound examinations.[7] As over 60,000 babies are born in New Zealand annually, this means that several thousand do not have ultrasound screening each year. The reasons for this are unclear.

The Ministry of Health expects nearly 150 cycles of IVF/PGD will be carried out in New Zealand each year. Of these, 40 will be to detect serious inheritable genetic diseases and will be funded by the Government. The remainder are paid for by the individuals concerned.

ECART has not reported any applications to use PGD to create a baby whose umbilical cord blood could be used to treat a sibling suffering from a serious illness or disorder, sometimes referred to as a 'saviour sibling'.[8] There are only a few conditions for which this is possible, so this use of IVF/PGD is likely to remain very uncommon.

1.2 Why discuss pre-birth testing now?

The desire to have a healthy baby is universal among expectant parents. But views are mixed on the extent to which pre-birth testing helps – and should be allowed to help – achieve this outcome.

Pre-birth testing has allowed many families to avoid having children who suffer from painful, disabling or fatal conditions. For others, it has given them time to adjust to the knowledge that their baby may be born with a disability or medical condition. On occasion, testing can make pre-birth treatment possible.

But certain forms of pre-birth testing are controversial. Some pose risks for the foetus; in particular miscarriage may occur when chorionic villus sampling or amniocentesis are used. The results of some tests can be unreliable or open to different interpretations. The knowledge that an unborn baby may have a disability or serious medical condition can be enormously distressing for parent(s) and families. So too can the prospect of terminating a pregnancy, or discarding embryos with particular genetic conditions. Some people are totally opposed to the use of PGD to create what have been called 'saviour siblings' (see above). Some see the potential for PGD to be used for non-medical reasons (such as sex selection) as equally unacceptable.

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[5] Human Assisted Reproductive Technology Order 2005 Schedule, Part 2.

[6] Ministry of Health, 2007. Report on Maternity: Maternal and Newborn Information 2004, p25.

[7] Statistics on Māori mothers are not available.

[8] ACART Annual Report 2006/2007, p13.

Government keeps a close eye on all emerging reproductive technologies and public attitudes to them, locally and overseas. Pre-birth testing is no exception. In countries such as Australia and the United Kingdom, PGD is now being used for reasons other than the prevention of fatal or seriously disabling conditions – for example, to select embryos that are free of certain treatable conditions or problems that may not emerge until later in life ('late onset' conditions, such as Alzheimer's and Huntington's). Other genes tested for may only suggest the child will have a predisposition to a condition: such 'low penetrance' conditions include cancer or high blood cholesterol levels.

Toi te Taiao: the Bioethics Council recognises that the public controversy generated by such uses is likely to be duplicated in New Zealand. It is therefore important to consider the question: should PGD be expanded in these directions here – and if not, why not?

There are other reasons to talk about pre-birth testing now. The legislative and policy framework is under regular review to ensure it can respond to new developments and pressures: the previous guidelines on the use of PGD, for example, expired in November 2007 and decisions on new guidelines have not yet been made.

Meanwhile, concerns have been raised in some quarters – including by the Ministry of Health's National Screening Unit – that some women may be undergoing unnecessary amniocentesis screening for Down syndrome, sometimes resulting in the miscarriage of unaffected foetuses.[9] The Screening Unit has recommended to government a range of improvements to the screening process.

Government funding of PGD is another issue to be considered. Currently, most New Zealanders using PGD pay for it themselves: public funding is available only to those wanting to test for serious inherited genetic disorders. But the number of people wanting access to PGD for other reasons – such as to detect conditions linked to advanced maternal age such as aneuploidy (structural chromosomal abnormalities), or conditions associated with infertility – is likely to grow. There may well be demand for PGD to receive considerably more public funding than the $500,000 currently allocated each year.[10]

For all these reasons, this is a good time for New Zealanders to think and talk about pre-birth testing in general. Toi te Taiao: the Bioethics Council decided that the discussion should include, but not be confined to, PGD as it remains relatively rare in New Zealand. On the other hand, many New Zealanders have personal experience of the more routine forms of pre-birth testing (such as ultrasound scans) and are thus better prepared to discuss the broader implications of these tests.

In 2007, the Bioethics Council decided to initiate discussion of the cultural, ethical and spiritual aspects of pre-birth testing, and to make recommendations based on what it heard.

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[9] Ministry of Health. 2007. *Antenatal Down Syndrome Screening in New Zealand 2007: A Report of the Antenatal Down Syndrome Screening Advisory Group to the National Screening Unit.* Wellington: Ministry of Health.

[10] Hon. Pete Hodgson, 'Funding to screen for serious genetic conditions,' media release, 12 December 2005 (available at http://www.beehive.govt.nz/release/funding+screen+serious+genetic+conditions, accessed 9 April 2008).

2. Deliberating about pre-birth testing: a new approach

2.1 About deliberation

The world over, there is a trend to greater public participation in government decision-making. In our own country, legislation such as the Resource Management Act 1991, the Local Government Act 2002 and the Human Assisted Reproductive Technology Act 2004 require mandatory public input into a wide range of government activities. As citizens, we have come to expect – and demand – a voice in policy decisions that affect us.

Traditionally, public participation has taken the form of consultation. Experts and policy-makers identify issues and develop questions; members of the public are invited to respond to these agendas through written or oral submissions to commissions, select committees or panels.

In recent years, new approaches have emerged which more actively involve the public in setting the parameters of the discussion and framing the issues under scrutiny. Rather than being the subjects of consultation, ordinary citizens are able to participate in *deliberation* with decision-makers and other members of the community. Deliberative events are conversations in which citizens define and shape the issues, and listen to the arguments of others – as well as saying what they think.

The importance of active public participation in policy decisions involving science, including biotechnology, is being increasingly recognised. But how might effective engagement between the non-specialist public and the world of science be achieved? In the past, the engagement has often been one way. Policy-makers have assumed that, by arming the public with scientific facts, people will be better equipped to understand (and perhaps embrace) new technologies. However, as ongoing public resistance to developments such as genetic modification suggests, the mere availability of information does not in itself generate greater understanding, let alone acceptance.

The need for better forms of communication and exchange about new technologies and their uses has become increasingly clear. Not only do ordinary citizens have the right to express their views about developments that affect them, but they can also offer insights and knowledge that complement and enlarge the knowledge of experts. Science and technology are not just specialist and technical forms of knowledge – they have social, cultural and spiritual dimensions as well, which need to be reflected in policy decisions.

For all these reasons, *public deliberation* has emerged as one of the most effective ways for decision-makers, experts and the public to approach especially challenging problems, including those linked to biotechnology. While it has much in common with *dialogue*, deliberation goes beyond it. Deliberative forms of engagement require people to do more than express their views. They have to explore and compare a range of viewpoints or approaches, and find courses of action that work in the best interest of many different people. Some other essential features of deliberation are:

- It begins from a different starting point than traditional forms of consultation, where experts or policy-makers frame the issues they believe to be important and present them to the public. In deliberation, the beliefs, concerns and values of the public are used, firstly, to frame potential options and then, to determine the best course of action.
- Participants in deliberation have to weight the benefits and the consequences of these potential options.
- Participants usually progress from a stance based on personal experience and opinion, to judgments based on a wider range of information, experience and argument. In deliberation, people talk *through* a problem, rather than talking *about* it.

- Deliberation promotes civic involvement and responsibility.
- It can increase trust between the public and decision-makers/government agencies.
- It can produce a unique form of non-expert or 'socially constructed' knowledge that synthesises a range of viewpoints and experiences.
- It can turn personal opinion into sound public judgment.

In other words, a deliberative approach has the potential to produce better, longer-lasting and wiser policy decisions.

Toi te Taiao: the Bioethics Council considers that the public deliberative approach used to produce this report could be a model for government agencies interested in involving citizens in the development of public policy and regulation in many different fields.

> "Briefly put, deliberations aren't just discussions to promote better understanding. They are the way we make the decisions that allow us to act together. People are challenged to face the unpleasant consequences of various options and to 'work through' the often volatile emotions that are a part of making public decisions.
>
> "Some say the biggest benefit is that [deliberative] forums help people get a handle on complex public policy issues or understand different points of view before they act. Others say participation makes them feel less isolated, more a part of a community, more disposed to join together in civic action. Still others say that years of forums have changed the way their communities approach decision making and problem solving. Repeated deliberation, they report, changes people, and that gives them the confidence that they can eventually change their communities."
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> Kettering Foundation, *Making Choices Together: The Power of Public Deliberation,* Dayton, Ohio: October 2003, p4.

2.2 The Bioethics Council's use of deliberation

In 2007, the Bioethics Council decided to use a specific set of deliberation processes to engage the public in its work on pre-birth testing. Based on the National Issues Forums approach, we followed a three-stage process. (For more about the process – including full details of when and where deliberative events were held, how they were conducted and who took part – please see Appendix B and C. A diagram showing the key stages in the process is in Appendix A. Readers may also refer to the Council's evaluation reports, available at www.bioethics.org.nz).

Stage 1: Framing the issues

To inform the Council's thinking, we read widely in the subject, conducted a literature review and were briefed by experts. Then we interviewed 11 people with significant expertise and experience in various fields related to pre-birth testing. These 'key thinkers' remain anonymous. All these resources contributed to our understanding of the issues and resulted in a brochure outlining pre-birth testing's important scientific, cultural, ethical and spiritual aspects.

To begin engaging the public, everyone on the Bioethics Council's mailing list was invited to register their interest. A wide range of government and non-government organisations were also asked to publicise the project. A brochure was prepared outlining the scope of the topic, and sent to anyone willing to attend a day-long 'framing' meeting in their town or city[11] where the issues involved in pre-birth testing would be identified or framed. These people also received a questionnaire to gather the views of friends, family and colleagues.

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[11] The brochure is available at www.bioethics.org.nz

Fifty-six participants – most of whom had interviewed at least five other people beforehand – then attended what were referred to as ‘framing days’. Six were held around the country during July and August 2007, including a hui for Māori and a Pacific fono. The goal of issue-framing is to bring ordinary members of the public together, so they can create a document that expresses the basic concerns behind the way people see an issue.

Four distinct approaches emerged from the participants’ discussions; approaches that reflected different and competing ways of dealing with pre-birth testing. The issues associated with all four were presented in a document known as a Choicebook; it also contained background information on the scientific, ethical and social aspects of pre-birth testing, targeted at laypeople.[12]

Stage 2: Deliberative events[13]

The Council recruited people for a series of face-to-face deliberative events around the country, identifying potential participants with help from NGOs, organisations and community groups with an interest in pre-birth testing and also using the Council’s own databases. In some areas, participants self-selected by responding to newspaper advertisements.

Eighteen events were held, including four hui and a Pacific fono. In total, 256 people attended. More than 80 percent were women. Many participants were involved in the health or disability sector in some way, either as professionals or volunteers. Many were parent(s) or grandparents, including of children with disabling conditions, while others had particular concerns about child disability. A high proportion had strong pro-life views, usually associated with Christian beliefs, and some were affiliated to pro-life groups. A small number were teachers in the area of biology, and a smaller group comprised students.

Each event lasted three hours and was guided by an independent facilitator; Council members also attended. Participants worked their way through the Choicebook, discussing the advantages, disadvantages and consequences of each approach. They were encouraged to examine positions different from their own views, and to identify any common ground for policy recommendations. Sometimes, groups found it easy to make explicit recommendations; at other times, this was more difficult and discussion focused mainly on people’s responses to issues posed by the different approaches to pre-birth testing.

Some groups did not finish working through all the approaches. This was the case with the Pacific fono, where both the process and the subject matter were unfamiliar to some participants. Consequently, this event was devoted more to awareness-raising than policy development, and would perhaps have worked best as an initial (and very valuable) stage in a two-stage process.

Online deliberation

From November 2007 to February 2008, people could also take part in online deliberation. This enabled a broader mix of people to participate, contribute and develop recommendations for future policies. It also provided a mechanism to get feedback on the face-to-face events. The online interactions were designed to closely mirror those events.

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[12] The Choicebook is available at www.bioethics.org.nz

[13] For more details on the deliberative events and who participated, see the evaluation report by the Centre for Research, Evaluation and Social Assessment (CRESA) at www.bioethics.org.nz. A summary of the key findings from the CRESA report can also be found in Appendix C of this document.

Before they deliberated online, people were asked to complete an online version of the Choicebook; 406 began doing this and 281 completed all the questions. Participants also contributed more than 60 personal stories and ideas about pre-birth testing, while 58 people took part in three online deliberation groups – moderated online conversations that aimed to further explore the issues and approaches presented in the Choicebook in a similar way to the face-to-face deliberative events. Those who participated in the online processes were recruited by several methods, including high-profile advertisements on the TradeMe website. The online deliberation was hosted by Ascentum's dialoguecircles.com platform, an internet-based toolkit that has been custom-built for online deliberation.

After the online deliberative phase ended, the Bioethics Council asked Ascentum to prepare an independent report analysing the online deliberation methodology and the nature of the public's participation, and summarising the input collected. It is available in full on www.bioethics.org.nz, while a summary appears in Appendix B.

Stage 3: Evaluation

The pre-birth testing project showed that the engagement generated through deliberative methods is different from that created by traditional forms of public participation. Clearly, deliberation has an important part to play in a continuum of possible participatory techniques.

This section summarises the many valuable lessons about deliberation that have emerged from our work on pre-birth testing. As well as Council members' own thinking, it also reflects the independent evaluation undertaken by the Centre for Research, Evaluation and Social Assessment (CRESA), which examined and commented on the deliberative project before it even began. CRESA staff then observed several framing events and public deliberations, distributed questionnaires to participants, analysed their responses and conducted follow-up phone interview for the framing events.[14]

Key lessons:

- While few participants changed their thinking about pre-birth testing, they did acknowledge some shifts in outlook – more compassion for people facing difficult decisions associated with pre-birth testing, more openness to the views of others (although this did not necessarily mean willingness to change their own), and a greater interest in public dialogue in general.
- Participants rated the planning and principles underpinning the deliberative events highly, and were very positive about representation at the events, their lack of bias, clear purpose and resourcing. They said the events provided the chance for open and free discussion, and allowed them to meet interesting and diverse people. However, some expressed frustrations about time constraints, the structure or facilitation of events, and a lack of diversity in some groups.
- Despite the 'newness' of deliberation as a public participation tool, participants were clearly enthusiastic to be involved. As well as being keenly interested in the topic of deliberation, pre-birth testing, they had also become interested in the deliberative process itself. Some compared it favourably with other public consultation processes they had been involved in, and said deliberation was a better way to get the public involved in decision-making about important issues.
- Participants considered that there was room for those managing and facilitating deliberation to develop their skills and understanding of the process.
- The evaluators noted that the capacity of the public to participate in such events also needed to be developed. They said that both goals could be achieved with more opportunities to tackle public issues through deliberation, and with tangible evidence that the effort is worthwhile.

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[14] The CRESA evaluation is available in full on www.bioethics.org.nz, and its summary and conclusions appear in Appendix C.

- Recruiting participants for deliberative events is challenging. In some locations, we struggled to attract sufficient numbers. Recruiting Māori and Pacific participants, and people from new migrant communities, was a particular challenge. Placing newspaper advertisements helped with recruitment, but we found that self-selected participants were less willing to take up the central challenge of deliberation – to confront their own values and views, and explore those of others. Community groups were extremely helpful in recruiting participants, but there are questions about whether this approach achieves sufficiently diverse representation.
- The majority of participants were women. With the face-to-face events, this was doubtless influenced by the timing of sessions (daytime) and the fact that many participants were recruited via community organisations in which women are especially active (kindergartens etc). But it also suggests that pre-birth testing may be seen by many in the community as primarily a 'women's issue'.
- We found the online deliberation forums attracted participants who had not previously been involved with the Bioethics Council. Placing advertisements on TradeMe generated considerable interest. Women were again in the majority. Participation in online deliberation is most available to people who have access to computers and familiarity with accessing information online.
- Many participants in the face-to-face events felt the time allowed was too brief, especially for exploring the trade-offs inherent in various approaches. We noted a difference with the online forums where, over several weeks, participants' positions and attitudes visibly moved. However, even here participants felt frustrated by time constraints: "I feel like I've gone to a concert and left just after the warm-up act and before the main performance – it would be great to do more work on this somehow," said one contributor.
- More work needs to be done on finding ways to capture and report on the richness of the face-to-face discussions. Asking participants to write down the results of their discussions did not always capture the detail and depth of group discussions.
- Participants and those running deliberative events need good information, both about the topic under discussion (material presented in everyday language that is still technically accurate) and about the deliberative process itself. Facilitators need to have a good understanding of the principles of deliberation, and must be able to adapt and use them in a range of situations.

2.3 Four approaches to pre-birth testing

To encourage New Zealanders to discuss pre-birth testing, the Bioethics Council developed a Choicebook reflecting the values, interests and concerns raised by participants in the framing exercises. The Choicebook set out four approaches to the issue, which provided the starting point for the deliberations.

The four approaches are not exclusive or absolute – an individual may be attracted to aspects of several approaches or to a single approach in its entirety. They simply represent four different ways of thinking about pre-birth testing that reflect the interests, concerns and motivations of the participants.

The approaches are summarised below, together with a selection of comments that show how a particular group of participants approached and explored each of the four approaches. These conversations have been selected not so much for *what people said* as for *how the discussion unfolded over time*. They are effectively snapshots of the deliberative approach in action – people adopting new perspectives as they become more comfortable with each other, asking questions, considering the benefits and tradeoffs that various positions entail, and having their own thinking challenged, modified and enlarged.

One: *'My choice, my right'*

This approach holds that only the parent(s) of an unborn baby should decide whether to have pre-birth testing, and what to do in response to the results. Nobody else should be able to interfere with these decisions, including government and ethics committees. This approach promotes personal responsibility and the freedom to make personal choices. It calls for the removal of all restrictions on PGD, on pre-birth testing in general and on the decisions made as a consequence of testing.

Talking about 'My choice, my right' (snapshots from a deliberation)

Jonathan

As I mentioned in my previous post, I have been a paraplegic since birth. The reason why I support approach one is that I believe that parents are in the best position to judge for themselves whether or not they [can] manage with a child with some form of disability or illness; after all it is the family who are left with the consequences of their decision.

However, there are downsides to this approach as well. There is a risk that parents put themselves first and decide simply on a whim not to proceed because it is easier and they would rather not have the hassle which could result in children with disabilities been denied the chance of having a go at life. At its most extreme, a situation could arise where people with disabilities are weaned out of society through the use of this technology commonly known as eugenics.

Kelly

Jonathan raises some important considerations, and I agree with him. Raising an individual with a disability or medical condition can be at times very overwhelming, but equally can be the most incredible experience you'll ever encounter. The most valuable things in this approach I feel is to be in control of your own life, to be able to make decisions that directly impact on you – but in order to do this you need full information. Experiences that are important for this approach might be knowing of others raising children with 'difference' and understanding the costs to yourself may be too high... The flipside to this is that, as Jonathan says, we will end up denying individuals of 'difference' to be born. But how many parents are told 'yay, you are going to be giving birth to a child with multiple challenges?'

Brett

I think I agree that parents must have reproductive choice; that how their bodies are 'used' is up to them. They should be able to decide whether to have children or not and when to have them or not. But what seems to be left out is the child. Does the child have a choice? What on earth does that mean? If the child does have a choice in some way (and I think it does) then, as the child cannot speak for itself, who will speak for it? And how do you speak honestly for an unborn child? So yes, I agree that parents must have the choice, it is their life – but it is also the life of the child, isn't it?

Nicci

Jonathan's earlier comment about a society weeding out disabled people pre-birth is something I'm not sure is realistic (I don't wish to offend you Jonathan, just express my view). I knew no-one with disabled children, so my own personal society was disabled-people free. Yet I was prepared to have one, if not two, disabled children rather than none [Nicci had twins, and declined amniocentesis because of the risk of miscarriage]. But I fully agree with your key point: it was my choice to make that decision. I'm just not sure how much society pressure really does infiltrate into such a personal choice. But I guess it is hard to say one way or another because of the subtle and variable factors that influence our decision-making.

Sam (moderator)

Thanks Jonathan, Kelly, Nicci and Brett for grappling with the initial questions on what supporters of Approach 1 would find valuable... A number of costs/consequences have also emerged:

- the possibility of eugenics
- this approach does not give the unborn child a 'say' in the decision or address how the child's 'voice' could be represented
- an Approach 1 policy and new technologies may change our conception (no pun intended) of having children. Children may become commodities rather than humans
- some people do not want to make such hard choices and would prefer someone else (anybody) to do it for them.

Nicci

Sorry, I'm not wanting to be dismissive of those who have raised concerns about forms of eugenics. I accept that the way my comment was written it did sound dismissive, and I apologise. I wanted to raise the general point that we shouldn't ban a good thing because of fear of a bad consequence. Of course, the best way to bring in anything which has a potential for bad consequences is exactly the sort of discussion and consensus building we're trying, and it can be useful to raise a hypothetical bad consequence in order to test ideas against.

Two: *'Life is a gift'*

People who support this approach oppose abortion or the destruction of embryos because they believe every embryo or foetus has a right to life (whether on religious or other grounds). Moreover, they say that pre-birth testing is founded on the assumption that the life of someone with a disability has less value than the life of someone who does not. This approach suggests that when it comes to unborn children, we should interfere with nature as little as possible – including natural genetic diversity.

Supporters say pre-birth testing should not be permitted at all, or only if it does not lead to abortion or the destruction of embryos. Other actions favoured by this approach include increasing support for people with disabilities and their families, and more education/information to better equip people to make complex moral judgments.

Talking about 'life is a gift' (snapshots from a deliberation)

Monique

Obviously this issue resonates with me personally, and I must admit I have an extreme position on the view that Life is a Gift. I find it hard to see the My Life My Choice point of view, but do enjoy robust debate and am glad to be able to participate.

Nicci

Hi Monique... I think your situation is a great example of some of the issues this discussion will be examining. What do you [do] when you're faced with risk factors, but no certainty about whether they will eventuate...

For this approach is the careful consideration that is being given to the right of the pre-born to experience the life it has now has the potential to develop. Against this approach is that quality of life is not a factor, simply life itself. A society based on this approach may well grapple with issues of overpopulation (all pregnancies must be completed, and possibly all those who can get pregnant should be encourage to do so), as well as resource deprivation.

> ***Monique***
> I'd just like to note this process is great, as it gets you to examine not just oppositional approaches, but examine the values you hold dear yourself.
>
> I hold the 'life is a gift' view through my life experience, logical processes and some scientific theorising. I believe that life begins at conception, and acting to terminate this process is the taking of life, and should be done only in the most extenuating of circumstances. I do not say never, because some conditions are so grievous, the baby cannot survive till birth, or the process endangers the mothers life. I do not have any particular religious affiliation, and it probably says a lot about the Christian/women's lib influence overshadowing any such debate that I feel I have to note that...

> ***Brett***
> An amazing post, Monique, thanks. I agree and I don't. Or perhaps I share your uncertainties.

> ***Kelly***
> I wouldn't class myself as extremely pro-life nor am I extremely pro-abortion/termination... I am quite a post-structuralist/modernist (i.e. I view life in many shades of grey; not just one defining way). And I guess my experiences as a nurse and my personal experience of raising a child with a disability has shaped this... I think I sit a bit on the fence with this approach.

> ***Ben***
> Monique – full credit to you for putting your beliefs out there. And personally, as a rabid atheist (born and raised), even more cred for having your 'pro-life' opinions outside of a religious context. ...I believe that Life is a gift, it really is. And I'm very much all in favour of letting people live (ie pro life/living). However there are some fundamentally flawed areas of this policy.

> ***Nicci***
> Thank you everyone for sharing on what is possibly the most controversial of the approaches and the hardest to make recommendations on. I think my recommendation on Approach 2 would be 'status quo' re abortion - and you've already heard my thoughts on making PGD available to IVF parents with a failed pregnancy history. Along with that I would recommend the parents are able to choose which, if any, embryos go back and which if any, are carried to term.
>
> I think this forum is working well for this approach – there is something about the anonymity of it that makes it much easier to 'listen' to what people are saying rather than have assumptions (based on age, gender, race etc) infiltrate your thinking as can happen when you try to dialogue face-to-face. I think people are being very responsible with their postings, and trying hard to focus on the issue, not just their viewpoint.

Three: 'Tāngata whenua'

This approach says that it is important that Māori values and the Treaty of Waitangi are part of New Zealand's policies on pre-birth testing. It also calls for Māori to be better informed about the issue so they can engage with it, develop appropriate tikanga, and ensure these tikanga are respected by health providers and scientists.

This approach says Māori must be involved in developing policy and information resources. It calls for Māori women to have better access to pre-birth testing and to antenatal care in general, and for more meaningful participation by iwi, hapū and individuals in research projects that use their genetic material.

Talking about 'Tāngata whenua' (snapshots from a deliberation)

Mihi

Kia ora everyone, my perspective is primarily Tangata Whenua which compliments that of other indigenous global values. I am not an expert by any sense of the word but i have a strong aversion to western medical practises and quite frankly the advancement of science scares me a lot. However, i am certainly open to new ideas and concepts .... I agree with Melanie that education is pertinent for intending parents and that it is also important that children are informed of the responsibilities and consequences of pending parenthood.

Ultimately i believe it is the mothers choice to continue or terminate pregnancy, but of course there are many issues whereby that decision may be taken out of their hands and for good reason. And Jen you give me good reason to re-consider my perspective ... [although] my heartfelt response is to say NO to all testing where one can mess with/determine genealogy (whakapapa).

Where do we draw the line for pre-birth testing? Do we draw a line? This primarily is what we're being asked to deliberate. How can one measure the pain of the woman who is unable to conceive a healthy foetus to one who seeks only a son or a daughter, for reasons that genuinely create valid anxiety. Why should one take preference over the other and how do we measure this? In the case of the saviour sibling if technology allows us to detect one disease why not all?

Many women are choosing not to have children ... there are so many other factors out there that contributes to this choice. Personality, global activity such as war, extreme poverty, disease and the impact on the infinite number of children being born into this kind of environment weighs heavily on a woman's decision. The requirement for pre-birth testing doesn't even feature.....

Apart from the legal requirement to consult with Tangata Whenua i believe that many are of the mind that traditional values of Maori have a positive influence in establishing our uniqueness as a country ...

At the recent public deliberation i attended the discussion for the most was in favour of pre-birth testing, the concern was for the management and disposal of foetal matter, blood, samples etc and lack of information thereof.

Nicci

The benefit of this approach is that it takes a holistic view. The pre-born is not just a son or daughter, but also a grandson, grand-daughter, niece, cousin or nephew. It considers the impact on the mother and the child together in the context of the effect on the family. It implies that the parents and child and perhaps family must be consulted at each stage of their decision-making. For example, if the mother gives blood from her and the baby to be used for screening test, does she then get consulted about what happens to the blood? I suspect that supporters of the Tangata Whenua approach would say that she should.

Marilyn

I empathise strongly with the tangata whenua approach because it involves the whole of society taking note of where we've come from, as well as where we're headed... I also think this is very much a 'New Zealand' way – we actually do operate quite differently from lots of other cultures in my experience...

Nicci
I'm going to move onto the problems. The mother, who ultimately is legally responsible for the child, and its upbringing, will have little or no say in the decision if the family decide to over-rule her. The family may offer support, but not provide it. The mother, for extremely legitimate reasons, may not trust the family and yet is being forced to co-operate with them... [With this approach] where do you draw the line? What if you have made a decision as a whanau and other members of your hapu hear about it and want you to change your mind? What about the women's privacy? Once she informs the family of the pregnancy, where are the lines to be drawn around that. Do they have access to all the same information she does?

Kelly
I agree that these are the real tensions surrounding this approach. As I've said, the collective versus the individual can ultimately cause dissention. I have cared for Māori who are dying, and witnessed some tense moments between family members as to 'who' makes the ultimate decision within the family to cease treatment. And pre-birth testing I can imagine would have parallels to this.

Four: 'It's about information, knowledge and the public's involvement'

This approach calls for better information about pre-birth testing, made available in more accessible forms nationwide. Information is needed both before any tests are carried out (so that the parent(s) fully understand the benefits, risks, accuracy and implications of proposed tests) and afterwards (so they can make informed, unpressured decisions in light of the test results). Individuals' decisions about pre-birth testing must be based on more than medical information alone – their cultural/spiritual/ethical perspectives, experience and knowledge are important too. Moreover, the public also needs high-quality information about future developments in pre-birth testing: possibilities such as 'designer babies' challenge everyone's fundamental beliefs about what it is to be human and 'who gets born?'

Talking about 'Information, knowledge and the public's involvement'
(snapshots from a deliberation)

Kelly
I am an avid supporter of this approach. The [more] knowledge you have about anything, the more empowered you are able to give a balanced decision... However, I am still very upset hearing from families (all around the world) who have similar experiences to mine and my husband's. The information given at the time of a genetic diagnosis was so incredibly clinical and devoid of all human reality, which is shocking in this day in age... Quite often [you find] the information you require from the 'experts' dealing with it on a regular basis. I have done postgraduate studies, and even though I am able to decipher scientific research, it is still the parents that I go back to for further learning.

Kelly (a day later)
I really like approach four. But I understand that knowledge can sometimes be questioned as to how accurate it really is (as many of us have said). And as most of us realise, knowledge is always changing in response to new research. So, how up to date can we possibly be?

Brett

Knowledge is vital. The information-knowledge-wisdom continuum suggests that knowledge is not enough and that we need wisdom, which in one way is the life experience that deepens knowledge. While I don't think suffering is good for us, I think it does deepen us (whether we like it or not!). And so when [facilitator] Sam suggests that we need 'properly trained' people to help us, I say yes, but that is nothing like enough. I worry that attitude will restrict those who will be offered to help us will only be those with a specialist training.

Nicci

I'm still thinking about Approach 4 in general. Take for example what we now know about smoking. Most of us have knowledge that smoking is harmful... A pregnant woman smoking is less common than it used to be, but is still not uncommon. But what has changed is that those women become the focus of strong criticism from others, even hatred. If we live in a 'my choice my right' society, which arguably is the dominant option in society at present, then these woman should have the choice to smoke during pregnancy and the right to do so. But they are largely condemned for doing so, and partly because society views the pregnant woman as transferring costs to them as our taxes then pay for the hospital care of the [ill child].

What if the risks and consequences of carrying a disabled child to term were equally well-known as smoking? As the knowledge gets better and better, are we ever going to see ourselves in a position where mothers are condemned for bringing those children into the world? Is 'Knowledge is Power' another way of saying 'Majority rules' – once we all know what is 'best', woe betide those who opt for something else?

Marilyn

In one sense we all seem to be saying the same thing; that the information and support needed varies and that we turn to different sources for comfort, advice, help or information.

Nicci

Sam wants us to search for common ground ... Can I approach it the other way for a minute? What do we disagree on with regard to approach 4? We have talked about knowledge is power. I've sounded a note a caution: is loading people up with knowledge just another way of getting them to do what the majority wants? Is loading people up with information when they have just received potentially devastating news giving them opportunity to process it appropriately? Can people trust the information?

Marilyn

I know it is sacrilege, but I think we ought to be using advertising, entertainment and communications people more extensively in getting the issues out there and discussed. Even this forum only just raises the issues: it is not long enough for us to arrive meaningfully at any deeply held conviction. Taking time to fully explore personal feelings and responses is more productive and satisfying in the end. Public debate doesn't have to be about solving problems with regulation and legislation; it should really be about enabling people to make good decisions which they will be happy with, hopefully for the rest of their lives. That takes time and discussion and lots of thinking – which really means bringing it into people's daily lives.

3. What the Bioethics Council heard

Deliberation is tough. The following is a composite picture of the experience, based on comments and observations by those who took part in deliberative events:

> Imagine you're about to enter a room with a dozen or so other people, the majority of them strangers. For the next three hours, you will talk about a topic on which you feel passionately – or perhaps one you've never thought much about before. You're a bit nervous. You're looking forward to morning tea.
>
> Very quickly, you sense that you don't have much in common with some in the group. You're suspicious of some, dismissive of others, maybe drawn to a few.
>
> The facilitator asks you to share your opinions with these strangers. Perhaps you relish the chance to voice your views; you've held them for years, they reflect your lifetime's experiences, and you've read a lot about the subject. You have your say.
>
> But then it's your neighbour's turn. What he says is shocking, perplexing, downright wrong.
>
> There's worse to come. Rather than giving you a chance to argue, the facilitator wants you to say something positive about your neighbour's viewpoint. You're asked to imagine the decisions and actions it might give rise to. You struggle to put yourself in your neighbour's shoes. Now someone's in your shoes too, pushing you to explain your thinking, your values, the course of action you favour and the possible consequences. You feel uncomfortable, but there's no getting away from it.
>
> The discussion picks up. It becomes both broader and deeper as each person in the room begins to explore their own opinions and those of others.
>
> At the end of three hours, you're drained. You began by stating your opinion and by dismissing (privately or aloud) the opinions of others. You've ended with a shared sense of what is valuable to the other people in the room, and the future costs and consequences of a wide range of viewpoints – including your own. The opinion you held at the start may remain the same, but it's been enlarged and informed by the others you've encountered. You're keen to find out more about the topic, and to keep on exploring it with your new companions.

What the Bioethics Council heard from the deliberations about pre-birth testing (both the face-to-face events, and the online exchanges) was shaped by the process described above.

At these deliberative events we heard something more than we had heard in previous dialogue events organised by the Bioethics Council. In the past, we certainly heard viewpoints challenged and enlarged as people interacted with one another. But the deliberative process added another dimension, as people considered a variety of possible responses. As they did so, they negotiated to produce policy directions that the group could share, or identified key policy issues for decision-making.

By attending these events and analysing the discussions (including the online forums), Council members came to appreciate how different deliberation is from many other forms of public engagement. Traditional processes such as receiving written submissions on an issue, or debate in public meetings, encourage individuals to contribute their views forcefully. But they do not enable dialogue.

Usually, public participation is a step towards decision-taking – decisions that will be taken not by citizens themselves, but by government or some other public agency. Deliberation, on the other hand, is social decision-making. It is dynamic and interactive. It requires engaging with the views and values of others, and reflecting on one's own views and values. It is not better than traditional forms of public participation, but it is particularly well suited to exploring issues where people have a range of views and which involve difficult ethical choices and tradeoffs.

It is hard to fully reflect the rich and dynamic nature of the deliberation on pre-birth testing here. A written report cannot adequately convey how people's views on the four approaches were tested and developed through interaction with others.

One participant said, after contributing online for three weeks, " I think each one of us could probably make a good case [now] for our least favoured approach, and identify the 'negative' effects of our most favoured one". Another described the effort of trying to consider other perspectives: "I am trying to identify the negatives of this approach, regardless of whether or not I agree with them". Several spoke of developing a new awareness of others' perspectives and how they might be accommodated. Sometimes, this led them to reconsider their own position, as in this online response to J, a participant who had suffered eight miscarriages and was frustrated by her ineligibility for PGD: "Ultimately I believe it is the mother's choice to continue or terminate pregnancy, but of course there are many issues whereby that decision may be taken out of their hands and for good reason. And J, you give me good reason to re-consider my perspective". Other participants said that being forced to adopt the viewpoints of others did not change their minds, but had certainly opened them: "[I've had] much to think about since you informed me of your personal issues. My view hasn't changed all that much, but now I feel more confident about expressing it after the in-depth consideration we have participated in".

Setting aside the inherent difficulties of capturing the deliberative experience, this section attempts to reflect the discussion we heard. Some of the viewpoints recorded here were expressed by different people at a single event, or across several events. But others were voiced by particular individuals at different stages in the deliberation, again demonstrating the capacity of the process to change the way people think or clarify their ideas through discussion with others. As an online participant said after making an initial contribution; "there's my first thoughts. Don't shoot me if I change my mind later!"

This is not an exhaustive record of what we heard, nor does it necessarily reflect the views of the Council itself. The section is organised around six dominant themes that emerged consistently and clearly out of the deliberations on the four approaches. The discussion of each theme begins with a selection of participants' comments ('What People Said'). For practical reasons, we have quoted primarily from the online deliberations, as there were verbatim records. However, very similar comments were made in the face-to-face events. Where comments were made at Pacific or Māori framing events, this is noted. At the end of the section is a list of the specific actions people called for as they discussed pre-birth testing with others participating in this project ('What People Wanted').

3.1 Valuing human life

What people said

Most of these comments were made in response to 'Life is a gift'.

"I agree that parents must have the choice, it is their life – but it is also the life of the child, isn't it?"

"For me, the use of PGD is justified ... to try and create life, rather than restrict it."

"It comes down to your moral viewpoint on, where does life begin? Is it equally repugnant to you to destroy an 8-cell embryo as an eight week old foetus – as an 8 month old (nearly full-term) pregnancy? You probably draw the line somewhere along that spectrum But where? And why?"

"My view is that any deviation from the life is a gift approach to human life – the sanctity of which is inherent in the human condition – is destructive to society and individuals."

> "Nature is random and cruel. Humans don't leave nature to decide everything – when they do, nature punishes." (From a Māori framing event.)

> "The question over screening siblings' compatibility for medical procedures is the hardest one for me. Where does one child's right to life take precedence over another child's right to be left alone, when they can't make their own decisions legally?"

> "Someone who has a beloved daughter who is dying or suffering may well want a 'saviour sibling' to help their child, but that doesn't remove the ethical issues. Much of our medical technology is used to relieve suffering of many kinds, our own suffering and that of those we love, but I am not sure that we actually want all suffering to vanish from the world."

> "There is a shift in paradigm from pregnancy being a gift or fate, to the idea of a tentative pregnancy...[where] we have all the tests before deciding whether to continue with it." (From a Pacific framing event.)

> "To be able to recreate life is indeed an amazing thing – but many prospective parents do not realise that nature can get the replication process wrong ... I wouldn't class myself as extremely pro-life nor am I extremely pro-abortion/termination. I just feel that each individual case needs to be viewed as just that: individual."

> "Do we have a moral obligation to 'make' the most healthy children we can?" (From a Māori framing event.)

> "I do not believe in human life at any cost. I personally want to be able to choose euthanasia rather than continue... in a dementia-befuddled state and I think it would be bizarre if we accepted one form of 'life choice' without the other."

> "It doesn't matter what the test results show – we will always keep the baby. It is a gift from God and not to be tampered with." (From a Pacific framing event.)

> "Life is precious – but there is a bucket load of humans on this planet. Do we really need to have that many more?"

> "Every second I unwittingly make the choice almost all people with disabilities make. To live. I love life, I love my intellectual disability, I love my profoundly different way of being. It's a global phenomenon to choose life."

> "Providing care and respect to the least 'valued' in our societies is the greatest indication of civilisation; of being human."

> "It is hazardous to go against 1 billion years of evolution." (From a Māori framing event.)

In talking about the value of human life, people often said it derived from the absolute uniqueness of every individual. Many saw individual life as a point of connection between past, present and future — a connectedness that was something to be treasured and maintained. While this was a universally-held view, it was particularly expressed by Pacific and Māori participants, with the latter often discussing it in terms of whakapapa (see also Section 4).

Defining when life begins

While participants generally said that life was precious, there was some divergence in how people defined life – particularly the point at which life might be said to begin.

We heard from people who felt that all the genetic material for a new human was in existence from the point of fertilisation, and therefore an embryo has a right to life and/or the status of a human being. Others felt that life could more properly be said to begin when the embryo was implanted in the mother's womb; in the context of PGD, they saw a fertilised embryo in the laboratory as less significant than one in an already established pregnancy. For people with this viewpoint, selecting embryos through PGD was therefore preferable to aborting a foetus if a serious disability or genetic condition was identified. Others thought that an embryo's moral significance or 'right to life' increased as pregnancy progressed and the embryo developed, and this meant that they also tended to favour PGD as an alternative to abortion.

Sometimes, reflection on when life begins led participants to wider conversations about abortion. We heard widespread concern about the present abortion rate in New Zealand (17,930 for the year ended December 2006).[15] Some thought this pointed to a need to tighten up the abortion law, while others felt the law needed to be more rigidly applied. Still others thought research was needed into why so many women have unwanted pregnancies, despite freely available contraception. There were also suggestions that men should take more responsibility for unwanted pregnancies, perhaps by being required to pay for abortions. However, as the project was not designed to explore public views on abortion, it is not possible to draw conclusions in this area.

Valuing diversity

We heard that people value not only life itself, but also its inherent diversity. Some participants talked about the richness that comes from the presence of people with different capabilities in society, and said that we would be diminished by their absence.

Advocates for people with Down syndrome, for example, expressed concern about the proportion of Down syndrome pregnancies that are now terminated when identified through pre-birth testing (currently, more than 90 percent).[16] Although they did not necessarily believe that termination should be prohibited, these participants were saddened that a group of people was effectively disappearing from society. However, those who held such views often distinguished between the situation of a woman discovering she was pregnant with a Down syndrome child and one carrying a child with a painful, life-threatening and/or fatal condition such as muscular dystrophy.

Some of those who spoke strongly about the need for diversity believed that abortion and PGD should be prohibited if it was being used solely to prevent the birth of a child with a disabling condition. They said there were many people who would be willing to adopt these children if the birth parents could not keep them. (However, we heard no evidence to support this assertion, and other participants pointed to the prevalence of disabled children being placed in institutions when legal abortion was unavailable in the past.) Some of those who opposed abortion and PGD on these grounds also said that delivering a baby with a serious condition at full-term – even if it did not survive, or was severely disabled – would be less distressing for a woman than having a termination, especially late in pregnancy. However, others said this was a purely personal matter that only the parent(s) could decide.

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[15] www.stats.govt.nz

[16] Ministry of Health (2007). *Antenatal Down Syndrome Screening in New Zealand 2007: A Report of the Antenatal Down Syndrome Screening Advisory Group to the National Screening Unit*. Wellington: Ministry of Health.

3.2 The difficulty of decision-making

What people said

Most of these comments were made in response to 'My choice, my right' and 'Information, knowledge and the public's involvement'.

"We need to understand that not everyone is going to agree with our views and that the choices that people make may upset us – but it is the right decision for them personally (and they have to live with that decision)."

"The majority can control the decision-making. We need minority voices to count." (From a Pacific framing event.)

"This issue raises the question as to whether or not personal morality should dictate Government policy and result in interventions." (From a Māori framing event.)

"Since we have put ourselves in control of our fertility and are making our own choices about who lives and dies … then we have no choice but to take on the job making these decisions as well."

"Often what we need in difficult circumstances are people who have just been exposed to a wide variety of life's joys and disasters and learned from them."

"Medical professionals tend to make the decisions for women by the way they present the information." (From a Māori framing event.)

"When you are in emotional turmoil – for example, when you have been told that your precious child faces a very real threat – your ability to process information is severely constrained. You are very susceptible to whatever people say to you and suggest to you. If anything, you need to be cocooned and given a chance to slow everything down and not make choices until you have to."

"To be honest, my daughter's difficulties are sometimes very frustrating and painful for all of us (her included) – so therefore it has to be an individual decision. After all, the parents in reality are the ones who need to have enough strength in order to deal with this 'lived experience' and guide their child positively through their life."

"I soul-searched regarding my potentially disabled twins and made the decision for me. I would not and could not make that decision for anyone else – or in conjunction with anyone else."

"Society as a whole is affected either directly or indirectly. We are essentially 'one'." (From a Māori framing event.)

"If a parent is given no information, misleading information, poor information, incorrect information, or is subject to internal or external pressures, all these things impair their ability to choose. The idea that an individual 'knows best for themselves' is flawed."

"If you have never been in the position of having to contemplate terminating a very wanted pregnancy because you know the child you carry is going to die from an inherited genetic condition, you can't possibly understand the horror these couples face."

"Sound ethical considered decisions … are more likely to be made within a wider context, not just at the point when a difficult decision has to be made. What society accepts or rejects as a whole is crucial, and it shouldn't just be the burden of a few people who're at childbearing stage."

> "How much can we trust the reliability of technology experts/doctors? An example of this was thalidomide." (From a Pacific framing event.)

> "I long for a daughter and sister for my [four] boys to "balance" our family...I have thoroughly researched the new PGD technology available for sex selection, which is freely available in the US, and we are currently considering using this technology to weigh the chances of our next (and final pregnancy) being a girl. I believe I should have the right to decide whether or not to take advantage of such wonderful advancements in medical technology as PGD for sex selection. I don't believe it is up to the Government or policymakers to be able to make such personal choices on my behalf. We are a loving, hard-working family and have the resources to take care of another child; if there is a technology that allows us to increase our chances of it being a girl then we plan to take advantage of it."

Who decides who gets born, and on what bases should decisions be made? These were perhaps the most contentious questions explored in the deliberation, and people were reluctant to provide definitive answers. We noted how frequently people doubted the motives and capabilities of others as decision-makers: the view that other people could not be trusted to make good decisions, or to know what was right for one's own family, was widespread. On the other hand, we heard enormous sympathy for the plight of parents faced with very difficult decisions about what to do in response to test results, and the challenges of living with the consequences of those decisions.

The role of parents

Most people felt that the parent(s) should be free to decide whether to accept or decline pre-birth testing. However, from some, we heard that there should be restrictions on amniocentesis because of the risk of harm to the foetus.

When considering decisions that might be made in the light of a test result that indicated disability or the prospect of problematic genetic conditions, people's views were more mixed. The arguments we heard largely echoed those surrounding the wider debate about the ethics of abortion. Some were adamant that the parent(s) should never be able to decide to have an abortion as a result of pre-birth testing, nor to have PGD (as it often results in the disposal of those embryos not selected for implantation). Usually, this view went hand-in-hand with the belief that life began at the moment of conception. On the other hand, we heard strong support for women's reproductive autonomy; that forcing a woman to continue a pregnancy was a breach of her rights. These participants said that preventing women from choosing termination would also encourage a return to unsafe 'backstreet' abortions, and greater suffering for women.

Among those who thought pre-birth testing and termination were acceptable if used to prevent the birth of a baby with a disabling condition, most believed that the decision whether to terminate or proceed with pregnancy should rest with the parent(s). Some people argued this from a practical point of view: only the parent(s) could decide whether they could cope with the financial, emotional and social challenges of raising a child with a disabling condition. These people often expressed concern about the possible impact on other children in the family, too. Others felt that all such significant decisions (whether to test, whether to terminate, whether to create embryos that might be discarded, whether to proceed with a pregnancy that might lead to the birth of a child with a serious condition) could never be made in the abstract – only when we are personally faced with such dilemmas can we decide what is right for us. Some people pointed out that although we might think we could not cope with a child with a disability, people are often able to exceed their own expectations.

There was a keen awareness of the difficulties facing the parent(s) forced to make these decisions. Participants noted that the parent(s) often needed to make very rapid decisions. The decision whether to terminate a pregnancy following an amniocentesis must also be made very quickly: abortion becomes more problematic after 20 weeks of pregnancy, yet amniocentesis might not be performed until around 17 weeks.

Decisions may also have to be made on the basis of uncertain or ambivalent information about the possible impact of a disabling condition. Will it be severe, or serious – and what do these terms mean anyway? What is serious to a health professional may be acceptable to a parent; what is unacceptably burdensome for one family may be manageable for another. There are particular problems for the parent(s) faced with the prospect of having a baby with a low penetrance condition, where they know only that there is a possibility the baby will have a condition or a later onset condition that might not emerge until later in life (such as Huntington's disease). Many felt that such uncertainties would make it very hard for the parent(s) to decide about whether to test or whether to proceed with a risky pregnancy, even with expert advice.

The role of fathers in decision-making was raised by some, including several Māori participants. We heard that fathers were sometimes excluded from decisions in which they had a right to be involved, and subsequently excluded from the pregnancy and from caring for a disabled child. Others commented that pre-birth testing might prompt some men to leave the mother to raise a child with a disabling condition on her own. We heard concerns that some couples do not discuss the possibility of having a disabled child until confronted with the prospect, at which point they may disagree about what to do. Again, this highlighted the pressures placed on the parent(s) required to make rapid decisions about, or in response to, pre-birth testing and the need to be informed early on. On the other hand, some people pointed out that as most pregnancies are normal, there was no need to cause unnecessary anxiety by emphasising what might go wrong.

The role of others

We heard strong support for whānau/family involvement in decisions about whether to have pre-birth testing, and what to do in the event of a result that indicates a disorder. This view was expressed by many non-Māori participants as well as Māori and Pacific participants, who often spoke of the need for health professionals to actively encourage and facilitate whānau/family support when the parent(s) was facing difficult decisions. Both Māori and non-Māori tended to agree that collective decision-making by the wider whānau should be voluntary; if the parent(s) did not wish to involve other family members, that was their prerogative. There was little support for the view that extended family members should be able to over-rule the wishes of the parent(s).

Some people felt that society as a whole had the right to be part of decision-making – that pre-birth testing involved far-reaching decisions about 'who gets born?' that go beyond the interests of individuals. This was related to widespread support for a regulatory authority to establish limits on uses of pre-birth testing in some circumstances, such as non-medical uses, even among those who believed firmly in the right of the parent(s) to make decisions about their families.

There was also support for the role of health professionals (fertility clinics, geneticists) in helping the parent(s) understand the probabilities of having a child with a certain condition, and the uncertainties inherent in the information. Some said it was important for these professionals to provide as much information as possible about the severity of a potential impairment, so the parent(s) could decide whether to proceed with the parent(s) PGD and/or go ahead with or terminate a pregnancy.

Others called for committees to be established to make such decisions on a case-by-case basis; we also heard from those who were suspicious of such government-appointed committees, and thought decisions about the seriousness of a condition should also rest with the parent(s). There was recognition, too, that a condition's seriousness would be affected by non-medical factors related to the parent's personal circumstances, such as whether there were other disabled children or if family assistance was available.

We heard some skepticism about the role of researchers and medical professionals in guiding decisions about pre-birth testing. Some participants were concerned that tests could be developed primarily for commercial or academic purposes rather than to meet medical needs, and that the parent(s) could be persuaded to have tests that were unnecessary or even unsafe. On the other hand, some said the parent(s) could be dissuaded from having tests by health professionals who were anti-testing – a decision they might later regret. The view was also expressed that many health professionals automatically assumed that a mother/parent who had undergone pre-birth testing would choose to terminate the pregnancy if they received a result that indicated a genetic disorder; there was some discomfort that health professionals viewed termination as the 'default option'.

Some people said that the parent(s) making a difficult decision about pre-birth testing would appreciate input from other parents who had children with the particular disabling condition, and/or from NGOs working to support the parent(s) and children with these conditions. This theme is discussed further under 3.3 (Information about pre-birth testing) below.

The scope of decisions

There were widely differing views about the nature of decisions that should properly be made by mothers, parents and whānau, and those that should be made in conjunction with (or even solely by) health professionals and other experts.

It was thought by some that the decision to embark on PGD should not be left to the parent(s) alone, because the parent(s) needs expert advice from geneticists and other health professionals to decide if a potential impairment is sufficiently serious to justify PGD. However, in cases involving a condition that was already in a family, some thought the parent(s) was best placed to decide whether to have PGD and/or to terminate an affected pregnancy. This was particularly so with late onset or low penetrance conditions. An example was the cancer genes BRCA1 and BRCA2, the presence of which only indicates an increased probability that cancer will occur at some future point. If it does, there may be treatments available – but they are unpleasant and there is no certainty that treatment will be successful.

Differences in opinion were particularly apparent when discussing the more controversial potential applications of PGD – such as sex selection or selection intended to produce babies with 'desirable' genetic qualities, or to create a baby whose cord blood could be used to treat a sick sibling. Many people seemed uneasy with the thought of the parent(s) being completely free to make such choices. Some felt these uses were simply 'going too far' in interfering with nature, and could eventually pave the way for alarming trends such as the genetic modification of embryos. Others expressed concerns because of the high costs of PGD, saying that this meant the wealthy would be able to 'choose' the genetically desirable children they wanted. Some people also noted the possibility of the parent(s) choosing to use PGD to have a child with a feature commonly thought to be a genetic defect – deafness, for example, which is commonly seen as an impairment but may be valued highly within the deaf community.

On the use of PGD for sex selection, people were unclear about whether and where to set limits. Concerns were expressed about wider global trends, with some parents in some countries known to prefer male children, and the possibility that such preferences could take root in New Zealand. Some thought that if the parent(s) was desperate to have a baby of a certain sex, it was preferable to determine sex by PGD than to have an ultrasound and subsequent abortion. Others pointed out that very few people would undergo expensive and invasive procedures such as IVF and PGD merely because of a preference for a particular sex, so if it were allowed the overall effect would be minimal.

Generally there was acceptance of the use of sex selection to avoid a sex linked medical condition, but its use for social reasons such as family balancing was more controversial.

There was also discomfort with the notion of a tissue-matched baby being used to save the life of a sick sibling, generally because of concerns about the future emotional and physical welfare of the baby. However, participants also expressed sympathy for the plight of the parent(s) with a seriously ill child, and acknowledged that there was no reason to assume the tissue-matched baby would be any less loved than their sibling or a baby conceived in any other circumstances. Some pointed out that the parent(s) who would go to such lengths to help their sick child would be likely to treat all their children with care.

Most participants admitted to knowing little about such controversial applications of PGD. What knowledge they had was often based on sensationalist or superficial information, in which emotive terms such as 'designer babies', 'spare parts children' and 'saviour siblings' were freely used.

3.3 Information about pre-birth testing

What people said

Most of these comments were made in response to 'Information, knowledge and the public's involvement'.

"This...is about acknowledging the specialist knowledge and motivation of parents in their children's issues. And... acknowledgment that there is more to a health difficulty than just a clinical diagnosis." (From a Māori framing event.)

"It is the parents' right to choose, but how can they make an informed choice if they are given no information or options and if doctors, medical staff and counsellors are not available or trained to assist?"

"My husband and I were told of our daughter's condition [while] geneticists stared at her. We were given a photocopied page from a book from the 1980s and sent on our way, with no further support. In my mind that is appalling and disrespectful, and unfortunately it is still occurring."

"Following the tests, people may have unrealistic expectations as to what the child should be and raised expectations that they would have a 'perfect' child." (From a Māori framing event.)

"The information-knowledge-wisdom continuum suggests that knowledge is not enough and that we need wisdom, which in one way is the life experience that deepens knowledge. While I don't think suffering is good for us, I think it does deepen us (whether we like it or not!). And so when [it's suggested] that we need "properly trained" people to help us, I worry that those who will be offered to help us will only be those with a specialist training. The problem is that specialist training often puts on blinkers."

"Information needs to be delivered in an accessible manner - both in terms of being understandable but also emotionally accessible. A good rapport with one's midwife (or other clinician) is particularly helpful, but I imagine that many people do not find themselves able to ask for further clarification at the risk of sounding ignorant...

I think also that information needs to come from a variety of perspectives. Ideally the clinician would aid that, but often they do not. The perspectives of parents and people who have experienced the disability (or whatever) in question is invaluable. Referring a person to support groups (or even online forums!) can be just as beneficial as referring them to a specialist clinician."

> "Public information is almost always culturally skewed. It may not be in your first language, it may not consider your religious requirements, it may not be at your level of literacy."

> "People should be presented with a range of different ways of thinking about pre-birth testing such as the perspectives of the church." (From a Pacific framing event.)

> "To transmit information about risk is particularly difficult. Statistics are often complex and are conceptually very slippery. The professionals themselves often misunderstand the statistics. It is not an easy area, and has the misfortune of looking straightforward when it isn't."

> "Is loading people up with knowledge just another way of getting them to do what the majority wants? Is loading people up with information when they have just received potentially devastating news giving them opportunity to process it appropriately? Can people trust the information?"

> "Often people really want the human touch – the opinion behind the face. How many of us want to ask the doctor: what would you do? We don't want the medical, we want the emotional information. The trick is getting the balance.

> "I recommend government-funded patient advocates to help with PGD decisions There's quite a successful model operating like this in the hospital for lactation consultants – it's a bit of a lateral leap to apply it to PGD, but I believe it is possible."

> "Humans overwhelmingly pick up information visually and a lot of people would much rather watch a movie than read a pamphlet. It is more expensive initially but when you consider it could be something available on a podcast with additional written information and links to various support groups ... I think that could be a highly accessible, safe way of conveying complex information effectively."

> "We mustn't only provide information to those who have to make decisions. Whether you are childless from choice or circumstance, or you are old or young, does not preclude your being able to have a say in the society you want to live in or that your family may live in."

Whatever people felt about the different forms and applications of pre-birth testing, and whoever they felt should make decisions, most believed there was a need for better information about the issue — for parents, for whānau and communities, and for decision-makers. Even those who vehemently opposed the destruction of embryos and abortion believed more information would encourage the parent(s) to make better decisions.

Some concerns were expressed about the information currently available to parents before undergoing pre-birth testing, particularly ultrasound and amniocentesis. It was said that the gravity of the possible consequences of tests was not always fully explained: some parents saw having an ultrasound as a social event, or a chance to 'take a picture' of their unborn child. Some participants said the personal views of health professionals about whether testing was necessary or desirable sometimes determined the information they gave to the parent(s).

Others noted an assumption among medical professionals that the parent(s) would inevitably opt for a termination if testing revealed a serious problem with the baby — the information made available to the parent(s) pre-supposed this choice. We were told that even when people may think they are making a free choice, the way the options are framed and presented can significantly affect their decision.

Some said there was a need for information about pre-birth testing and its implications to be made available earlier in pregnancy. Because of the speed with which the parent(s) may have to decide whether to continue a pregnancy after amniocentesis or a second ultrasound, it was imperative that they had time to consider the options well before actually undertaking these tests.

There was concern that the unreliability of tests was not always adequately explained, and we heard personal accounts from those who had delivered healthy babies after a condition had been incorrectly diagnosed. On the other hand, we also heard of the difficulties health professionals faced when explaining mathematical probabilities and risk to parents, and the fact that there is great variability in the possible effects of a condition that has been diagnosed. It was said that some people had unrealistic expectations of technologies such as pre-birth testing, and needed information that explained its limitations.

The nature of the information provided to parents was also a concern to some. They said it tended to be wholly medical, and did not acknowledge the emotional, spiritual and cultural dimensions of pre-birth testing. Medically-focused pamphlets and leaflets were not necessarily the best or only way to deliver information about pre-birth testing to parents. Many thought access to skilled counsellors and to people with first-hand experience of having a child with a disabling condition were also extremely valuable, particularly for parents who might be considering termination. Supporters of people with Down syndrome, for example, said many in the wider community do not know a child with the condition and do not understand how variable the effects of having an extra chromosome are.

We also heard that more needed to be done to inform Māori and Pacific people about pre-birth testing so they could develop their own views about new birth technologies and make informed decisions. Discussion at the Pacific fono confirmed that Pacific communities particularly lack information. For Māori, new approaches to information (including non-medical material, and the use of media other than print) were seen as being particularly important, and there were calls for Māori to be directly involved in its preparation and presentation.

3.4 Access to pre-birth testing

What people said

Most of these comments were made in response to 'My choice, my right' and 'Information, knowledge and the public's involvement'.

"We may end up with two classes – the medically engineered and those occurring naturally." (From a Māori framing event.)

"PGD needs to be available for all, not just the financially elite."

"In healthcare, Māori do still tend to be a disproportioned group who access services. And there is much debate and research out there that argues why this is so."

"Where should we put limited resources? Maybe we should put resources into people who already have diseases and illnesses." (From a Pacific framing event.)

"I hope that when women choose to have children, they will be supported to have the best possible pregnancy and birth experiences – regardless of any disability of the mother or baby, or issues of socio economic, family or ethnic, background. And that our society will welcome all children equally."

> "The one thing the Government should do in the future is to give first priority to allowing pregnant women to access pre-birth testing where they have a reasonable risk of passing on a genetic illness or disability to their child ... Couples who undergo IVF often only have a small proportion of the embryos that are harvested implanted. Why should the same right not apply to a woman with a genuine reason for wanting to choose? I don't support designer babies...but I do support the right to use the knowledge and the advances we as humans have achieved to spare innocent children and their families from unnecessary illness, disability and pain."

There were widespread calls for all women to have equal access to pre-birth testing throughout New Zealand. People were concerned that not all forms of testing are available outside the main urban areas. We were told that women in rural areas are less likely to have access to ultrasound, amniocentesis and PGD, with lack of knowledge, transport, travel time and childcare all mentioned as potential barriers.

There was acknowledgement that some women also face particular barriers in accessing pre-birth testing, especially Māori, Pacific, new migrant, rural and lower socio-economic women. Because Māori and Pacific women are less likely to receive early antenatal care than non-Māori, they are less likely to know about and take advantage of pre-birth testing, or to consider it important.[17]

Because of this concern for equal access to pre-birth testing, a wholly 'user pays' approach was rejected. But in considering alternative funding methods, participants drew distinctions between different forms of pre-birth testing – some were seen as essential, while others were regarded as 'add-ons'. In general, it was thought that a certain number of medically appropriate tests should be available to all, free of charge. Parents wanting further tests should pay for them themselves. However, people conceded that this might mean only the relatively wealthy could access the more specialised forms of pre-birth testing, including some uses of PGD. Again, the choices of rural women would be more limited.

Throughout the deliberation, there was recognition of the cost implications of extending access to pre-birth testing to all, regardless of their capacity to pay. People talked about the need to prioritise government health spending and questioned whether money should be spent on pre-birth testing at the expense of treating common conditions – or, given that most pregnancies are normal, at the expense of improving routine antenatal care.

3.5 Concern for families of children with disabling conditions

> ### What people said
>
> ***Most of these comments were made in response to 'Information, knowledge and the public's involvement'.***

> "We need to remember that people need support and respect, not judgement."

> "There are many individuals/families from the disabled and medical community who would love to extend their support to others facing tough decisions, etc. It would be initially costly to instigate, but the benefits of having key people/groups that could be utilised for individuals/families would be extremely positive."

> "We may create new social categories between those who have been tested and found to be OK and those who haven't." (From a Māori framing event.)

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[17] Ministry of Health, 2007. *Report on Maternity: Maternal and Newborn Information 2004.*

> "Currently the majority of those babies that have Down Syndrome are aborted. They may very well have gone on to have full and satisfying lives that enriched that of those around them. I'll hazard a guess that a good proportion of parents thought their only option to be: 'we'll have an abortion and try for a "normal" child."

> "In my experience in the health profession, and in the disability sector, families are kept very much in the dark re help/support/services. In general, NZ needs to improve this markedly. A lot of agencies do not network with other agencies... It's actually been my daughter's psychologist who has put us in touch with services that we've been eligible for years, and nobody has told us about it. And I am a reasonably assertive person, and I worry about other families who feel less able to 'shout' – something that I still don't like to do, but occasionally am forced to."

> "If we become more co-ordinated and put the child and their family in the centre of all of this, then we're working 'for' the family (and society in general)."

> "Already in the community there are many support services (e.g,. Parent 2 Parent, Epilepsy Foundation etc). But as far as I know, there is nothing that quite ties it all in together for this particular issue. From my (and others') experience, the medical team deal with the medical 'stuff', the community organisations deal with the community 'stuff' and the intersection between the two can sometimes be very messy."

> "As a carrier of Cystic Fibrosis and having witnessed what it can do to someone, I have no problem with testing for it. The guilt I would feel if I brought a child into this world with a death sentence attached is just not worth it (especially when I have the opportunity to avoid it)."

> "People need to know that it was shattering having this DS baby, but it passed; we love him and wouldn't be without him. He has every right to be here and while his life is more difficult in some ways, he's still having a great time. Every time we hear that a baby with DS has been terminated we feel sorry for the people (and the baby of course) because they don't know what they have missed out on."

> "We should value the variation among people in society." (From a Māori framing event.)

> "I probably wouldn't have continued with my pregnancy if I had have known ... I feel guilty every day that I inflicted the pain and torment [my son] lives through from others every day. He is teased and bullied for being different and then there are the lack of co-ordination, social skills and the learning disabilities. If you had the option would you put another human being through that every day of their life?"

Concern for the families of children with disabilities often emerged in the context of discussions about the need to value life in all its diversity (see 'Valuing diversity' in Section 3.1) and the need to equip people with better information (see Section 3.3).

Whether or not people agreed with abortion and/or PGD, there was widespread agreement that disabled people and their caregivers should be fully supported – both financially (through state funding) and socially. We were told that the support available to those born with a disabling condition is considerably less than that available from ACC for people injured by accident. This places considerable burdens on families caring for disabled children, and makes them heavily dependent on their private resources.

We also heard that the parent(s) who chose to continue a pregnancy knowing that their child could be disabled should receive more social support, rather than face condemnation and disadvantage. A public campaign to promote acceptance of disability, similar to recent mental health campaigns, was advocated by some.

There were concerns about the situation of families already affected by genetic conditions, who particularly need good access to well-funded genetic counselling services when making reproductive decisions. For many people faced with such decisions, whānau support was also vital; the need for appropriate facilities in hospitals and clinics was again raised in this context.

3.6 Concern for the future

What people said

These comments were made in response to all four approaches.

"We really need to think long and hard about the decisions we make now. They might just be the thin end of the wedge towards limitless testing."

"Just because a technology is available, does this mean it should be used?" (From a Māori framing event.)

"In this case, we might start to get things like 'transplant tourists' which [are] fairly harmless. But at worst we might get, as is now happening in [some countries], a severe skewing of the gender ratio following the abortion of female foetuses, and the result of that, it is feared, will be that there will soon be trafficking in women. The point I'm trying to make is that individual decisions can mount up and have profound social consequences."

"Is technology driving societal pressure values and expectations for pre-birth testing, or is society?" (From a Pacific framing event.)

"My age, nuchal scan and quadruple blood test resulted in my baby being given a 1 in 3 chance of chromosomal abnormalities. I told my in-laws about the results of the tests so that they were aware how our pregnancy was progressing... As a result I endured weeks of daily phone calls demanding that I have an amnio as soon as possible, as I would have to terminate the baby if it was not 'perfect'. I'd always considered I was pro-choice... [but I] would not contemplate killing my child simply because he was not going to be my in-laws' definition of a 'perfect' grandchild."

"Pre-birth testing could lead to further marginalisation of minority groups as disabled people would become more marginalised as they were selected out." (From a Māori framing event.)

"Given [the] freedom, some people might try and create what they conceive as the 'perfect' child contributing to the 'perfect race' ... [This] could easily widen the disparity between the rich and poor."

"Technology is sophisticated, but it can only offer tests and terminations, not cures." (From a Pacific framing event.)

"What if a person had a huge personal fear of dementia, perhaps through seeing a parent with it, and a test was developed that definitively showed who would develop it? The parents find out their unborn child will develop dementia, and have the option to abort. Personally, I feel that this is pushing the envelope too far."

> "The 'push' for scientists to get 'results' to 'justify' their funding is huge, not to mention their career advancement and promotion prospects (however ethical these people are). The other issue is the big corporates, especially drug companies that are behind the development of technologies such as we are discussing. There is plenty of reading out there which shows they are way more concerned about shareholder profits than the good of humanity."

> "There is a risk that the results might be used by insurance companies to refuse coverage to people who come from whanau with a history of genetic disease." (From a Māori framing event.)

> "I have a slight personal worry that over time, more and more genetic tests may be developed & we'll end up like the movie 'Gattaca'! Perhaps my problematic genes (I am a coeliac & my daughter has Type 1 diabetes, both autoimmune problems related to genes) might cause embryos to be rejected in the future – which is a depressing thought because we both lead relatively normal, although complicated, lives."

> "The future generations are going to be the real participants of what technology can test and inform us about in this issue of pre birth testing. Therefore I believe we need to involve young people in this discussion: teens at high school should be exposed to ethical debate about pre birth testing."

> "There is increasing pressure to have a perfect child and what will happen if the child doesn't live up to the parents' expectations in terms of health and personality?" (From a Māori framing event.)

As we have heard from the public on other biotechnology issues, New Zealanders have a keen sense of responsibility to future generations. Participants were concerned that this generation should not knowingly bring harm into the world through the development and use of pre-birth testing.

We also heard unease about the 'slippery slope' if pre-birth testing were allowed to develop unchecked. Without adequate guidelines and oversight, procedures such as routine testing for less serious conditions, and PGD for genetic enhancement or for sex selection could become commonplace. People were concerned that this could change our thinking about what is 'normal': we could become a society in which 'eugenics', 'designer babies' and gender preference were acceptable. Moreover, people feared that the expense of such forms of pre-birth testing could effectively create two social castes – the genetic 'haves' and the 'have-nots.'

Various other issues were touched on, but did not become central to the discussions. People were generally reluctant to discuss how to handle emerging tests for late onset and low penetrance conditions, and carrier testing. Some said that the parent(s) should be free to test for conditions like predisposition to cancer, if it meant preventing the birth of a child who might one day suffer from a painful, potentially fatal disease. Others felt this was unacceptable, as a child might enjoy many years of life before developing cancer, by which stage better treatments may be available. There was also the possibility that the child would not develop the condition at all.

While few people addressed the ethics of carrier testing (which determines whether an unborn child has a condition that they might pass on to their own children, although they would probably not suffer from it themselves), some saw this as a positive development that might allow families to virtually eliminate conditions such as haemophilia.

For all these reasons, there was a general view that pre-birth testing should be regulated to some degree. This was entwined with a desire to protect the reproductive autonomy of the parent(s), and concern about the appropriate role of Government in reproductive decisions. There was much discussion of how these different imperatives – the collective and the individual – could be balanced in the future. People said that if we are to continue to impose some limits on pre-birth testing, we also need a legislative and administrative regime capable of responding flexibly to what are sometimes unique and completely unforeseen individual circumstances.

3.7 Personal experiences of pre-birth testing

The following personal stories were supplied during the online deliberations.

(1)

"Pre-birth testing raises many ethical challenges, and everyone has an opinion based on their own personal experience. Someone who was born with a genetic condition and raised in a loving family will argue vehemently against pre-birth testing. Someone who was born with the same level of disability but was not raised in a loving family – was in fact mistreated and abused – will wish that pre-birth testing had been available before he/she was born.

For others, we have carried a pregnancy to term, loved that growing life with everything we had, then found out after that baby was born that something was seriously wrong. We have watched a much loved son or daughter struggle with the most basic components of life – breathing, eating, living without pain – watched our son or daughter have countless needles and medical tests – learned CPR knowing full well that one day the life of our son or daughter will depend on us knowing it and responding in time. We watch our baby struggle, not knowing if he or she will survive the first year. And when that child dies, we grieve. We grieve deeply, every day, and we miss that child every day for the rest of our lives.

Imagine you are the parent of a child who has inherited a lethal genetic condition. Imagine the fear we feel going into a subsequent pregnancy, knowing that we have a 25%, or even 50%, chance of conceiving a baby with the same genetic illness, and with the same outcome. Imagine living with that fear for 40 long, terrifying weeks if there is no diagnostic tool. Imagine trying to fight for your baby's life, knowing the second time that child will die.

Now imagine there exists the medical technology to know for a fact whether or not that subsequent baby carries the genetic condition that will kill him or her, and that you could find out before the first trimester of your pregnancy is finished. Imagine that you could spare a child that pain.

There are many lethal genetic conditions that cannot be diagnosed using the current technology. But for those that can be diagnosed, the technology should be made available to the parents. Parents have the right to decide whether or not to continue with a pregnancy if the diagnosis is lethal or will seriously impair quality of life. It is not the job of the government to take away the right of choice."

(2)

"I was recently tested for Down Syndrome via the nuchal fold measurement test. The scanographer did not say much, but I knew enough of the measurement theory to know that our figures were not good ones. Shortly after, while I was at the supermarket, a specialist called me. Would I have an amniocentesis? The risk of DS was 1 in 100 – 1%. A low risk reading would be one in several thousand. Suddenly we were faced with the issue of having at least one child born with a genetic disorder. I say 'at least one' because I was having twins. I knew that one twin would be at higher risk than the other, so assuming I had the bad news first, I enquired about the low risk twin. No, that was at even higher risk: 1 in 80. 'Yes, go ahead, book us in,' was my automatic response.

By the time the day was over, we knew we would not be having the amnio. The risk of miscarrying the twins was between 0.5 and 2% – about the same as the risk of the DS. What if we miscarried due to the procedure and lost the children? It had taken us six years to get pregnant, so our overriding concern was the safety of the children. Why did it matter if they had DS or not? We strongly felt that we had not contracted to have perfect children, but that we had made a life choice to be parents. Whether we felt like that because PGD isn't currently available or whether we would have felt like that if PGD was regularly used – we don't know. But we knew regardless of the result of the amnio, the pregnancy and the babies would stay. So why have it? We decided to enjoy the pregnancy for what it was, and not for what the outcome might be."

(3)

"I am the mother of one live child and eight heavenly babies. I have had seven miscarriages. My husband and I have been denied PGD because neither of us carries a 'disease' that would affect a future child.

I am furious that PGD is denied to women like myself who want to actively AVOID miscarriage. I am well researched in this field; I help advise women facing infertility and loss.

I am sickened by the 'Life is a Gift' precedence in this society. Life is a gift, yes, but so is it a responsibility. No, I don't want any office being able to perform selective sex transfers and no, I don't want someone building the perfect 'child' but the reality is that 25% of pregnancies end in miscarriage. When a woman becomes a recurrent miscarrier her chances of miscarriage become 60 to 80%, versus the small frame of a successful pregnancy.

Why deny her the right to avoid miscarriage and loss?

PGD isn't the answer to recurrent loss; in fact, some people think it reduces the chance of pregnancy in a woman with recurrent loss. But having ridden the ride, I would rather not conceive than carry a much wanted and loved child and lose it to a random chromosomal fluke."

3.8 What people wanted

Over the course of the public deliberation, we heard a number of specific calls for action, which are listed below. They contributed significantly to the recommendations formulated by Council (see Section 5). However, our thinking on the issue was shaped not only by the public deliberations we conducted, but also by the initial interviews with 'key thinkers' and our own reading in the field. Moreover, some of the actions identified by participants concerned issues that fell outside the scope of this project (such as abortion or adoption) and so have not been further addressed.

Specific actions sought by participants included:

- the parent(s) to be free to decide whether to have screening and testing during pregnancy
- limits on the use of PGD (such as bans on non-medical sex selection and reproductive cloning), which are reviewed regularly
- guidelines covering discarded embryos, the treatment of eggs, and other issues relating to PGD/IVF
- increased funding for PGD, so that it covers PGD in cases of infertility and advanced maternal age
- equal access for all New Zealanders to all forms of pre-birth testing, and to permitted uses of PGD
- better funding for genetic counselling, lead maternity carers, education, and training medical professionals about cultural concerns

- involvement of iwi leaders in decisions about DNA patenting
- Māori tikanga, points of view, values and concepts to be incorporated into pre-birth testing information, education and practice
- medical information for those facing pre-birth testing that is balanced, up-to-date and accessible
- a wide range of other information to be available – contacts for groups/individuals providing spiritual or cultural advice; material that reflects the perspectives of the disabled and positive aspects of disability; other media such as videos and podcasts
- co-ordinated involvement by non-medical people and society in general in developing pre-birth information and policy, and supporting parents who are making decisions
- government-funded patient advocates to support people facing decisions about pre-birth testing and PGD
- greater resources for the parent(s) of disabled children
- support for disabled people to reach their full potential
- public discussion of New Zealand's high abortion rate
- replace the Abortion Supervisory Committee with an ethical committee that would review the views on abortion of all New Zealanders
- no abortion
- simplification of adoption processes
- a multidisciplinary group with 50 percent consumer input to consider pre-birth testing further.

4. E kore au e ngaro he kākano i ruia mai i rangiātea:[18] Māori deliberations on pre-birth testing

The traditional Māori world view is drawn from early cosmological narratives that explain the origin of all things in the world.[19] At the centre of these narratives is Tāne, who is responsible for creating physical life forms from the basic sacred elements. Life force already exists within the Māori universe, but it is Tāne who places life within plants and shrubs, birds and forest fauna, and ultimately within mankind itself. Whilst in pursuit of a female companion Tāne draws on the fecund soil of the *kura waka*, the womb of Papatuanuku, and creates Hine-ahu-one to become his wife.

Tane, in his ignorance, experiments with Hine, leaving behind the basic human secretions throughout her body in the form of hūare (saliva), kea (mucus) and hupe (phlegm) until he successfully procreates and their children are born. One child, Hine-tītama, becomes the guardian of the world of the dead. The other children, Tiki-auaha and Io-wahine, become the progenitors of all human life and because Tane is imbued with tapu, or the holy power of being a god, so too do each of his descendants inherit a degree of tapu.

It is whakapapa that connects us to these earliest god ancestors and it is this that creates the caution of the current generation of Māori when it comes to modern reproductive technologies. Applying the traditional view to a modern day context, the extraction of eggs for pre-birth testing, for example, is thus extracting essential tapu elements that form the basis for procreation and the perpetuation of whakapapa.

Whilst reproductive interventions were employed during traditional times, they were in the context of a Māori world view and were much less invasive. Hirini Moko Mead, for example, explains that when a couple were having difficulty conceiving “they would enlist the help of a tohunga to perform the ceremony known as whakatō tamariki (planting the seed of a child).”[20]

Although the spectrum of modern Māori opinion is as diverse as other sectors within our community it is inevitable that these traditional views continue to influence Māori thought. The Māori world view, therefore, continues to have implications for how we might test, store or dispose of human eggs – or, in fact, consider the general question of pre-birth testing.

4.1 Engagement with the issue

Ko te kai a te rangatira, he kōrero.

From the deliberations, it was clear that Māori, as with the public at large, are not well informed about pre-birth testing, about new developments in PGD, and about the services and procedures available in New Zealand. Participants in deliberative events and key informants interviewed at the start of this project suggested that Māori lack information and access to services for a range of reasons. These include an absence of culturally appropriate resources, low participation of Māori women in early antenatal care, and socio-economic factors.

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[18] For explanation see Mead, H. M., & Grove, N. (2001). *Nga Pepeha a nga Tipuna*. Wellington: Victoria University Press.

[19] Narratives are tribally specific, although there are many commonalities. The view here draws on narratives from Ngati Kahungunu, Ngati Porou and Ngai Tahu.

[20] Mead, H. M. (2003). *Tikanga Māori: Living by Māori Values*. Wellington: Huia Publications, p 291.

There is also a perception that infertility and genetic issues are not relevant to Māori.[21] The Māori fertility rate is falling which follows national trends,[22] and Māori are also participating in research into genetic conditions that affect their whānau.[23] Concerns were raised about technologies that require the retention of tissue, blood or other genetic material for research purposes as these are subject to considerations related to tikanga as well as holding implications for cultural and intellectual property rights.

Māori expressed a mix of support and caution for pre-birth testing and recognition that while it may alleviate suffering and distress, it may also involve risks and unacceptable interference with nature. Emerging technologies used for therapeutic reasons, rather than for genetic enhancement, were regarded more favourably. There were however, reservations about the scientific/commercial agendas that influence the development of reproductive technologies and also a degree of mistrust towards State providers.

> "Messing with the natural order is dangerous. Pre-birth testing is acceptable only in determining the medical status of the child and how as a parent you accept responsibility for premium care of that child. From a tāngata whenua perspective, it is the responsibility of the whole community."

4.2 Decision-making

Rapuhia he oranga mō te iwi.

There are many views on the way in which whānau influence and determine decisions. In every area of life, Māori make decisions both individually and collectively, and pre-birth testing is no exception. The desire for whānau to be more involved in pre-birth testing decisions, as supporters and advisors to the parent(s), and to ensure collective interests are considered alongside individual interests was emphasised at deliberative hui.

Some participants stated that whānau will support whatever decision is made by an individual or couple, providing there is no risk to the wider whānau as a result. Others said individuals/parent(s) would follow the lead of the wider whānau when making decisions that could place the whānau under financial, emotional or social stress. For example, the parent(s) would recognise that choosing to continue a pregnancy after a disabling condition had been diagnosed would place demands of many more people than themselves alone.

Others discussed the practical ways in which health professionals and health services could better encourage whānau involvement. Most emphasised a need for physical places and adequate time for whānau to participate at the time possible testing was discussed, when test results were revealed, and when decisions about proceeding with or terminating a pregnancy were made. The value of a face-to-face discussion, rather than the impersonality of a telephone conversation, was emphasised.

> "Contraception education isn't strong enough...I hear the discussion about the right to have abortion etc: it's just that our girls are too vulnerable and we have to have education way before that."

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[21] See, for example, Marewa Glover in "Māori Infertility and Assisted Reproduction Study", a media release from the Auckland University Faculty of Medical Sciences and Health, 7 March 2006 (available at http://www.fmhs.auckland.ac.nz/faculty/news/news_details.aspx?ArticleID=329, accessed 29 April 2008) or in "If embryos could talk", transcript of a presentation to the Bioethics Council's Talking Embryos seminar, 25 September 2006 (available at http://www.bioethics.org.nz/about-bioethics/issues-in-focus/human-embryos/her-transcripts/5-marewa-glover.html, accessed 29 April 2008).

[22] For more on fertility rates, see Statistics New Zealand (2005), *Māori Population: Looking out to 2021*, a discussion paper prepared for the Hui Taumata 2005 Steering Committee.

[23] Ramari Viola Port, *He Whakamatautau pi tauo mo te mate pukupuku: Nga Tikanga a te ao Māori. DNA Testing for Cancer Susceptibility: The Needs of Māori*, PhD thesis, University of Auckland, 2007.

4.3 Information

Nāku te rourou, nāu te rourou, ka ora ai te iwi.

Māori want more and better information about pre-birth testing, and also about broader matters such as IVF, genetic conditions, antenatal care, and the Code of Rights. Such information needs to use language, concepts and presentation formats that are relevant to Māori, and to incorporate a wide range of non-medical perspectives. For example, the 'risks' of pre-birth testing may also include risks associated with whakapapa and such ideas need to be presented to parents considering testing alongside explanations of the technology.

> "I want the best surgeon to open me, cut me up and take my bad bits out. But I want the best communicator to tell me what my options are...cos there are different people for, say, liaising at an iwi level than, say, with teenagers in Otara."

Many said the key to increasing Māori awareness and discussion of pre-birth testing was to ensure that iwi, hapū and Māori organisations (health services, churches, community groups etc) were involved in preparing and presenting information, at hui and elsewhere. There were also calls for information to be available in the Māori language.

> "Apart from the legal requirement to consult with tangata whenua, I believe that many are of the mind that traditional values of Māori have a positive influence in establishing our uniqueness as a country."

4.4 Access

Ko te manu kai ana i te hua, nōna te ngahere, ko te manu kai ite mātauranga, nōna te ao.

The need to ensure Māori women have equal access to pre-birth testing services, including genetic counselling, was one of the strongest messages to emerge from the deliberations. The present barriers they face are both logistical and economic. Amniocentesis and ultrasound testing, for example, are currently available free of charge at clinics run by District Health Boards, which may be out of reach for reasons of cost and distance. The alternative is to have such tests privately, which may be prohibitively expensive for some Māori women.

The fact that many Māori women do not receive first trimester antenatal care clearly influences their awareness and use of pre-birth testing. A number of factors contribute: a scarcity of Lead Maternity Carers in some places, the tendency of women expecting a second or subsequent child to feel they do not need early care, the negative impact of unplanned pregnancy and unemployment. A campaign aimed at tackling these barriers to early antenatal care may well improve Māori access to pre-birth testing at the same time.

4.5 Support for families of children with disabling conditions

He aha te mea nui o te ao, he tangata, he tangata, he tangata.

The Māori view of disability may be influenced by both traditional and contemporary considerations. For example, in the past in some tribes a child who inherited a condition such as 'waihape' (club foot) was valued rather than viewed as having a disability. These days, parents who have such children arrange for them to undergo corrective procedures. As the care of children tends to be spread across the whānau, when a child is born with a disabling condition, there might be as much concern for the impact on the financial and emotional resources of whānau as for the individual child and its parents.

Financial and social support for families choosing to care for a disabled child was a priority for Māori. There was also acknowledgement of the predicament of those parents who chose to terminate a pregnancy after pre-birth testing; in particular, there were calls for greater support for women who felt guilty about their decision. There was also a desire to improve Māori access to genetic counselling, including by Māori counsellors, as a way of avoiding passing on inherited conditions.

4.6 The future

Mā te māramatanga ka puta mai te oranga.

Understanding Māori perspectives on matters such as reproduction, birth, disability and death is essential to the future of pre-birth testing in this country. This includes a greater understanding of the need for whānau support, a commitment to improved antenatal care for all, and more acknowledgement of the non-medical dimensions of pre-birth testing.

> "The Council and Government need to talk to people who work in this area or people in the community who deal with whānau every day…Talking to iwi groups is fine but talking to the parents actually having the babies and those supporting them is the best approach."

4.7 Personal experiences of pre-birth testing

He mana anō tō te mātauranga Māori.

> "Prebirth testing is a good thing if you're going to avert a serious medical condition, but not if you are wanting it for gender selection."

The following personal stories were provided by Māori participants.

(1)

"Our whānau knew that there was a problem because some of our baby boys started to get sick between the ages of 4 and 10. Parents would often notice changes in behaviour first. Next, the boy would develop problems with vision, hearing, speech, swallowing, walking and coordination. There was sometimes fatigue, seizures and an increase in skin pigmentation. This would progress until they died a few years later. We thought this was because of a mākutu.

The hospital had taken blood samples from our whānau years ago and sent them to America for testing but we did not know why or what the results were. Then we saw a programme on TV showing a child just like ours and so we started investigating and eventually found out what the disease was. It is a disease the girls carry and usually only boys actually get.

We found out that we could be tested so the girls could find out whether they were carriers and the boys whether they had the disease. But some girls who were carriers still wanted to have babies so we found out that they could be tested once they were pregnant to find out whether the baby was a girl or boy. If it was a boy they could have amniocentesis and then if the baby had the disease they had to decide whether to end the pregnancy.

This is a very hard decision because it is well on in the pregnancy and some decide to go ahead with the pregnancy anyway. They talk it over with their whānau and it is very important to have whānau support, particularly if they go ahead with the pregnancy, because they will need support to raise the child. Usually the whānau is supportive of the final decision.

Our whānau does not know much about PGD but that seems a better idea than a late termination. We need someone who is Māori and who knows about PGD to come to a hui and korero with us so we can understand and make decisions. We don't want to just be sent pamphlets or books."

(2)

“I had a twin pregnancy. A chorionic villus sampling (CVS) identified a genetic condition in one twin and soon after the foetus died leaving the well twin to continue developing in the womb. The dead twin did not abort as expected after my kaumatua carried out a special karakia to ‘ask it to wait until 9 months had passed when the well baby could be born.’

I was advised that: “...Kei te pai ia kei roto i tana whare tipuna. Mā te wāhi ngaro ia e tiaki...” [Leave him where he is (i.e don’t send him back to Hinenuitepo just yet), he is safe inside the house of the ancestors.]

My husband and I believe in te ao wairua from where all children come from and that the wairua of the dead twin stayed around until the well twin could be born.

Nine months later the well baby was born and a tangi was held for the dead twin. Both male babies were named, Te Hoa Ngaro (The lost friend) and the surviving twin was named Morehu (The survivor). I had taonga cut from pounamu and named both pieces after the twins.

Two years and two months after the surviving twin was born I moved out of my grieving state and was able to finally farewell my son’s soul to the spirit world. Our family held a ceremony similar to an unveiling with poroporoaki, waiata, karakia, a stone and the release of balloons so that Morehu the surviving twin could also participate in the ceremony.

I believe that I lost the unwell twin because of the genetic disorder identified by the CVS test and that this disorder was due to the fact that I was an older mother (42yrs,) where such risks are a lot higher than a younger mother.”

5. The Bioethics Council's thinking

5.1 Valuing human life

The sanctity of human life, and the need for policies and laws that recognise it, has been one of the most strongly-expressed views whenever the Council has sought public input on biotechnology issues. Once again, it emerged as a fundamental principle in these deliberations – whether it was framed in religious or humanist terms, whether expressed by Māori or non-Māori, and whether people supported or opposed abortion in some or all circumstances.

Talking about the importance of human life in the context of pre-birth testing revealed widespread public concern about the present abortion rate. This was expressed by people with widely diverging opinions about the permissibility of abortion. There seem to be no obvious or well-researched explanations for the prevalence of unwanted pregnancies, and this suggests a need for further research. However, as the project was not designed to discuss abortion and only a limited range of views was heard, this report does not address the issue.

Even though New Zealanders attach supreme value to human life, there is a wide spectrum of views about the practical implications of this commitment. Participants had wide-ranging views on whether an embryo in a laboratory has the same 'right to life' as a foetus in utero, whether one life can be prioritised over another (for example, a mother's or her unborn baby's, a sick child's or an embryo's) and in what circumstances it is acceptable to 'interfere' with nature. These questions are especially pertinent in the context of more controversial emerging uses of PGD, and our recommendations in this area appear in Section 5.6 below.

5.2 Decision-making

We gained a deep appreciation of the anguish and difficulties parents face when making decisions about, or as a result of, pre-birth testing. These decisions are never made lightly or easily, and they may give rise to lifelong regrets and doubts.

On the other hand, we believe that it is right that these decisions *are* made by the parent(s), with the support of whānau/family if they wish. It is also necessary and appropriate for the parent(s) to receive non-directive advice from health professionals and other experts (including non-medical experts) when making decisions. However, parents must remain the key decision-makers, including when considering whether to use PGD (see also Section 5.3). The Council considers that the parent(s), in partnership with fertility clinics and geneticists, must determine whether a disorder is going to cause a child to be 'seriously impaired.'[24]

In some cases, such as those involving technologies that have implications for society at large, it is also appropriate for citizens more generally to have a say in decision-making. This points to the ongoing need for sound regulatory frameworks and oversight by state agencies. Regulation and oversight can ensure that pre-birth testing developments (especially the more controversial uses of PGD) are not driven exclusively by those with the capacity to pay for expensive procedures, or those who will make money by providing those services. This is not to imply that commercial providers are in any way unethical: only that there is a clear role for state oversight.

We noted that, at present, most uses of PGD are 'established procedures' so do not require Ethics Committee oversight. However, the creation of tissue-matched siblings to enable the use of cord blood to treat a sick child is tightly regulated. We do not consider such restriction to be justified (see Recommendation 8).

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[24] Under the HART Order 2005 Schedule, Part 2, certain uses of PGD are permitted without Ethics Committee oversight providing the disorder will cause the child to be 'seriously impaired'.

We consider there is scope for changes that could make decision-making easier for the parent(s). In particular, we think that the important role that whānau or wider family members can play in decision-making – if the parent(s) choose to involve them – needs greater acknowledgement. It is not enough for this to be enshrined in the Health and Disability Commissioner's Code of Health and Disability Services Consumers' Rights:[25] more needs to be done to ensure people know their rights and are able to exercise them.

We gained a strong sense that there were very different world views underpinning the way people approached decisions about pre-birth testing. For Māori (although a wide diversity of viewpoints exist), the starting point for any decisions about pre-birth testing is likely to be the collective rather than the personal. The whānau, rather than the individual, is likely to be seen as central in the information-gathering and decision-making processes. The same may well be true for many other people. At a pragmatic level, this means health professionals, clinics and hospitals need to actively enable whānau to be present when test results are discussed and choices made, by making appropriate facilities available and allowing sufficient time for consultation with family members.

Although we appreciate that sometimes choices must be made rapidly (for example, following an amniocentesis), all steps should be taken to avoid rushed decision-making. Health professionals can help by making sure the parent(s) fully understand the findings, possible implications and next steps at every stage of pre-birth testing. This allows them the maximum time possible to deliberate and consult others if they wish.

We think it is important to acknowledge that pre-birth testing is not exclusively a women's issue. We encourage the active inclusion of fathers at every stage of pre-birth testing, information-sharing and decision-making. However, we also note that New Zealand women who experience pregnancy are more likely than men to have prime child-rearing responsibilities and are therefore disproportionately affected by the consequences of pre-birth testing decisions (for example, raising a child with a disabling condition). Mothers, especially sole parents, may therefore require particular support. We note that the vast majority (more than 70 percent) of those who participated in the deliberations were women, and many had direct personal experience of the difficult decisions associated with pre-birth testing.

Therefore, the Bioethics Council recommends that:

Recommendation 1

Decisions about whether to have pre-birth testing, and what to do in light of the results, should be made by the parent(s) within the existing framework of the Code of Rights.

- When making decisions, the parent(s) should have access to advice and counselling that is unbiased, non-directive and includes medical and non-medical information.
- We commend the inclusion in the HDC Code of Health and Disability Services Consumers' Rights of the right to have the opportunity to consult with whānau when making decisions. Efforts should continue to be made to ensure parents are aware of these rights.

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[25] See Right 1: Right to be treated with respect ("Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori") and Right 8: Right to support ("Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed). Available at http://www.hdc.org.nz/theact/theact-thecodedetail/

5.3 Information

The public deliberation process revealed a great deal about people's current knowledge of pre-birth testing, and the kind of information that has shaped their views.

Firstly, we see a clear need for high-quality information for parents about the pre-birth tests that are available, what they involve, and the decisions that might need to be made as a result. We noted however that provision of information alone does not guarantee understanding: the key relationship is between *understanding* and choice, not simply *information* and choice.

Information about pre-birth testing should be allied to a publicity campaign aimed at increasing awareness of the value of early antenatal care in general; where parents do not know about pre-birth testing, this is often because they do not see a health professional in early pregnancy. In addition, more research is needed into the reasons why some women do not have tests such as ultrasound screening.

We also noted a strong desire for different kinds of information. People wanted something more than medical data and expert reports alone: they wanted information that acknowledged the cultural, ethical and spiritual dimensions of pre-birth testing and the decisions it requires. Health professionals cannot be expected to be experts in all these areas themselves, but they should be able to refer patients to appropriate support groups and other resources available in the community (and we recognise that there are many such groups, whose expertise and diverse perspectives could help shape information about pre-birth testing). Tapping into these community resources may involve additional training for health professionals, and coordinated assistance.

We see an important distinction between resources that *inform* people facing difficult decisions about pre-birth testing, and those that *support* them in their decision-making. There is a need to do more than simply provide printed material – often, the most helpful resources are people. We found that participants in the deliberative events who knew little about pre-birth testing often engaged most deeply with the issues when they emerged via personal stories highlighting how particular individuals were dealing with them. Personal perspectives, and those of non-medical experts such as counsellors, may be as valuable to those confronted by pre-birth testing decisions as advice from medical experts. There are also opportunities to make personal stories available by means of media such as DVDs, podcasts, film and TV. Leaflets and posters should not be regarded as the only way to inform people or to increase understanding. This was often raised by Māori participants, who said korero was essential to allow the development of tikanga around pre-birth testing. Face-to-face dialogue remains the preferred way of sharing information and knowledge for many Māori and Pacific people.

We urge greater use of deliberative processes as a way of creating and deepening public thinking about how best to respond to the challenges of pre-birth testing. Our own deliberative events identified a thirst for this kind of participation, which can be built upon in the future. The tough social and ethical questions raised by pre-birth testing need to be aired in the public domain; it is especially difficult for parents to make hard choices if they have never before encountered the issue or had an opportunity to talk about it with others.

Therefore, the Bioethics Council recommends that:

Recommendation 2

High-quality, appropriate information about pre-birth testing is made available by health professionals to parents and to the wider community. Information needs to be:

- accurate and comprehensive
- timely: it must be made available before each test or stage of testing, giving the parent(s) as much time as possible to think about the choices
- non-prescriptive: in particular, it must not present termination of pregnancy as the automatic option after a test result indicating a disorder
- wide-ranging: information for parents should recognise the wider dimensions of pre-birth testing, and contain contact details of support groups, counsellors and cultural advisers
- part of best practice: the requirement for health professionals to give such information should be built into their best practices, training, assessment and audits, contracts and services, as well as being part of the role of advisory groups
- appropriate: information and resources must be available in a range of forms and media appropriate to the needs of different individuals and communities, and disseminated through appropriate fora such as kanohi ki te kanohi (face-to-face dialogue) and through language of choice (Māori, English, Pacific and other languages as appropriate).

5.4 Access

We heard a clear call for more equitable access to pre-birth testing services throughout New Zealand. There are two main ways to achieve this: increasing awareness of pre-birth testing (see 5.3 above for recommendations in this area), and making testing more widely available across the country.

We know that some women do not receive antenatal care early enough in pregnancy.[26] We consider that more research into the reasons is needed, as pre-birth testing cannot occur without early antenatal care. We are also concerned that not all parents from families affected by genetic conditions have equal access to genetic counselling, which is especially relevant in the context of PGD. There is a shortfall of clinical geneticists and genetic counsellors in New Zealand – it has been suggested that there are perhaps as few as half the number required – and that many medical professionals lack knowledge of genetics.[27] Genetic counselling services, as well as tests for serious conditions, need improved public funding.

We heard that some people believe that not all tests are currently available nationwide. This means that many women – especially Māori, Pacific, new migrant, rural and lower socio-economic women – face perceived barriers of cost and distance. However, there is a lack of information about precisely which tests are available in different parts of the country, who provides them and who pays.

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[26] See Ministry of Health, 2007. *Antenatal Down Syndrome Screening in New Zealand 2007: A Report of the Antenatal Down Syndrome Screening Advisory Group to the National Screening Unit*. Wellington: Ministry of Health. Chapter 4.0.

[27] See the Human Genome Research Project, *Genes Society and the Future* Volume II (University of Otago, 2007), p21 and also Ramari Viola Port, *He Whakamatautau pi tauo mo te mate pukupuku: Nga Tikanga a te ao Māori. DNA Testing for Cancer Susceptibility: The Needs of Māori*. Unpublished PhD thesis, University of Auckland, 2007.

Therefore, the Bioethics Council recommends that:

Recommendation 3

> Research is undertaken to determine why some women do not have pre-birth tests such as ultrasound scans.

Recommendation 4

> Steps are taken to recruit and train more genetic counsellors and geneticists and to provide an adequate national service, with particular reference to cultural needs and differences.

Recommendation 5

> The Ministry of Health continues to work with Māori health providers to identify barriers to antenatal care for Māori women, and the Bioethics Council supports further initiatives to eliminate these barriers.

5.5 Living with disabling conditions

The parents of all children with disabling conditions – including those who decide to go ahead with a pregnancy after a disabling condition is diagnosed – need greater public support, both financial and social. Clearly, life is tough for these families. The decision to proceed with a pregnancy after a positive pre-birth test should not be dictated by a family's personal resources.

We are concerned that as fewer people in the community have conditions such as Down syndrome, there may be community pressure on parents to avoid having children with these conditions. We consider that publicity campaigns reflecting the stories of families and communities living with disabilities/genetic disorders would increase understanding and acceptance in the community.

An important step is to ensure parents and families are better connected to the many existing resources and the voluntary support organisations already working hard in the community. The kind of support parents require will vary at different times and in different circumstances – people needing genetic counselling require other kinds of assistance than those who have received a positive amniocentesis result, or whose baby has just been born with a disabling condition.

Frontline health professionals, especially general practitioners and lead maternity carers, have a key role to play in linking families to resources and support. We strongly support the National Screening Unit Advisory Group's recent call for more training of health professionals in this area.[28]

Therefore, the Bioethics Council recommends that:

Recommendation 6

> The costs and benefits of better coordinated support services for the disabled should be reviewed.

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[28] Ministry of Health. 2007. *Antenatal Down Syndrome Screening in New Zealand 2007: A Report of the Antenatal Down Syndrome Screening Advisory Group to the National Screening Unit*. Wellington: Ministry of Health.

5.6 Future developments

While there are clearly public concerns about some of the emerging applications of PGD – such as non-medical uses, the creation of embryos to help sick siblings, and the selection of embryos that will not be at risk of developing particular conditions until later in life – people are also reluctant to draw firm distinctions between acceptable and unacceptable uses.

There are mixed reasons why the public has misgivings about establishing firm boundaries around PGD. Ambivalence about how best to balance individual freedoms with the social implications of expanding the use of PGD is undoubtedly one factor. We note too the significant part played by the media (including popular literature) in shaping public thinking, raising expectations and creating fears about PGD. More work is needed to better understand and develop public thinking, and to inform policies around emerging technologies.

Using PGD to create embryos that are tissue-matched to sick siblings

We have great sympathy for the parents of seriously ill children who contemplate this course of action. It has occurred only relatively rarely internationally, and as yet there is no evidence of psycho-social harm to the tissue-matched babies.[29] However, more research into the ongoing effects is clearly needed.

At the same time, we share the concerns expressed by some participants for the rights and welfare of any baby conceived for this reason (which may or may not be via PGD: tissue-matched babies have also been conceived naturally). It is important that there is both protection and advocacy for tissue-matched babies, throughout the pregnancy/birth and beyond. In most cases, only the baby's cord blood is needed to treat the sibling's condition; however, it is possible that a bone marrow or organ transplant might be required later as well. This raises questions about whether children should be donors of bone marrow and/or organs, and whether it is appropriate for parents to make donation decisions on their behalf.

The HART Order 2005 does not include PGD with tissue typing as an established procedure. The interim guidelines provide that ECART may only approve applications if the sick sibling is suffering from an inherited disorder; it is not permitted to alleviate other disorders. We do not believe there is any reason to continue making this distinction, as outlined in our submission to the Advisory Committee on Assisted Reproductive Technologies in September 2007.

Therefore, the Bioethics Council recommends that:

Recommendation 7

Research is undertaken on the use of preimplantation genetic diagnosis (PGD) to create embryos that are tissue-matched to sick siblings. This work should primarily examine:

- the nature of public concerns
- whether tissue matched children are adequately protected by present laws
- the nature of tikanga Māori associated with this use of PGD.

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[29] Jeanne Snelling, Embryonic HLA Tissue Typing and Made-to-Match Siblings: The New Zealand Position. *Medical Law International*, 2008, 9(1) 13-44.

Recommendation 8

> The present distinction between using preimplantation genetic diagnosis to create embryos that are tissue-matched to sick siblings suffering from inherited conditions and using it to help siblings suffering non-inherited conditions should be removed. The only requirement should be that the sick sibling is suffering from a serious condition for which no other treatment is reasonably available.

Using PGD for sex selection

We support the use of PGD to select embryos of a particular sex where it is done to prevent a child being born with a sex-related condition. As far as sex selection for the purposes of 'family balancing' is concerned, we have not heard sufficient cultural, ethical or spiritual concerns to justify banning it – providing PGD is undertaken at the parents' own cost. We think further investigation of the reasons for apparent public concern about the use of PGD for sex selection is warranted. The reasons for people's concerns about sex selection for family balancing remain unclear. Perhaps they stem from a perception that this is a comparatively trivial application for a technology with profound implications, or they may be related to distaste for practices in some countries where girl babies are routinely aborted or abandoned in favour of boys.

Therefore, the Bioethics Council recommends that:

Recommendation 9

> There is insufficient cultural, ethical and spiritual reasons to prohibit the use of preimplantation genetic diagnosis for sex selection for social reasons such as 'family balancing'.

Using PGD for late-onset or low-penetrance conditions

Currently, the HART Order 2005 allows for PGD without Ethics Committee oversight where it is used to prevent or treat a 'single gene disorder' and there is a 25 percent chance of an affected pregnancy. The term 'single gene disorder' is not defined, so seemingly applies to late onset or low penetrance inherited conditions.

Most people who commented found it difficult to formulate limits in this area, but tended to think that the parent(s) would be in the best position to decide – especially if they had experience of the condition in their families.

Therefore, the Bioethics Council recommends that:

Recommendation 10

> The current provisions allowing the use of preimplantation genetic diagnosis (without the Ethics Committee on Assisted Reproductive Technology's oversight) for late-onset or low-penetrance conditions be retained.

Using PGD for carrier testing

Currently the use of PGD is an established procedure providing there is evidence that the future individual may be seriously impaired as the result of the disorder. In most cases this would exclude using PGD for carrier testing – for example, in a family affected by cystic fibrosis – as a carrier usually does not have the condition.

We heard little comment about the use of PGD to select against unaffected carrier embryos. We consider that this should be a matter for parental and clinical judgment rather than requiring Ethics Committee approval.

Therefore, the Bioethics Council recommends that:

Recommendation 11

> The use of preimplantation genetic diagnosis to select against carrier embryos be included in the HART Order 2005 as an established procedure.

6. Summary of recommendations

Recommendation 1

Decisions about whether to have pre-birth testing, and what to do in light of the results, should be made by the parent(s) within the existing framework of the Code of Rights.

- When making decisions, parent(s) should have access to advice and counselling that is unbiased, non-directive and includes medical and non-medical information.
- We commend the inclusion in the HDC Code of Health and Disability Services Consumers' Rights of the right to have the opportunity to consult with whānau when making decisions. Efforts should continue to be made to ensure parents are aware of these rights.

Recommendation 2

High-quality, appropriate information about pre-birth testing is made available by health professionals to parents and to the wider community. Information needs to be:

- accurate and comprehensive
- timely: it must be made available before each test or stage of testing, giving the parent(s) as much time as possible to think about the choices
- non-prescriptive: in particular, it must not present termination of pregnancy as the automatic option after a test result indicating a disorder
- wide-ranging: information for parents should recognise the wider dimensions of pre-birth testing, and contain contact details of support groups, counsellors and cultural advisers
- part of best practice: the requirement for health professionals to give such information should be built into their best practices, training, assessment and audits, contracts and services, as well as being part of the role of advisory groups
- appropriate: information and resources must be available in a range of forms and media appropriate to the needs of different individuals and communities, and disseminated through appropriate fora such as kanohi ki te kanohi (face-to-face dialogue) and through language of choice (Māori, English, Pacific and other languages as appropriate).

Recommendation 3

Research is undertaken to determine why some women do not have pre-birth tests such as ultrasound scans.

Recommendation 4

Steps are taken to recruit and train more genetic counsellors and geneticists and to provide an adequate national service, with particular reference to cultural needs and differences.

Recommendation 5

The Ministry of Health continues to work with Māori health providers to identify barriers to antenatal care for Māori women, and The Bioethics Council supports further initiatives to eliminate these barriers.

Recommendation 6

The costs and benefits of better coordinated support services for the disabled should be reviewed.

Recommendation 7

Research is undertaken on the use of preimplantation genetic diagnosis (PGD) to create embryos that are tissue-matched to sick siblings. This work should primarily examine:

- the nature of public concerns
- whether tissue matched children are adequately protected by present laws
- the nature of tikanga Māori associated with this use of PGD.

Recommendation 8

The present distinction between using preimplantation genetic diagnosis to create embryos that are tissue-matched to sick siblings suffering from inherited conditions and using it to help siblings suffering non-inherited conditions should be removed. The only requirement should be that the sick sibling is suffering from a serious condition for which no other treatment is reasonably available.

Recommendation 9

There is insufficient cultural, ethical and spiritual reasons to prohibit the use of PGD for sex selection for social reasons such as 'family balancing.'

Recommendation 10

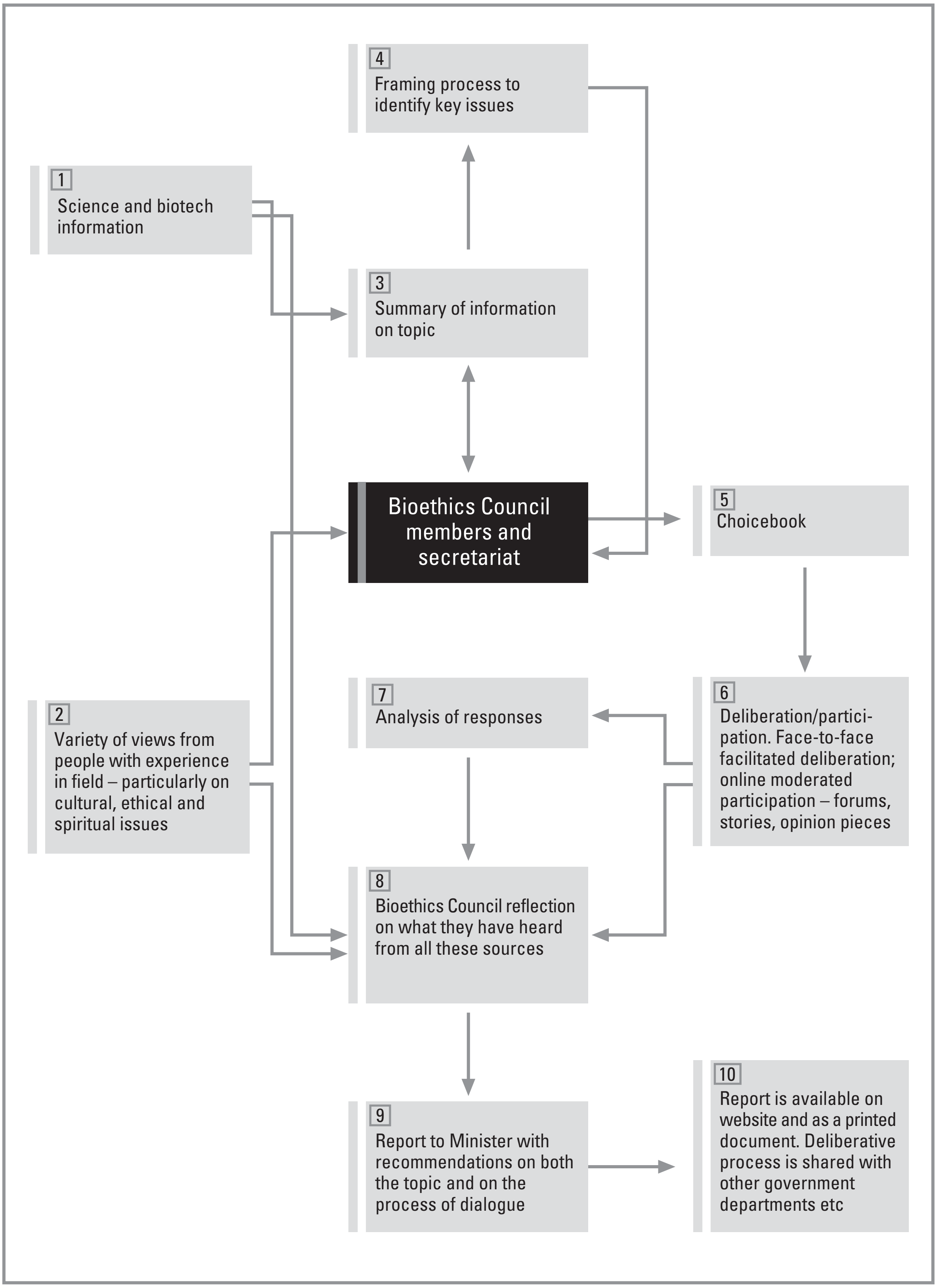
The current provisions allowing the use of preimplantation genetic diagnosis (without the Ethics Committee on Assisted Reproductive Technology's oversight) for late-onset or low-penetrance conditions be retained.

Recommendation 11

The use of preimplantation genetic diagnosis to select against carrier embryos be included in the HART Order 2005 as an established procedure.

APPENDICES

Appendix A: The 'Who Gets Born?' process



Appendix B: Executive summary from Ascentum's final report on the Bioethics Council's Online Deliberation, 26 March 2008

Toi te Taiao: the Bioethics Council (the Council) is scheduled to report to Government in May 2008 on the issue of pre-birth testing. Because pre-birth testing is an issue which touches the lives of so many men, women and children, the Council opted for a very public and participatory approach to framing the issue and developing its recommendations. The end goal was to ensure that the views and values of New Zealanders were reflected in the recommendations that the Council will make to Government – while ensuring that these recommendations are just, reasonable and practical.

An important component of this public engagement initiative was an online deliberation process, which comprised an online choicebook, a stories and ideas submission process, and three online deliberation groups.

> This report outlines the online deliberation methodology and provides an analysis of the input collected through the online deliberation choicebook.

The online deliberation website was launched on 2 November 2007 and closed on 13 February 2008. During this period, a total of 406 choicebooks were initiated (the final completion rate was 69 percent, indicating that 281 of those who began the choicebook responded to the last question).

The following summarises participants' general views on the four approaches that were explored in the choicebook:

Approach 1: 'My choice, my right'

In general, participants were inclined to agree that mothers/parents should have some power on their pregnancy and the tests they undergo. They mostly agreed with letting mothers/parents make their own decisions with respect to whether or not to screen or test, and whether to terminate or continue a pregnancy. However, most believed that it remains important to establish clear guidelines delineating how and for what purpose preimplantation genetic diagnosis (PGD) may be used.

Approach 2: 'Life is a gift'

Participants were widely in favour (over 90 percent support) of the actions from the 'life is a gift' approach that related to helping and supporting persons with disabilities. However, issues regarding embryos and testing generated more division amongst participants.

Approach 3: 'Tāngata whenua perspective'

Participants were generally supportive of actions that would ensure that Māori culture and values are respected. However, it is worth noting that for this approach contrary to the others, proportionally more participants had a neutral opinion across all questions put to them (10 percent to 22 percent). This can likely be attributed to the fact that the vast majority of participants were non-Māori (only 5 percent self-identified as Māori) and might therefore not be familiar enough with Māori values and culture to confidently express an opinion. Consistent with this, participants' responses to this section also reflected a more Western/individualistic perspective.[30]

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[30] The Council ran in-person events specifically for Māori: an issue framing event and four deliberative events.

Approach 4: 'Knowledge is power'

All actions presented in the 'knowledge is power' approach were extremely well received, with between 78 percent and 94 percent of participants agreeing or strongly agreeing with each proposed action.

Setting priorities

In the final section of the choicebook, participants were asked to imagine for a moment that they were the Minister of Finance and to reflect on how they would allocate each slice of $100M 'People's Dollars' in the Government's pre-birth testing programme. They were allocated a total budget of $400M.

Participants allocated the largest proportion of their budget to approach 4, 'knowledge is power' (35 percent), followed closely by approach 2, 'life is a gift' (32 percent). The actions suggested by these two approaches where also those that garnered most support from participants when they reviewed possible actions suggested by each of the four different approaches to pre-birth testing. Approach 1, 'my choice, my right' ranked third (20 percent), while approach 3, 'tāngata whenua perspective', received the least 'People's Dollars' (13 percent). These results are consistent with participants' general reactions to each approach, as outlined above.

On the basis of these choicebook results, a number of observations can be made with respect to participants' general views and attitudes towards pre-birth testing. In general terms, participants:

- were clearly family-oriented and had some experience with or knowledge of pre-birth testing
- were largely of European descent/Pakeha
- recognised the value of pre-birth testing and its potential contribution to foetal/infant/maternal health, but also were keenly aware of the risks associated with pre-birth testing (eg, inaccurate results, harm to the foetus or the mother)
- tended to believe that pre-birth testing should interfere with nature as little as possible (eg, PGD should not be used for sex determination)
- believed that 'saviour siblings' are firstly embryos/foetuses/children, and possible 'treatments' or 'cures' second, thus highlighting that the 'saviour sibling' should be treated with equal care and respect as the child that is ill
- found that making informed decisions with respect to if and what to screen/test for – and how to address the results of these tests – was very difficult and emotionally trying
- believed that decisions about pre-birth testing – and what to do about the results of these tests – belonged with the mother/parents (both in Māori and non-Māori contexts)
- valued life and inclusiveness, thus favouring approaches and actions that focus on helping and supporting persons with disabilities and being less supportive of approaches and actions that suggest discarding embryos and foetuses
- believed it was important to respect and support Māori values and culture, but not to the detriment of the right of mothers/parents to make their own decisions relating to pre-birth testing
- sought customised information on pre-birth testing that goes beyond the medical facts to include ethical, spiritual and cultural aspects
- sought advice and support from adequately trained professionals to assist in their decision-making process
- believed that the public has a role to play in the development of information and policies that relate to pre-birth testing.

Appendix C: Pre-birth testing Project Evaluation (CRESA)

By Julie Warren and Sam Mortlock, Centre for Research, Evaluation and Social Assessment (CRESA)

Summary and conclusions

The Bioethics Council is carrying out a public engagement process that seeks deliberative dialogue, the focus of which is pre-birth testing. Pre-birth testing includes a range of tests before birth that are available to identify whether a child may suffer from possible illnesses, diseases or disorders (including genetic and other conditions). Its use, particularly in genetic testing, is widening. The deliberative process is occurring in two stages, with the first stage (the Framing Exercise) completed over July and August 2007. This involved small groups of invited members of the public intensively working through a prescribed process over a 1-day period. The participants, through a facilitated process, were asked to collectively define the problem situation by identifying the underlying concerns and values, and develop three or four approaches to how pre-birth testing might be dealt with by decision-makers. Six of these exercises were carried out in July and August 2007.

The next stage, the wider deliberative process, will involve taking the approaches developed to a wider audience through a deliberative process.

The evaluation is also in two phases to match that of the deliberative process. Together they are intended to inform the Bioethics Council, as it builds on best practice in both deliberative dialogue processes and their evaluation. The evaluation approach has been informed by evaluations of similar deliberative dialogue processes internationally, and uses previously tested success criteria relating to the ‘acceptance’ of the exercise to the participants and the ‘good process’ that indicates the exercise has been conducted well. The ‘acceptance’ criteria include: representativeness, independence, early involvement, influence and transparency. The ‘good process’ criteria include: resource accessibility, task definition, structured decision-making, and cost effectiveness.

The first phase of the evaluation collected data on the achievement of these success criteria as well as seeking feedback from participants and facilitators about their experience of the exercises. Specifically, the evaluation sought their views of what worked and did not work in the New Zealand context (given that the dialogue process implemented is not a New Zealand model) and how the process could be improved.

Evaluation findings show a high achievement of the ‘acceptance’ success criteria. That is, participants rated the planning and principles underpinning the Framing Exercises highly. They were generally very positive about the extent to which the Framing Exercises provided a fair representation of views of the public about pre-birth testing, lacked any bias in their running, had clear purpose and were sufficiently resourced to enable effective participation. They also had confidence that the Bioethics Council would use the approaches generated as a basis for wider deliberation.

Participants were less positive about the ‘running’ of the Exercises. To some extent, this was a reflection of the newness of the process to New Zealand and the lack of familiarity of the process by the facilitators. For instance, they were less positive about the extent to which the nature and scope of the Framing Exercise was defined; and about the structure and conduct of the Exercise. Some were also concerned about the active role that some Council members took in the Exercises.

Participants’ motivations for participating in the Exercises included, in more or less equal measure, an interest in the technologies themselves and in the development of public deliberative processes in New Zealand. Some were also interested in ensuring that the values and viewpoints of Māori and other minority groups are represented.

People's expectations of the day and the value they gained were consistent with their motivations to participate. That is, they revolved around listening to and understanding a range of values and viewpoints on pre-birth testing, and participating in organising insight into public deliberative processes.

The improvements participants suggested were predominantly around delivery, including the facilitation. They were generally happy with the intention and structure of the day, although they had some concerns about the time available (most thought there was insufficient time to work through the process). Suggested improvements to the delivery of the process included a better description of the process, clearer directions at the start of the day and more clarity around the role of Council and Secretariat members (with some suggestion that their roles could be more passive, with participation when technical input was required).

The role of the facilitator or moderator is key to the effectiveness of the Exercises. The implementation of the earlier Framing Exercises reflected the facilitators' lack of familiarity (and sometimes understanding) of the intended structure of the event. However, as the facilitators became more familiar with the Framing Exercise process, their management of the process seemed to improve. Nevertheless, their reflections of the process, and the experiences of the participants, suggest that early cabability building is still necessary to ensure maximum benefit from future events.

Evaluation findings identified key competencies for facilitators as: a detailed understanding of the intended process; a firm, instructive approach to the facilitation; good organisational skills; and flexibility to accommodate participants' capabilities.

A major consideration for planning and conducting future Framing Exercises is their duration. Time constraints, when the Exercises were held over a 1-day period, meant that suggested time allocations for each phase of the Framing Exercise structure in the 'curriculum' guidelines could not be adhered to. Carrying out future exercises in two full or half days could address these constraints.

The evaluation findings clearly demonstrate the high value participants placed on being involved in the development of deliberative processes in New Zealand. Indeed, an interest in the development of such processes, and involvement in that development, was often as strong a motivating force as an interest in pre-birth testing itself.

The findings also provide evidence that the intention of the deliberative process implemented has resonance for the New Zealand public overall and, it seems, for particular cultural groups. The structure of the day was also sufficiently flexible to accommodate different cultural approaches to deliberation. However, Māori and Pacifica participants would like resources such as the brochure, the DVD, illustrative stories and any statistics used to reflect their cultural values.

There needs to be more recognition of the need for capacity building to maximise the benefits of such public deliberation models. For facilitators, time and other resources need to be devoted to ensuring that they have appropriate understanding of all aspects of the model – the theory and the practice.

And participant readiness to engage also needs attention. It may have been helpful to develop more resources to use at the start of the exercises that clearly lays out what the event will entail, what would be expected of participants and what outputs might look like.

Appendix D: Glossary of terms

Māori expressions used in this document

hapū	pregnant or subtribe
hapūtanga	pregnancy or subtribal
iwi	tribe
iwitanga	tribal
korero	discussion, debate
mana	status, dignity, pride
matauranga	knowledge
mauri	life force
tāngata whenua	people of the land (indigenous inhabitants/native people)
tangi	funeral, to cry
te reo	language
tikanga	custom, rule
tino rangatiratanga	independence
whakapapa	genealogy
whānau	family, wider family
whānaungatanga	familial relationships
whenua	land

Medical and scientific terms

Note: this glossary is aimed at the non-specialist reader and gives brief, general information only.

Abortion	Expulsion from the uterus of an embryo or foetus before it is viable (capable of surviving independently). It may be either spontaneous (occuring from natural causes) or induced (see 'Termination of Pregnancy').
Advisory Committee on Assisted Reproductive Technology (ACART)	The advisory committee established under New Zealand's Human Assisted Reproductive Technology Act 2004.
Amniocentesis	A medical procedure used in prenatal diagnosis of genetic risk factors. A small amount of amniotic fluid (which contains foetal cells) is extracted from the amnion or amniotic sac surrounding a developing foetus, and the foetal DNA is examined for genetic abnormalities.

Carrier testing	Carrier testing is used to identify people who carry one copy of a gene that, when present in two copies, causes a genetic disorder. This type of testing is offered to individuals who have a family history of a genetic disorder, and to people in ethnic groups with an established risk of specific genetic conditions. If both parents are tested, the test can provide information about a couple's risk of having a child with that genetic condition.
Chorionic villus sampling	A prenatal diagnostic test in which a small sample of the placenta is removed for genetic testing of the foetus.
Chromosomes	Nucleic acid protein structures contained in the nucleus of the cell.
Cystic fibrosis	A hereditary disease in which mucus is abnormally sticky, leading to obstruction of passageways in the lungs and in those associated with the gut. It causes progressive disability and early death.
Duchenne's muscular dystrophy	An inherited disorder characterised by rapidly progressive muscle weakness of the legs and pelvis, later affecting the whole body. It appears in early childhood and survival is rare beyond the late 20s.
Ethics Committee on Assisted Reproductive Technology (ECART)	The Ethics Committee established under New Zealand's Human Assisted Reproductive Technology Act 2004.
Embryo	Includes a zygote and a cell or group of cells that has the capacity to develop into an individual, but does not include stem cells derived from an embryo.
Established procedure	Procedures that are not prohibited under the Human Assisted Reproductive Technology Act 2004 and do not require Ethics Committee approval.
Fertilisation	The process (over 22–24 hours) whereby the male and female gametes unite to form a single cell, called a zygote.
Foetus	The early human form, from week eight until the birth of a child.
Gene	A section of the DNA molecule that contains a distinct package of genetic material and is located in a specific site on a chromosome.
Haemophilia	An inherited disorder of blood coagulation in which there is a permanent tendency to bleed (spontaneously or from injury) because an essential clotting factor is either partly or completely missing. The commonest form is sex linked as the gene is carried on the X chromosome.
Human Assisted Reproductive Technology (HART) Act 2004	An Act to secure the benefits of, and regulate, assisted reproductive technology and human reproductive research.
Huntington's disease	A genetic disease that causes cell death in localised areas of the brain, resulting in abnormal body movements, dementia and death. Its onset is usually in the third or fourth decade.

Implantation	The embedding of the early embryo in the lining of the uterus.
Informed consent	A person's voluntary agreement, based on adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic or preventive procedure.
In vitro	In relation to an embryo, a foetus, gamete or cell, this means an embryo, foetus, gamete or cell that is outside a living organism.
***In vitro* fertilisation (IVF)**	The uniting of egg and sperm *in vitro* (in the laboratory).
Late onset condition	A condition developing after childhood.
NGO	Non-government organisation.
Nuchal Translucency (NT) Screening Test	The NT test uses ultrasound to measure the clear (translucent) space in the tissue at the back of a developing baby's neck. In some developmental abnormalities, there may be an accumulation of fluid in this space. Babies with abnormalities tend to accumulate more fluid at the back of their neck during the first trimester, causing this clear space to be larger than average. For diagnostic purposes, the NT scan should be done when the woman is between 11 and 14 weeks pregnant.
Penetrance	The extent to which a genetically determined condition produces its specific effect in an individual carrier.
Preimplantation	The state of an embryo before it adheres to the lining inside the uterus. In most successful human pregnancies, the preimplantation state lasts for 8 to 10 days.
Preimplantation genetic diagnosis (PGD)	The genetic testing of an embryo before it is implanted into the uterus. Either the polar body of the egg or a cell from the four- to eight-cell embryo may be extracted for biopsy.
Prenatal diagnosis	A medical test intended to detect a disorder in the foetus during pregnancy; diagnostic techniques include amniocentesis, ultrasound and chorionic villus sampling.
Termination of pregnancy	A medically directed miscarriage before independent viability, using pharmacological or surgical means.
Ultrasound	A procedure that uses high-frequency sound waves to scan a woman's abdomen and pelvic cavity, creating a picture (sonogram) of the baby and placenta. Although the terms ultrasound and sonogram are technically different, they are used interchangeably and refer to the same examination.
Uterus	The womb; the female reproductive organ in which a fertilised egg implants and a foetus develops.

Appendix E: References, resources and further reading

Advisory Committee on Assisted Reproductive Technology (2007). *Annual Report 2006-2007*. Wellington: Advisory Committee on Assisted Reproductive Technology.

Frankin, S. and Roberts, C. (2006). *Born and made: an ethnography of pre-implantation genetic diagnosis*. Princeton, N.J. Woodstock: Princeton University Press.

Glover, Marewa and Rousseau, Benedicta (2007). 'Your Child Is Your Whakapapa': Maori Considerations of Assisted Human Reproduction and Relatedness. *Sites: a journal of social anthropology and cultural studies. New Series* Vol 4 No 2.

Gunning, J., ed. (2003) *The regulation of assisted reproductive technology*. Aldershot, Hants, England: Ashgate.

Human Genome Research Project (2007). *Genes Society and the Future* Volume II. Dunedin: University of Otago.

Mead, H. M. (2003). *Tikanga Māori: Living by Māori Values*. Wellington: Huia Publications.

Mead, H. M., and Grove, N. (2001). *Nga Pepeha a nga Tipuna*. Wellington: Victoria University Press.

Ministry of Health (2007). *Antenatal Down Syndrome Screening in New Zealand 2007: A Report of the Antenatal Down Syndrome Screening Advisory Group to the National Screening Unit*. Wellington: Ministry of Health.

Ministry of Health (2007). *Report on Maternity: Maternal and Newborn Information 2004*. Wellington: Ministry of Health.

Port, Ramari Viola (2007). *He Whakamatautau pi tauo mo te mate pukupuku: Nga Tikanga a te ao Māori. DNA Testing for Cancer Susceptibility: The Needs of Māori*. Unpublished PhD thesis, University of Auckland.

Snelling, Jeanne (2008). Embryonic HLA Tissue Typing and Made-to-Match Siblings: The New Zealand Position. *Medical Law International* 9(1) 13-44.

Statistics New Zealand (2005). *Māori Population: Looking out to 2021*. Wellington: Statistics New Zealand.

Tamasese Ta'isi Efi, T.A.T. (2007). Bioethics and the Samoan Indigenous Reference. Keynote address, UNESCO Regional Pacific Ethics of Knowledge Production Workshop, Tofamamao Conference Centre, Le Auvaa, Samoa 12 - 15 November. Available at http://www.unesco.org.nz/download/8_Keynote_Address.doc/

The Bioethics Council (2007). *Who Gets Born? Pre-birth Testing Choicebook*. Wellington: Toi te Taiao: The Bioethics Council.

List of relevant legislation

Crimes Act 1961

Health and Disability Commissioner's Code of Health and Disability Services Consumer Rights Regulation 1996

Human Assisted Reproductive Technology Act 2004

Human Assisted Reproductive Technology Order 2005

Local Government Act 2002

Resource Management Act 1991