

Submission to the Advisory Committee on Assisted Reproductive Technology on the Draft Guidelines for the Use of Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Testing

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 46 nationally organised societies. It has 26 branches throughout the country attended by representatives of those societies and some 150 other societies, as well as individual members.

The Council's functions are to serve women, the family and the community at local, national and international levels through research, study, discussion and action. NCWNZ welcomes the opportunity to consider this consultation document. This response was prepared by the Public Issues Standing Committee after consulting with members.

General Comments

Of primary concern for NCWNZ would be the rights of the child specifically produced for the purpose of donation. The child born for this purpose has no choice in the matter. It may be very difficult for them in later life, to deal with the reason for their being. There needs to be adequate protections for any child born from the use of this procedure and that having a legal advocate to protect their rights should be considered.

NCWNZ has stated in other submissions on new birth technologies that "too much emphasis on and publicity about the new methods of conception may result in the children being treated differently from other children by their parents, by the medical profession, by researchers, by society. They have an absolute right to be regarded in all matters as ordinary children."

This process is unlikely to be used very often but if the procedure is not permitted here, some parents might consider travelling abroad for the treatment, so perhaps it would be better to provide good domestic oversight of the procedure.

Specific Comments - Response to questions.

Question 1. Have the key issues been identified and adequately addressed in the guidelines?

The branches responded that guidelines are clearly set out and identified and have adequate safeguards included.

An opposing response was that PGD using HLA tissue typing is contrary to the Catholic Church's teaching.

It is believed that PGD using HLA tissue typing should continue to be restricted and not be extended to benefit close relatives rather than be genetic siblings.

There are questions about the legal considerations. Has family separation been taken into account?

Question 2. Do you have any other comments for improving or clarifying the guidelines.

One organisation responded that the wording is vague. Parents need to know and understand that there is no compulsion to have the procedure done, despite medical and counselling efforts. There should be an addendum i.e. “but do they know that there is no compulsion to undertake the procedure”.

It is of great concern that the dignity of children is being compromised with these extreme procedures. Are babies becoming “commodities”? Is a baby a means to an end? This group felt this research is close to ethical boundaries.

Question 3. Do you have any other comments for improving or clarifying the guidelines?

Members had no other comments to add.

Conclusion

NCWNZ is pleased to have the opportunity to participate in this consultation process. The NCWNZ Book of Resolutions reflects discussion on the establishment...’of a multi-disciplinary committee to monitor the development and use of artificial human reproduction technology...’(9.2.1, 1984) Then, as now, the membership was cautious about these developments, as in 1992 there was a call for the then ministers.. ‘to expedite the establishment of national guidelines for assisted reproductive technology’.(9.2.4). A further call in 1994 asked that the ‘...report “Assisted Human Reproduction: Navigating Our Future” be referred to the Justice and Law Reform Select Committee for public submissions in order to facilitate and expedite legislation on the vital issues involved.’ (9.2.5)

It is encouraging that as technologies become more precise in their ability to assist safe healthy human reproduction, public consultation is still being undertaken.

Many of the issues raised in the summary of submissions included in the discussion document are echoed by NCWNZ members, yet in general it was felt that the guidelines as drafted would adequately cover all contingencies likely to be raised in this difficult and sensitive area of families’ hopes and dreams.

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