

# More thought needed on prenatal screening

by Elizabeth Callinan

There is a Frida Kahlo quote that I love. It translates as: 'I don't want you to think like me, I just want you to think.' The Mexican artist was no stranger to disability. She had polio as a child and injuries from a later car accident further impacted her mobility. Frida's words have resonated with me as I've become immersed in the ethics of prenatal genetic screening.

Around 400,000 Australian women will become pregnant this year. Ask these women and their partners what they want for their child and they'll likely tell you 'I just hope they're happy and healthy'. In many people's minds, the first step towards this goal is pre-natal screening. Non-invasive prenatal screening (NIPS) is a relatively new procedure where the mother's blood can be tested at 10 weeks to screen for chromosomal conditions such as Down syndrome.

President and CEO of biotech giant Illumina, Francis deSouza, recently tweeted about the astonishing worldwide growth of NIPS. He reported an estimated 8 million performed globally in 2019 – up 20% from 2018.

In Australia, the Medical Services Advisory Committee is currently considering an application to place this test on the Medical Benefits Scheme (MBS). If included on the MBS, this would mean more Australian women accessing screening technology earlier in their pregnancy. But there is concern within the Down syndrome community and beyond about the ethical implications of the wider use of prenatal screening without providing information to make an informed choice.

Families rely on accurate and balanced information from healthcare providers when making decisions about whether or not to continue a pregnancy based on their screening results.

In the case of Down syndrome, how are women and their partners supported to understand what an extra 21st chromosome really means? Or what it doesn't?

Those in the Down syndrome community know that it is not uncommon for health professionals to apply a medical model of disability by confusing Down syndrome with disease and assuming a lifetime of suffering for the child and their family. Years later, many still recall word for word the medical response to the diagnosis, often beginning with 'I'm sorry'.

In a recent hearing for the Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability, Toni Mitchell recalled how she was told during an ultrasound, 'it's highly likely your son has Down syndrome . . . so here's your appointment for a termination.'

Australian pathologist and scientist Professor John Rasko understands that Ms Mitchell's experience was not an isolated incident. In his 2018 Boyer lecture series he said, 'When pregnant women and their partners take up the option of prenatal testing, there's an in-built expectation that they'll end the pregnancy if Down syndrome is diagnosed.'

Professor Rasko recognised that for many people living with Down syndrome or other genetic differences, and for their families, selective termination is personal. He wondered, 'Doesn't it imply to some extent that their lives are basically not worth living? That it would have been better had they never been born?'

Well, yes. When I hear that nine out of ten prospective parents choose termination following a Down syndrome diagnosis it's hard to not take it personally. Don't they want a child like mine?



When I watch the soft focus prenatal screening marketing videos promising ‘relief’ and ‘reassurance’ it’s hard not to feel the value of my daughter’s life is being called into question. When I read the list of potential problems that health professionals hand out to prospective parents about a Down syndrome diagnosis, I immediately begin drafting counterpoints.

Self-advocates and their families are often eager to tell prospective parents a different story.

In contrast to the medical model, which views genetic differences such as Down syndrome as aberrations to be avoided, many in the Down syndrome community understand disability through the lens of the social model of disability. This model was first articulated by British sociologist, author and disability rights activist Michael Oliver and he originally used it to refer to physical disability. More recently it has been adapted to include intellectual disability. The social model advocates for better understanding and accommodation of disability as an expected part of human diversity. The phrase ‘I wouldn’t change you for the world, but I’d change the world for you’ is familiar to many within the Down syndrome community and captures the paradigm of the social model.

In Professor Rasko’s Boyer lectures he discusses how he reconciles his attitudes – those of valuing people with chromosomal differences while also supporting screening technology. He explains that he draws ‘a sharp line between embryos and people’. But is it really that straightforward? Can Professor Rasko genuinely say that he values the lives of people with Down syndrome while supporting the science that leads to the routine selective termination of embryos for the sole reason that they have the same chromosome count? Can he have it both ways?

***How do prospective parents make sense of the vast chasm between the medical and social model? Is their decision making impacted by the economic imperative of biotech companies to advance the wider adoption of NIPS?***

The Down syndrome community has embraced social media to spread the word about the extraordinary ordinariness of our lives. A slogan often shared on Facebook ‘Keep calm, it’s only an

extra chromosome’ reminds everyone that Down syndrome is the most common genetic difference. But in our eagerness to tell others what we know, are we sometimes guilty of placing too much emphasis on our own personal circumstances?

Like Frida, I don’t want everyone to think like me, I just want them to think. But the ethical implications of widespread and easy access to NIPS have not been thought through. We are not ready.

When biotech companies celebrate the rapid adoption of screening technology, they need to also think about what it is to make decisions about a wanted pregnancy based on inaccurate and incomplete information. They need to listen to self-advocates like Down Syndrome Advisory Network member Claire Mitchell who urged in a recent video message ‘Don’t screen for Down syndrome without telling families what it really means’. They need to think about how they can balance their commitment to shareholders without compromising the ethical application of their technology.

Health professionals who offer prenatal screening in clinical settings need to think about what informed decision making looks like. They need to think about the information, and the time, which prospective parents need to make decisions about screening that fit with their beliefs, values and life circumstances. They need to think about their reaction to the words ‘Down syndrome’. Do these words evoke only a list of symptoms or lives of value?

The Minister for Health needs to think about the implications of the wider use of NIPS – as will occur if a decision is made to include it on the MBS. How can health care professionals be educated to support prospective parents? And finally, he needs to think about his responsibility to challenge stigma and bias against Down syndrome and disability.

If these people aren’t thinking about these things, then they should be. And after careful thought we need action. Prospective parents deserve more. We all do. And we need it now.

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*Elizabeth Callinan has a child with mosaic Down syndrome and is on the Editorial Committee of Voice.*

*For more information about Down Syndrome Australia’s position statement on prenatal testing and online petition go to the Voice website [www.downsyndromevoice.org.au](http://www.downsyndromevoice.org.au)*

