

CONFRONTING THE DISTORTIONS: Testing for Down Syndrome

by Lisa Bridle

Dr Lisa Bridle is a bioethics worker at Queensland Advocacy Inc and the mother of ten year old, Sean, who has Down syndrome. As part of her doctoral research, she interviewed mothers of children with Down syndrome about their experiences of prenatal testing.

Prenatal testing, once limited to women considered 'high risk', is increasingly a routine part of all pregnant women's antenatal care. Testing is presented as not only benign and unproblematic, but also as fulfilling responsible pregnant behaviour.

Alongside this construction of prenatal testing as a 'beneficial medical advance', disability continues to be constructed in wholly negative and prejudicial ways. Earlier testing and multiple, periodic forms of testing entrench a consensus that the rational response to a positive prenatal diagnosis of disability is termination.

One mother in my study had revealing discussions with a geneticist shortly after her son's birth:

'One thing the genetic counsellor said was, you know, when you have a child with Down syndrome you do need to consider the impact socially, the child has on society, that they will never be a wage earner and that they draw from society and I remember thinking at the time that's one very odd sort of statement!'

The genetic counsellor then suggested Jenny consider the impact having one child with disability was already having on her daughter and her marriage.

‘(I thought) have I let the whole of society down and my family down and my daughter down? Is this what you’re saying to me? I’m unable to contribute to society because I’ve got a child who is non-productive, excuse me?...He’s like three months old...I mean John may grow up to be a terrific artist, or he may just be himself and give a lot of people a lot of joy. Then, the relationship with Emma, I felt crucified over that. And then my marriage...and I felt well there’s probably not a lot left when you take that away.’

The idea that people with disability contribute to their families and to the community and that the experience of disability adds to our understanding of what it is to be a human being, is readily dismissed as irrational or sentimental. Even where it is acknowledged that parents can find the experience rewarding, they are considered ‘lesser’ rewards.

Because there are few treatment options, testing is fundamentally linked to the option of ‘therapeutic’ abortion. This reality is often obscured. Prenatal diagnosis is marketed as a form of ‘reassurance’ rather than a form of prenatal selection. In fact, testing may merely relieve the anxiety which has been artificially raised by the testing itself. Testing also offers a very limited form of reassurance; a normal set of chromosomes does not rule out the possibility of disability.

There is also the existence of the implied ‘next step’ and a momentum which makes almost instantaneous decision-making preferable to any prolonged introspection about the implications of a positive test result. Statistics indicate that less than 16 per cent of couples continue pregnancies following a diagnosis of Down syndrome. Proponents of prenatal testing often offer the high rates of termination as proof that they are meeting consumer demand.

How different the statistics might look if couples were given access to families with disability—if they were told first-hand about not only the demands but the resources, not just the stresses but the rewards, that siblings are not usually adversely affected but share warm relationships with their brother or sister with disability, that many couples find their marriage enriched not threatened and that overall the experience is positive and ordinary. Indeed, a genetic counselling service which actively encourages post-diagnosis contact with families who have a child with Down syndrome reports that 38 per cent of couples continue their pregnancies.

In my previous role as a parent support contact for the Queensland Down Syndrome Association, countless professionals have told me that parents are not coping with the news or that they are severely depressed. When I speak to the parents and listen to what they have been told (or significantly not told), I am not surprised that they are ‘depressed’. I know that my own reaction to Sean’s birth was made so much more difficult by the pity and scaremongering of some professionals.

There can be no doubt that for most people, the news that your child or potential child has a disability will be painful, disorientating, even devastating. My ongoing contact with families I first met in those raw early days makes it clear however that parental ‘suffering’ does end, and that the great majority of families adjust well to their new circumstances, despite the often real demands which exist. If obstetricians and counsellors consulted families who had survived this painful early period, they may be more likely to offer more than an ‘empathetic’ termination.

The women I interviewed described remarkably similar stories of adjustment to the news of their child’s disability; familiar stories of disappointment and compromised dreams, gradually replaced by hopefulness and a realization that life continues ‘normally’ and ‘ordinarily’. The salience of the label of Down syndrome becomes greatly reduced. The participants described their initial expectations as foolish, rooted in ignorance and based on a skewed expectation that their life would be irrevocably changed in negative ways.

Routine testing can be difficult to decline and so can diminish autonomous choice. Many feminists have critiqued prenatal testing on the grounds that prenatal testing regimes contribute to the medicalisation of pregnancy and actually diminish women's control over their own bodies. Additionally many have recognized that decision-making often occurs without adequate knowledge of the purpose of the testing or about the conditions for which testing is conducted.

Down syndrome is 'well recognized' and particularly surrounded by unhelpful stereotypes. The diagnosis of Down syndrome is assumed to provide sufficient information on which to make a decision to continue or terminate a pregnancy. In contrast, while the chromosomal result for Down syndrome is definitive, the message from mothers of children with Down syndrome is that diagnosis does not tell you how your life or the life of your child will be.

It is the common wisdom of parents of children with Down syndrome that the first days after diagnosis are the hardest—the time when it is most difficult to think calmly and realistically. Some doctors push women to make decisions quickly while still reeling from the diagnosis. Julie was strongly encouraged to terminate her pregnancy the same afternoon she received the diagnosis.

“They were ready to take us up there straight away and do it. There was no, ‘Here’s the number for the Down syndrome association,’ or anything...there was no information. They were just thinking, ‘Down syndrome—get rid of it.’”

Prenatal diagnosis also raises profound questions about the value of children and the sort of human community we are creating. The journey into parenting any child is a leap of faith, one that requires considerable courage—we cannot control either our children or the circumstances they are likely to meet. When the child has a disability the fears can be more intense. However, many mothers I spoke with described a journey of surrendering control, of learning that there were ‘no guarantees’, a belief that ‘things happen for a reason’ and a discovery that giving up one’s prior expectations of motherhood and of your offspring could be a gift.

This idea that having a child with disability had brought a richer life was very common in my interviews. The positive changes included having one's prejudices about disability dismissed, discovering one's own resilience and strength and the ability to speak up for yourself and your child, and feeling a strong sense of what really mattered.

Many participants believed aborting children with Down syndrome was a 'loss for society'. While endorsing women's rights to testing and termination, and believing that testing was the right decision for her, Jenny felt some degree of complicity with a system which sees the prevention of Down syndrome as a social good. "I told someone that my doctor was doing the test and they said 'Oh, he's very good, he rarely misses one'. I just felt so ashamed! It's terrible, that's such a dreadful thing to say, and it's such a loss, and it's a loss for our society and the way we think and what we value...You hear stories about millionaires, or (successful) women...and they're being held up as these you know, icons and everything...(but) being just a really nice person like John is, and having such potential for joy and just, you know, being true, is not considered worthy."

There is a disturbing gap between the technological momentum of prenatal testing and discussion on the impact of these developments. The current practice of routine prenatal testing presumes that the ethical questions are 'settled'. They are not. We need to challenge the idea that reducing the incidence of Down syndrome through abortion is an honourable goal. We need to consider this goal as a threat to the richness and diversity of our community. We need to understand that people with disability are valuable and necessary members of our community. []