

POSITION ON GENETIC AND PRENATAL TESTING TECHNOLOGIES



CONTEXT

In taking this position we are concerned with the extremely high rates of termination of fetuses thought to carry disability related traits and the process and flow of research, development, assessment, approval and clinical and health care application of genetic and testing technologies (hereafter referred to as genetic and testing technologies) as well as the associated clinical, health care and public policy regulations and protocols for such technologies. We are further concerned that the protection of women's reproductive rights, which are recognized and supported by Inclusion Canada, are being used inappropriately and disingenuously as justification for the elimination of fetuses with disability related traits, reinforcing discriminatory and negative attitudes towards people with disabilities rather than the protection of the rights of women.

PURPOSE:

The purpose of this position is to make clear Inclusion Canada's position and bring detail to Inclusion Canada's beliefs and values with respect to principles that we believe must guide the processes involved in the production and use of genetic and testing technologies.

POSITION:

In taking a position related to genetic and testing technologies, we are motivated by the following concerns:

We are concerned that the pervasive stigma and devaluation of people with disabilities is replicated and reinforced by clinical practice which encourages both overtly and covertly the elimination of fetuses thought to be carrying disability related traits.

We are concerned that within the current practice regime and broader social attitudes towards people with disabilities prospective parents are unduly influenced towards termination of fetuses thought to be carrying disability related traits.

We are concerned that the accelerating trend towards the identification and termination of fetuses thought to be carrying disability related traits will both reduce the diversity present in society and reinforce negative and discriminatory attitudes towards people living with a disability and their families.

We are concerned that with the rapidly advancing field of research and development of genetic and testing technologies, and with associated health care and public policy regulation and practice, there is a lack of guiding values and principles to recognize and protect against negative impacts on people with disabilities and their families including:

- Continued and systematic devaluation of persons with disabilities;
- The danger of an erosion of the commitment to provision of needed supports to people with disabilities and their families as a public good; and
- Similarly, the danger of an erosion of the public commitment to inclusion and diversity.
- We are concerned that clinical ethics that do guide the current flow of research, development, approval and application of such technologies are based on a limited notion of personal autonomy and consumer choice without recognition of prevailing power structures that influence and manufacture demand for such technologies and reinforce a perceived duty to access such technologies as a matter of routine prenatal care.
- We are concerned that although this is an issue with far reaching public policy implications, there are not public spaces for discussion and negotiation of the potential impacts.

Given these concerns; and

Reaffirming our belief in the value, dignity and contribution of all human beings including those with disabilities,

Inclusion Canada opposes the selective termination of fetuses based on the presence of disability related traits;

Inclusion Canada opposes the continued investment of public funds in the expansion of genetic and related pre-natal tests for disability related traits while the current climate of prevailing negative attitudes towards people with disabilities remains the norm and calls for such funds to be redirected towards providing an adequate system of supports for the inclusion of people with disabilities within society;

Inclusion Canada renews its call for fair, balanced and disability positive information to be provided to both clinicians and prospective parents on the value, contribution and dignity of persons with disabilities within society;

Inclusion Canada opposes the use of pre-natal testing when conducted in a way which condones, supports and reinforces discriminatory or negative attitudes and practices towards people with disabilities and women through selective termination and calls for strict regulation to ensure such usage is eliminated.

Inclusion Canada will continue to work with key stakeholders to revise public policy, clinical practice and broader social attitudes in line with the above position.

DISCUSSION: WHY NOT CALL FOR AN OUTRIGHT BAN ON TESTING FOR DISABILITY RELATED TRAITS AND TERMINATION OF FETUSES THOUGHT TO CARRY THEM?

While our opposition to the termination of fetuses based on the presences of disability related traits would seem to lead naturally to a call for a ban on testing and termination, several factors mitigate against this position.

First, on a practical level, disability is a broad, non-specific concept. Testing is not done for disability per se, but rather for specific conditions, some of which may be disability related and others defined more as diseases or illness. In this context we would either have to ban all testing or create a list of those conditions for which we oppose testing. In the first case we would deny prospective parents the possibility of both preparations for the birth and potential interventions which may mitigate the condition. In the latter case, we would be faced with a large and ever expanding set of conditions and be forced to determine which constitute a disability and which are not and in essence be placed in the very position we are arguing against, that is, determining who is worthy of life.

Complicating this first practical issue is the fact that it is not necessary to provide the reasons for terminating a pregnancy. Advancing a position against testing or selective termination on the basis of disability, would encounter similar practical issues as those encountered by groups that wish to advance a ban on selecting for sex.

A second problem with a call for an outright ban is more theoretical, that is the conflict over the rights of prospective parents to comprehensive pre-natal care and information, women's reproductive rights and the rights of persons with disabilities to live in an inclusive society where their genetic characteristics are not devalued as a matter of public policy—i.e. public funding of screening and testing for such traits, defining them as abnormal, and funding genetic counselling which may encourage termination on that basis. While questions of rights are often ones of balance, this 'balance' is partially complicated by the fact that fetuses under Canadian jurisprudence do not have rights. In essence an outright ban on testing would privilege one set of rights over these others.

A related concern has to do with liability issues. To actively withhold information or readily available tests from prospective parents would engender wrongful birth claims against the health care practitioners and potentially the State for failure to provide optimal pre-natal care. While the latter case would be debatable it is almost certain to engage the State in a lengthy and complex legal challenge which they are unlikely to want to take on.

A final concern is more political. The advance of equality rights cannot be achieved without solidarity between disadvantaged groups. Rightly or wrongly in this case, a call for a ban on testing and/or terminations would be seen as a challenge to women's reproductive rights. This has become more acute of late with those opposing women's reproductive rights using the pretense of protecting persons with disabilities in order to restrict women's reproductive rights. A more productive approach would be to engage the women's movement in discussions on the need to ensure that pre-natal technology is not used to knowingly or otherwise, to reproduce discriminatory norms through the elimination of female or disabled fetuses. This would lead to stricter regulation of health

This would lead to stricter regulation of health decision making and genetic counselling processes rather than an outright ban on testing or termination.

Ultimately no ban on testing or termination will address the root cause of the problem, the pervasive negative attitudes towards disability. On the other hand, if we continue to work towards a society which values diversity in all its forms, the need for a specific response to pre-natal testing and termination will be reduced. While the goal of a fully inclusive society remains elusive, this remains the only real solution to the problems presented by pre-natal testing and the elimination of fetuses with disability related traits.

Resolution 2013-2: Inclusion Canada Position on Genetic and Prenatal Testing Technologies

BE IT RESOLVED THAT Inclusion Canada opposes the selective termination of fetuses based on the presences of disability related traits;
Inclusion Canada opposes the continued investment of public funds in the expansion of genetic and related pre-natal tests for disability related traits while the current climate of prevailing negative attitudes towards people with disabilities remains the norm and calls for such funds to be redirected towards providing an adequate system of supports for the inclusion of people with disabilities within society;
Inclusion Canada renews its call for fair, balanced and disability-positive information to be provided to both clinicians and prospective parents on the value, contribution and dignity of persons with disabilities within society;
Inclusion Canada opposes the use of pre-natal testing when conducted in a way which condones, supports and reinforces discriminatory or negative attitudes and practices towards people with disabilities and women through selective termination and calls for strict regulation to ensure such usage is eliminated.
Inclusion Canada will continue to work with key stakeholders to revise public policy, clinical practice and broader social attitudes in line with the above position.
Passed by Inclusion Canada membership at the December 1, 2013 Annual General Meeting.