

Perfection is a matter of perception. Not what society tells us

Kylie Lang

It's ironic that in October, Down Syndrome Awareness Month, we read that all pregnant women in Australia could have access to a Medicare-funded blood test to detect the syndrome, sparking fears terminations may reach 100 per cent.



Joelle Kelly — with three-year-old daughter, Josee, who was born with Down syndrome — is concerned we are “screening out those that society deems not worthy of life”. (Pic: Tara Croser)

To hell with awareness; let's discourage difference. Let's decide which children get to live or die, based on societal standards of perfection.

Why stop with chromosomal abnormalities? Why not question the value of babies with anatomical “defects” including club foot, congenital heart problems, cleft palates, and spina bifida?

Let's agree on parameters for perfection, shall we, and accept nothing less. Perhaps enact a law for the prevention of “genetically diseased offspring” as the Nazis did in 1933.

Am I drawing an unfairly long bow?

Ask parents of children with Down syndrome. They'll tell you about the enormous external pressure they feel from the moment a prenatal diagnosis is confirmed. They'll anguish too over their own emotional, physical and financial

capabilities and over the long-term prospects for their unborn child. But I'm yet to hear of a parent regretting their decision, which makes me wonder if enough people are receiving enough information.



Professional model Madeline Stuart, who has Down syndrome. (Pic: Supplied)

It wasn't so long ago — the 1970s — that children with Down syndrome were locked away in institutions.

Currently in this country, 95 per cent of diagnoses result in termination of the pregnancy. The non-invasive prenatal testing (NIPT), which can be done at 10 weeks' gestation, is available privately for \$495 but an application for Medicare Benefits Schedule funding is now with the federal Department of Health.

As some argue that taxpayers shouldn't fit a \$108 million annual bill to detect only 100 babies, fertility doctors raise the grim possibility that free testing at 10 weeks will lead to terminations based on gender preference.

Where will it end?

Joelle Kelly, whose three-year-old daughter Josee has Down syndrome, [told the Courier-Mail](#) this week she was "extremely concerned that we are just screening out those that society deems not worthy of life".

"When Josee came into our lives I was surprised by what she brought to our family; she opened up our eyes and we all see the world differently."

I agree with Down syndrome Australia chairman Angus Graham, who is calling for a drastic improvement in the education and counselling provided to expectant parents: "So much negative language is used in the delivery of the news — words like 'burden'. In extreme cases, we have heard of women being given no options apart from termination."

In the 1980s, a child with Down syndrome had a life expectancy of 25. Today, that person could live into their 60s.

Some become champion swimmers, like Queenslanders [Michael Cox and Taylor Anderton](#), or models like [Madeline Stuart](#) and [Parker Abianac](#) (a winner of the 2016 Bonds Baby Search).

Many complete mainstream school and go on to join the workforce.

Three years ago when non-invasive prenatal testing was introduced, Qweekend magazine interviewed [Michael Cox and his family](#).

Proud mum Nikki said Michael was an inspiration, but “if we try to make everybody the same, we’re going to lose something very basically, fundamentally important in humans”.

In that same story, one of the most powerful in the magazine’s history, we also met 11-month-old Nicholas Love.

The blonde-haired, blue-eyed boy who featured on our cover won a legion of hearts.

Sadly, in May this year, Nicholas died of complications from a strep infection.



Annie Love with then 10-month-old Nicholas in 2013. (Pic: News Corp Australia/Russell Shakespeare)

On Monday, to mark Down Syndrome Awareness Month, his mother, Annie Love, said that despite her broken heart, she would not have missed out on even one moment of knowing Nicholas.

“Going through prenatal testing and diagnosis was an incredibly difficult time,” she wrote on her Mummalove blog.

“We had to come to terms with the fact our baby was considered ‘imperfect’ by society’s standards before we even had him in our arms and could get to know him. And yet Nicholas ended up being the absolute light of our lives.

“In this world, we are often sold a fantasy about what perfection looks like. We

are encouraged to avoid pain and challenge, to take the easiest road possible. But in taking the path of least resistance, we often miss out on the most amazing experiences and the real beauty that life has to offer.

“Although Nicholas may not be in our arms, I will always be his mother. And I will always be an advocate for people who have Down syndrome... because if I can help one family to see that their child is worth fighting for, one medical professional to see that one child is worth saving, one person to see the beauty and value in all human beings, then it is worth every word shared.”

Kylie Lang is an associate editor at The Courier-Mail