



## Pre-natal screening, testing and choice: The Misconceptions of Disability

### Introduction

Medical models of disability have been instilled in the health professional tenet and have influenced the values and perceptions of parenting and family that the lives of people with disability have been under threat from before birth.

First trimester screening for Down Syndrome or Trisomy 21 is increasingly accurate. In hospital and medical information, first trimester tests are heralded as a means to inform parents about potential problems during the pregnancy, and to reduce complications for women who choose abortion.<sup>1</sup> By that standard they are successful. Few fetuses with trisomy 21 detected in the first trimester are likely to be born at all.

The literature explains testing as risk reducing, and as a way to ensure that women suffer no harmful effects from reproductive processes. Commonly, women are encouraged to see the birth of a child with Down syndrome as a “harmful effect” of their pregnancy.

It is difficult to justify prenatal screening for some conditions associated with disability as a means to protect the health of the foetus or child, or as a means to protect women from the harmful effects of reproduction. Prenatal tests<sup>2</sup> for Down syndrome, cystic fibrosis, femaleness or brown eyes should be seen for what they are, and more importantly, what they are not. They are not medical procedures intended to protect or restore an individual’s physical or mental health. Principally, they are procedures to identify potentially unwanted fetuses. Testing may be sought to guide the management of delivery and labor, but more often its purpose is to provide information about foetal characteristics so a woman can decide whether or not to continue her pregnancy.

### Different choices

To say that prenatal testing and any resulting abortion are not medical procedures does not mean that the practice of or motivation for it is without question. Women have a right to choose to end a pregnancy. They have a moral right to decide what to do with their bodies. A pregnancy test for a minor who has been raped and who does not want a child is not a medical procedure either, and nor is the abortion that may follow positive pregnancy test results.

The test and any subsequent abortion are justifiable, and a doctor is the appropriate agent to carry them out, but that does not mean they serve to protect or restore the patient’s health. If doctors properly can perform a non-healing intervention in aborting an unwanted foetus, should the same ethical reasoning apply when enabling parents to prevent the birth of a child with Down syndrome? The answer will depend on whether there is a distinct justification for the intervention that is not based on protecting or restoring the health of individual patients.

### Testing mythology: Public health

<sup>1</sup> See, for example, Mater Mothers’ Hospital. 2016. *Pregnancy—testing for Down Syndrome and other chromosome abnormalities - Information for expectant parents*. <<http://brochures.mater.org.au/brochures/mater-mothers-hospital/pregnancy%E2%80%94testing-for-down-syndrome-and-other-chro>>

<sup>2</sup> Prenatal diagnosis may be conducted, for example, *via* amniocentesis, chorionic villus sampling, or preimplantation genetic diagnosis (PGD).

Two reasons are commonly given for prenatal testing. The first is the public health rationale, and the second is enhancement of parental autonomy. The public health goal is to reduce the incidence of genetic disease and defects. Prenatal tests prevent disease and disabilities because they are a first step in preventing the existence of people with them.

Prevention by prenatal screening lacks one of the common justifications for public health measures: the prevention of medical harm to existing people. It may be reasonable to treat the incidence of disability among existing people as, in part, a public health problem. It is problematic to treat the existence of future people with disabilities that way.

A policy that provides for tax-payer funded screening appears to reflect a judgment that lives with those screened-for conditions are burdensome to the child, their family and to society: burdensome to the extent that to avoid them is a health care priority. That judgment exaggerates and misattributes many of the difficulties associated with those conditions.

The principal difficulties faced by people with disabilities and their families stem from discriminatory attitudes and practices. The remedy is social, legal, and institutional change, to be achieved by the same means as difficulties associated with being female or Catholic: through legislative and social reform. Condoning the selection of embryos and fetuses with disabling traits perpetuates the misconception that the problem is the disability rather than a society that could do so much more to welcome and include all its members.

### **Parental autonomy**

The second reason offered in support of prenatal screening is enhancement of parental autonomy. The justification for enabling a woman to decide whether to have a child surely is stronger than the justification for enabling her to decide what kind of child she will have.

Pregnancy makes demands on a woman's body, and parenthood involves an enormous, open-ended commitment. To treat the choice between having a disabled or a non-disabled child as one that is of a similar magnitude to the difference between having and not having a child at all exaggerates the burden of disability and ignores the social sources of so much of that burden.

People with disabilities and their families face difficulties in our present society, and perhaps some of those difficulties would remain even after comprehensive social reform. Few disabilities are so undesirable that they provide good reason for abandoning a parental project all together: for declining to become a parent to the child who would develop from the diagnosed fetus. Given the difficulties that a disabled child is likely to face in our present society, a prospective parent may have good reason not to cause disability, but that is not reason enough to select against a fetus with a disability. The ideal of unconditional welcome is one that is opposed to the exercise of selectivity through prenatal testing.

If a child develops a disease or a disability such as diabetes or acquired brain injury (most disabilities are caused by accidents or disease, not by genetic variations) loving parents incorporate the challenges into the way they raise and nurture that child. Society does not condone the rejection of those challenges.

If, on the other hand, we accept the use of biomedical technology to give parents greater choice in the kind of children they have, how could we justifiably limit that choice to the avoidance of genetic impairment? To be consistent, we must permit testing for any conditions parents might find burdensome or desirable, such as gender, sexuality, eye-colour, height, skin color or intelligence. Even if we are comfortable with such parental selectivity, enhancing it should not enjoy the priority given to measures that protect the choice about whether to become a parent in the first place.

## Conclusion

If we object to unfettered choice as a corruption or debasement of the parental role, we should not make an exception for disability. To do so is to treat disabilities as uniquely burdensome, in the face of contrary evidence from research on families with children with disabilities.<sup>3</sup> To assume that most genetically detectable disabilities impair the prospects for individual and family flourishing in a way that other potentially detectable characteristics do not is to stigmatize disability. Such stigmatization may be understandable when it is displayed by anxious couples awaiting a life-transforming event, but it should not guide the public funding of reproductive research or the formulation of reproductive policy.

Given the difficulties in justifying the public funding of research and development in prenatal screening, the money spent for that purpose might be better used for research on improving the health, functioning, and longevity of children with genetically based disabilities.

<sup>3</sup> For example, C Baxter *et al.* 1995. A longitudinal study of parental stress and support: from diagnosis of disability to leaving school in *International Journal of Disability, Development, and Education*;42:125-136. P Ferguson. 2001. "Mapping the family: disability studies and the exploration of parental response to disability" in G Albrecht, K Seelman and M Bury. 2001. *Handbook of Disability Studies*. Thousand Oaks, Calif: Sage Publications.