

**Missing the Forest for the Trees? A Disability Rights Take
on Genetics**
**Commentary on Stowe et al., Journal on Developmental
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As the paper "Looking to the Future: Intellectual and Developmental Disabilities in The Genetic Era" (this issue) suggests, the issues raised by genetic and related technology may in fact be the most profound that the disability community has faced since the heyday of the eugenics era. In light of this, it is somewhat puzzling why the authors have not chosen to articulate more clearly the primary concerns of the disability community or to provide a more critical analysis of these issues and some of the more pressing, albeit radical from some perspectives, responses that the disability community needs to be considering in earnest. Given that we are at a point where 60 to 80 percent of all fetuses with Down syndrome are being selectively aborted and the only reasons incidences rates are not dramatically falling are the rise in maternal age and the slow methodical consideration of all the nuances and complexities of genetics, this seems an insufficient response. Below I offer a somewhat more radical take on genetics and intellectual disability and offer some suggestions on what kinds of responses need to be considered.

As noted above, the termination rates for Down syndrome are already alarmingly high. With improvements in Maternal Serum Screening, which will be approaching the reliability of the invasive diagnostic test (CVS & Amniocentesis), and high definition ultrasound soon to be readily available, we can anticipate that more "conditions" will be identifiable at an earlier time and that more people will choose to undergo prenatal testing given that the risks of obtaining false negative or false positive results are reduced. Add to this the trend to extend testing to all pregnant women as opposed to those traditionally thought to be at high risk, something most Canadian Provinces now do or are planning to do, we can reasonably anticipate that more selective abortions based on impairments associated with disability will be the result.

A further concern is the rise in Pre-implantation Genetic Diagnosis (PGD) and embryo selection. In Canada, PGD is relatively uncommon at the moment. Regulated under the Assisted Human Reproduction Act, currently only sex selection is prohibited, but this is waived in cases of sex related

disorders. The specter of designer babies is no longer science fiction, and one can presume disability is not part of that design. From a more philosophical perspective, the question of "Who should inhabit the earth?" or, more specifically, "Is the world a better place without persons with disabilities?" is already upon us.

So what are the arguments from the disability community against the selection for disability-related traits? Overlaying all of the arguments is the theory of social construction. That is, that disability is not inherent in the individual but rather is a function of social norms, arrangements, prejudices, and perception. In light of this, the selective elimination of fetuses and embryos with disability-related traits is seen as the ultimate expression of prejudice, the elimination of an undesirable social trait through science and medicine. While sex selection is generally banned to prevent the reproduction of patriarchal norms, disability, it is argued, needs the same protection.

A key argument against selective elimination is known as the "expressivist" argument. Simply put, it argues that by allowing elimination based on disability traits, we are expressing and reinforcing negative attitudes towards those who currently live with such traits; and this can only increase discrimination and inequality against people with disabilities. Put more starkly, can we on the one hand support and encourage the elimination of disability-related traits while at the same time arguing for equality and inclusion?

Other key arguments include the "traits versus persons" argument. This argues that by eliminating based on a single trait we are allowing a single trait to stand in for the person, or a potential person; in essence the disability-related traits negate everything else the person might be or become. Related to this is the identity argument which argues that disability, rather than simply being a function of an impairment, can plausibly be seen to be a constituent part of a person's identity, similar to sex or race. Hence, elimination based on disability-related traits amounts to eliminating a devalued identity rather than a disease or disorder.

So the question is really, do we want a world where we weed out through technology persons who carry traits we currently devalue? We currently see a similar scenario playing out in India where up to 9 out of 10 female embryos and fetuses are being selected out; can we argue against this while supporting similar practices with regards to disability?

In light of the above, the disability community needs not only to educate itself, but to actively seek to prevent the unfettered use of technology based on social prejudice. But what can be done? We can begin by questioning the enormous sums of money being spent to identify and eliminate disability while families and individuals struggle to get basic services. Regardless of how one feels about the above arguments, the practical economics in publicly funded health and welfare systems creates important public policy questions about the use of scarce public funds. Currently in Canada there is a public consultation on further regulation of the PGD under the Assisted Human Reproduction Act. The disability community needs to be calling for serious limitations and controls on the use of PGD to reinforce social biases with regard to disability. The expanding profession of genetic counselling, which has been shown to reduce the rates of termination of fetuses with Down's syndrome markers, needs to hear from the disability community. We need to ensure that curriculum includes strong disability content which is unbiased and is reflected in practice. Finally, the disability community needs to continue in earnest working towards inclusion and changes to public perceptions of persons with disabilities. Ultimately, it will only be the full inclusion of persons with disabilities that will change the perception that disability is something to be feared and eliminated to something that is part of the normal fabric of a diverse and inclusive world.

References

- Stowe, M. J., Turnbull, H. R., Schrandt, S., & Rack, J. (2006). Looking to the future: Intellectual and developmental disabilities in the genetics era. *Journal on Developmental Disabilities, 13*(1), 1-64.

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