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Special Rapporteur on the rights of persons with disabilities

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**Questionnaire on the provision of support to persons with disabilities**

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**Introduction**

1. The New Zealand Human Rights Commission (“Commission”) welcomes the opportunity to respond on the Special Rapporteur’s ‘Questionnaire on the provision of support to persons with disabilities’.
2. 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.

**Lack of Data**

1. In general, there is a lack of data about support services and outcomes for people with a disability in New Zealand. Many studies relating to disability (for example, a 2013 survey carried out by the New Zealand Department of Statistics) relate more to barriers and challenges facing people with different disabilities rather than the efficacy or range of disability support services. This issue is exacerbated for people with an ‘invisible’ disability such as a neurodisability.
2. We understand the Questionnaire has been sent to other agencies in New Zealand, including the Office of Disability Issues. Those agencies will be able to provide more detail on some matters than the Commission can. There is a general lack of quality data relating to the outcomes for people with disability.

**Independent Monitoring Mechanism Report 2013-2014**

1. The Independent Monitoring Mechanism (“IMM”) was established by the Government in 2010 to fulfil obligations under Article 33 (national implementation and monitoring) of the Convention on the Rights of Persons with Disabilities (“CRPD”). It is made up of the Human Rights Commission, the Office of the Ombudsman and the New Zealand Convention Coalition Monitoring Group (a group of Disabled People’s Organisations that undertake research on the lives of disabled people). The IMM has released three reports monitoring the Government’s progress implementing the CRPD, and issuing a number of recommendations:

*https://www.hrc.co.nz/your-rights/people-disabilities/our-work/making-disability-rights-real/*

1. In particular, we point your attention to ‘Making Disability Rights Real’ July 2012- December 2013 report (at the link above). That report discusses a number of thematic areas where either service delivery or data collection regarding services could be improved. The Report discusses the need for a ‘people driven system’, that is:

*All supports and services must be provided in a manner that promotes individual autonomy and choice for disabled people to the greatest extent possible. People driven means: “I direct what happens to me”. Service provision should not be driven by the needs of multiple agencies but by disabled people themselves and their families.[[1]](#footnote-1)*

1. We also note at the same link above the IMM’s Interim Report ‘Article 24: The Right to an Inclusive Education’ June 2016. That Report examines the progress made in New Zealand toward the realisation of the right to inclusive education. The Report discussed the importance of services/reasonable accommodation to make inclusive education a reality. Despite a lack of data, the Report noted:

*From the available data, it appears that while improvements have been made, there is still a significant amount of work to be done to make New Zealand’s education system inclusive.[[2]](#footnote-2)*

**The New Zealand disability support workforce: 2015 survey of NZDSN member organisations**

1. A further report which may be of interest is the New Zealand disability support workforce: 2015 survey of NZDSN member organisations report published in June 2016.[[3]](#footnote-3) The report presents the results from the 2015 New Zealand Disability Support Network (NZDSN)[[4]](#footnote-4) and Te Pou[[5]](#footnote-5) workforce survey, with recommendations for future workforce development. While the report focuses on the disability support workforce, rather than the provision of support to people with disabilities, the key findings on pages 10-12 and background information on pages 14-17 may be useful.

**Pertinent examples of support services initiatives in New Zealand**

*Whānau Ora*

1. For Māori, living in the community involves all aspects of Te Whare Tapa Whā – physical, mental, spiritual and whānau health. Support structures/service delivery needs to take this holistic model of health into account and provide Māori and Pacific people the level of rangatiratanga or choice to which they aspire. For example,   
   New Zealand’s Ministry of Health (MoH) currently provides some services for people with a disability which are delivered by Māori providers or other organisations offering services specifically for Māori.
2. ‘Whānau Ora’ is an initiative built on Maori values which puts whanau (family) at the centre of decision-making about the services and opportunities they need and how they access them. Community, government and iwi (tribal) agencies that provide services to whānau are expected to work in a co-ordinated way that is responsive to whānau needs.[[6]](#footnote-6)
3. Whānau may use the services of a [navigator](https://www.tpk.govt.nz/whakamahia/whanau-ora/navigators/), a practitioner who helps them to identify their needs and aspirations, plan for the future, and access co-ordinated services in areas such as education, primary health and employment, to carry out the plan. This initiative, which is open to people with disabilities, has a positive focus on self-determination as well as familial, cultural, indigenous ties.

*Enabling Good Lives*

1. “Enabling Good Lives’ was a small initiative commenced in 2011 to trial/pilot a person-centred approach to service delivery to people with disabilities. Its approach was very consistent with the ethos of the CRPD and it may be up-scaled in future.[[7]](#footnote-7)

*Family Funded Care*

1. Until recently, government policy meant that individuals were not eligible to receive funding for the provision of care to disabled family members.
2. This policy was held to be discriminatory by the Courts and in October 2013, the MoH introduced a Funded Family Care (FFC) policy. This permitted a small number of disabled people aged over 18 with ‘high or very high needs’ to receive funding to employ family members with whom they live (excluding spouses or romantic partners) to provide some disability support services.[[8]](#footnote-8)
3. An evaluation commissioned by the MoH to assess the FFC policy’s impact and effectiveness at the end of its first year, found the policy had a number of positive impacts. These included improved finances for family carers, improved health for both the disabled person and their family carers, and more opportunity to get out in the community leading to a better quality of life.[[9]](#footnote-9) As one parent stated:

*I think for [disabled daughter] being able to get out and about, it’s a plus. We did Christmas in the Park. We’ve gone to [larger town] shopping. Days like that shows her the bigger, wider world is a reasonably friendly place for people with disabilities.*

1. The evaluation did find that the FFC policy could be improved. Under the current policy, people receiving support are required to give their informed consent to take up the funding and have a number of responsibilities as an employer of their family member(s) providing care. The evaluation found that it was likely that the majority of those eligible would lack the capacity to comply with these requirements.[[10]](#footnote-10) This was reported as a reason for the limited uptake.[[11]](#footnote-11)
2. The level of payment was also an issue, with the majority of families viewing the minimum wage rate as unfair given non-family carers get paid a higher rate to do the same work.[[12]](#footnote-12)
3. The Public Health and Disability Amendment Act (No 2) 2013, passed shortly after the court determination that the previous policy was unlawful, prevents anyone from making claims of unlawful discrimination to the HRC, Human Rights Review Tribunal, or court, in relation to the policy on a number of grounds, including disability and family status unless the complaint was lodged before 15 May 2013.[[13]](#footnote-13) That the legislation currently prevents people from bringing unlawful discrimination claims is of concern.

**Conclusion**

1. There is a general lack of good data regarding the provision of support to people with disabilities in New Zealand. Notwithstanding that, we hope you find the suggestions in this letter useful.

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1. Independent Monitoring Mechanism Report ‘‘Making Disability Rights Real’ July 2012- December 2013 report p 15 [↑](#footnote-ref-1)
2. Independent Monitoring Mechanism Interim Report ‘*Article 24: The Right to an Inclusive Education*’ June 2016 p [↑](#footnote-ref-2)
3. <http://www.tepou.co.nz/uploads/files/resource-assets/the-new-zealand-disability-support-workforce-2015-survey-of-nzdsn-member-organisations-final-v2.pdf>. [↑](#footnote-ref-3)
4. <http://www.nzdsn.org.nz/about/> [↑](#footnote-ref-4)
5. <http://www.tepou.co.nz/about> [↑](#footnote-ref-5)
6. https://www.tpk.govt.nz/en/whakamahia/whanau-ora/ [↑](#footnote-ref-6)
7. <http://www.enablinggoodlives.co.nz/> [↑](#footnote-ref-7)
8. Ministry of Health’s Funded Family Care Policy at <http://www.health.govt.nz/system/files/documents/publications/evaluation-funded-family-care-aug15.pdf> [↑](#footnote-ref-8)
9. IbidP.4-7. [↑](#footnote-ref-9)
10. Ibid P.20. [↑](#footnote-ref-10)
11. Ibid P.37. [↑](#footnote-ref-11)
12. Ibid P.25. [↑](#footnote-ref-12)
13. Public Health and Disability Amendment Act (No 2), s. 70E. [↑](#footnote-ref-13)