



Committee on the Rights of Persons with Disabilities: Day of General Discussion on Article 5

07 July 2017

Introduction

1. The New Zealand Human Rights Commission (“the Commission”) welcomes the opportunity to make a submission to the Committee on the Rights of Persons with Disabilities (“the Committee”). The Commission is New Zealand’s National Human Rights Institution (“NHRI”). It is accredited as an “A” status NHRI. It is an independent Crown Entity pursuant to the Crown Entities Act 2004 and derives its statutory mandate from the Human Rights Act 1993 (“HRA”). The long title to the HRA states it is intended to provide better protection of human rights in New Zealand in general accordance with United Nations human rights covenants and conventions. In terms of disability rights, the Commission’s primary function is to “protect the full and equal enjoyment of persons with disabilities”.
2. The purpose of this submission is to provide input into and stimulate discussion at the Day of General Discussion on Article 5 that the Committee is holding on 25 August 2017. We understand that the outcome of the Day will inform the drafting process of the Committee’s General Comment on Article 5.
3. The Commission is providing a focussed submission addressing screening policies that target specific populations of people with disabilities, particularly people with Down Syndrome. The Day of General Discussion provides an important opportunity to consider these issues in light of the principle of respect for difference and acceptance in Article 3 and the principle of non-discrimination set out in Article 5.
4. This submission draws on the outcomes of a side session the Commission facilitated about the celebrations, challenges, and future for people with Down Syndrome at the 10th Conference of States Parties on 15 June 2017. The Commission also draws the attention of the Committee to work undertaken in this area by Janet Lord, senior researcher at the Harvard Law School Project on Disability.¹
5. The social model of disability, which underpins the Convention on the Rights of Persons with Disabilities (“CRPD”), constructs ‘disability’ as a consequence of the

¹ Lord, J.E. ‘Screened Out of Existence: The Convention on the Rights of Persons with Disabilities and Selective Screening Policies’ (2012) 12 International Journal of Disability, Rehabilitation and Community 2; Lord J.E., Stein M.A., & Tolchin, D.W. (2012) Equal Access to Healthcare Under the UN Disability Rights Convention. In R. Rhodes, M. Battin, & A. Silvers (Eds.), *Medicine and Social Justice*. Retrieved from: <http://oxfordindex.oup.com/view/10.1093/acprof:osobl/9780199744206.003.0020>

interaction of an individual and an environment which does not accommodate an individual's differences and limits or impedes an individual's participation in society.²

6. The realisation of Article 5 of the CRPD is fundamental to the ability of people with disabilities to participate fully in society on an equal basis with others. States parties must ensure that all people with disabilities are equally protected and obtain equal benefit under the law; that they are protected from all discrimination on the basis of disability; and that reasonable accommodation is provided in order to eliminate discrimination.

Definition of 'discrimination'

7. The CRPD defines disability discrimination as "any distinction, exclusion or restriction on the basis of disability" that "has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms" and it extends to "all forms of discrimination, including denial of reasonable accommodation"³
8. As defined in the CRPD, disability discrimination applies not only to people with disabilities, but also to people associated with them, such as family members, friends, or support staff. Further, the CRPD creates legal obligations calling for positive action in rendering all rights (right to health, information, education, among others) accessible, and requires participation and respect for autonomy.⁴
9. Currently, Article 10 of the CRPD does not recognise the existence of legal protections from discrimination pre-birth. However, there is some recognition of the need for special safeguards before birth in the preamble to the United Nations Convention on the Rights of the Child which states:
10. "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth"⁵

How the discrimination principle applies to screening/termination policies

11. A disability-selective antenatal screening policy that has the purpose or effect of birth prevention of a protected minority group could be considered as raising issues of discrimination insofar as it impacts the social (and other rights) of the protected group. Practically, birth prevention of a specific group impacts on that group and the wider disability community in that it increases stigma in society, means there are fewer people with lived experience to advocate for protections and services, and adds to the notion that disability is a negative experience rather than a facet of human diversity.
12. This analysis appears to align with the understanding of discrimination expressed by the Committee on the Rights of the Child ("CRC Committee") in the context of sex selective screening practices where the CRC Committee noted that "[d]iscrimination against girl children is a serious violation of rights, affecting their survival and all areas

² OHCHR 'Monitoring the Convention on the Rights of Persons with Disabilities' 2010.

³ CRPD, 2006, Article 2.

⁴ CRPD, 2006, Articles 3 and 4(3).

⁵ UNCROC, 1990, Preamble.

of their young lives as well as restricting their capacity to contribute positively to society” and, further, that girl children “may be victims of selective abortion, genital mutilation, neglect and infanticide, including through inadequate feeding in infancy”⁶

13. Similarly, the Platform for Action adopted at the Fourth World Conference on Women states:

“[I]n many countries available indicators show that the girl child is discriminated against from the earliest stages of life, through her childhood and into adulthood. All forms of discrimination against the girl child and the root causes of son preference, which result in harmful and unethical practices such as prenatal sex selection and infanticide; this is often compounded by the increasing use of the technologies to determine foetal sex, resulting in abortion of female foetus.”⁷

14. The CRPD Committee has itself, in one of its first concluding observations on a state report, signalled its understanding of the practice of disability-selective screening and abortion. It observed that Spanish legislation, Act 2/2010 of 3 March 2010, decriminalising voluntary termination of pregnancy incorporates a problematic distinction according to which pregnancy may be terminated beyond the regular 14-week threshold to 22 weeks provided there is a “risk of serious anomalies in the foetus” “if the foetus has a disability” and, beyond week 22 in case of “an extremely serious and incurable illness” detected in the foetus.⁸
15. In its concluding observations, the Committee recommended that Spain “abolish the distinction made in the Act 2/2010 in the period allowed under law within which a pregnancy can be terminated based solely on disability.”⁹ In this regard the Committee recognised the implicit linkage between disability discrimination and the termination policy in Spain.
16. The Commission encourages the Committee to use the General Comment on Article 5 as an opportunity to build on this recommendation by considering the linkage between disability discrimination and screening/termination policies more widely.

Impacts for People with Down Syndrome

17. When taking a human right approach, the voices of those affected by human rights breaches must take priority. However, to the best of our knowledge, to date, people affected by disability screening/termination policies, including with Down Syndrome, have not been given the opportunity to be heard on such issues, let alone have their views prioritised. Subsequently, their experiences have not been included in frameworks such as this General Comment. Thus, the Commission wishes to conclude its submission by highlighting some impacts of screening/termination policies on people with lived experience of Down Syndrome and their families in their own words.

⁶ CRC Committee, General Comment No 7, Para 11.

⁷ Beijing Platform for Action, 1995, Para 259.

⁸ CRPD Committee, Concluding Observations, Spain, para. 17.

⁹ CRPD Committee, Concluding Observations, Spain, para. 18.

18. The Commission has received letters from mothers of children with Down Syndrome detailing the pressure to screen and terminate following a pre-diagnosis of Down Syndrome from clinicians. They talk of the only information being given to them being about potential medical conditions/limitations and the need to convince clinicians that they can “handle” a baby with Down Syndrome. This demonstrates that these issues intersect with Article 10 of the CRPD in terms of the inherent right all human beings have to life and Article 8 in terms the need for awareness raising about the capabilities and contributions of people with Down Syndrome.

19. Further, a young New Zealand man with Down Syndrome was asked by his mother what he thought of the documentary “A World Without Down Syndrome” and the issues it raises. She then sent the Commission a transcript of his statements on 2 June 2017. It reads:

“It makes me feel bad and I feel very uncomfortable and very sad to hear that parents choose not to have babies with Down Syndrome”

“I think people should let people be who they are they shouldn’t judge people or try to modify people”

“People should consider the rights of people with Down Syndrome. We have rights – human rights!”

When asked what he would say to parents who are expecting a baby with Down Syndrome, the young man stated:

“Don’t be stressed you’re having a baby with Down Syndrome, be calm and most of all love your baby with Down Syndrome”

20. Other young people with Down Syndrome have expressed similar messages about the rights and value of people with Down Syndrome. These have been made into two video clips made by the New Zealand Down Syndrome Association: “Dear Future Family, Whanau, and Communities”¹⁰ and “Dear Community”.¹¹

21. Another example is the recent TED talk presented by US-based advocate Karen Gaffney¹² who concluded that “Every life has value. Every life matters, regardless of the number of chromosomes we have.” The Commission encourages the Committee to view these video clips when examining this issue and to consider the value that listening to the voices of the affected can bring more generally.

22. While limited data about screening/termination rates is available in New Zealand, internationally screening/termination practices are at such a rate that Down Syndrome could soon be eliminated from regions of the world. Iceland, for example has reportedly not had any Down Syndrome births for five years¹³ while in 2014, termination rates in Denmark were reportedly 98 percent, which according to a local survey was

¹⁰ <https://www.youtube.com/watch?v=YVNMw-e0ffi>

¹¹ <https://www.youtube.com/watch?v=velayx3KObQ&t=1s>

¹² <https://www.youtube.com/watch?v=HwxjoBQdn0s&t=1s>

¹³ <http://www.bbc.com/news/magazine-37500189>

considered by 60 percent of Danes to be a positive development.¹⁴ The development of increasingly precise screening technologies raises the possibility that Down Syndrome and other disabilities, or indeed other human characteristics, could be eliminated across the world in years to come.

Conclusion

23. The Commission encourages the Committee to consider the issue of pre-birth screening practices in the context of the Article 5 discussion. In addition, the Commission strongly recommends that the Committee seek, and consider the voices and perspectives of those with Down Syndrome for the purposes of this discussion.

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¹⁴ <http://cphpost.dk/news/down-syndrome-heading-for-extinction-in-denmark.html>