



Health of Disabled People Strategy

A submission by Whānau Āwhina Plunket

March 2023



Introduction

Whānau Āwhina Plunket is the largest provider of health and wellbeing support services to tamariki under five and their whānau in Aotearoa New Zealand. We see over 82% of all newborn pēpi, including 60% of Māori pēpi in Aotearoa. We have been supporting pēpi, tamariki and their whānau for more than 115 years.

This submission is guided by our vision: In the first 1,000 days setting the path of wellness in our communities, for generations to come. Our vision is underpinned by our strategic goals: Pae ora (Healthy futures); Mauri ora (Healthy babies and children); Whānau ora (Healthy confident families); Wai ora (Healthy environments and connected communities) and our Equity goal (all our services are delivered equitably by 2025).

In 2020, Whānau Āwhina Plunket released Te Rautaki Māori – Ngā Pae o te Harakeke, founded on Te Tiriti o Waitangi principles. Te Rautaki Māori sets out the equity roadmap for Whānau Āwhina Plunket. This, along with our new strategy, is driven by our core values of māia, māhaki, tūhono and manaaki.

Whānau Āwhina Plunket's submission on the Health of Disabled People Strategy generally focuses on caregivers who look after their disabled tamariki (children). We specifically want to focus on disabled children as they are unable to advocate for themselves: they rely on their whānau and adults to voice and advocate for their needs on their behalf.

We do, however, acknowledge disabled parents and caregivers may experience challenges raising tamariki. These may include limited access to public services, participation in public spaces, and social isolation¹.

We welcome the opportunity to engage on the Health of Disabled People Strategy (the Strategy) – which has the potential to be transformational in how health and wellbeing is delivered to our communities and provides the opportunity to place Te Tiriti and equity at its core. Specifically, we see our role in supporting whānau with disabled tamariki as fourfold:

1. **Pae Ora:** Healthy futures for all
2. **Mauri Ora:** Early and consistent diagnosis, early referrals, and intervention so that we are anticipating and meeting the needs of disabled tamariki. **(Healthy tamariki)**
3. **Whānau ora:** Provision of relevant and responsive support to whānau caring for disabled tamariki. **(Healthy confident whānau)**
4. **Wai ora:** Removing environmental and social barriers that restrict life choices for disabled tamariki by linking carers to relevant groups and organisations, providing carers with the support they require. **(Healthy Environments and connected communities)**

Whānau Āwhina Plunket submission

Whānau Āwhina Plunket recognises and is committed to the provisions of the:

- a) United Nations Convention on the Rights of the Child (Children's Convention)², specifically, Children with disabilities (Article 23)
 - Basic health and welfare (Articles 6, 18(3), 23, 24, 26, and 27(1-3))

¹ Parchomiuk, Monika. "Social context of disabled parenting." *Sexuality and Disability* 32.2 (2014): 231-242.

² <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

- Education, leisure and cultural activities (Articles 28, 29 and 31)
- b) United Nations Convention on the Rights of Persons with Disabilities³, specifically,
- General Principles (Article 3) respect for the evolving capacities of children with disabilities
 - Children with disabilities (Article 6) full enjoyment of all human rights on equal basis with other children, the best interests of the child shall be the primary consideration, and the right to express their views freely on all matters affecting them
 - Respect for home and the family (article 23)
 - Education (Article 28), Health (Article 24) and Participation in cultural life, recreation, leisure and sport (Article 31)

In New Zealand, key statistics⁴ on disability project key areas to highlight in the Strategy. For example, in 2013,

- Māori and Pacific people had higher-than-average disability rates - ***that equity need to be forefront of the strategy.***
- For children, the most common cause was a condition that existed at birth (49 percent) - ***that the Strategy focuses on 0-5 years is critical for a life-course approach.***
- 73 percent of disabled children had impaired speaking, learning and developmental delay, sometimes referred to as ‘invisible impairments’ – ***that assessment and diagnosis need to be inclusive and accessible to different types of disability, for children under 5s.***
- 12 percent of disabled children received extra help with personal care at least once a month because of their impairments. For 10 percent of disabled children, their caregiver reported an unmet need for help around the house because of the child’s impairment - ***that greater support for carers is needed.***

Whānau Āwhina Plunket delivers the National Well Child Tamariki Ora (WCTO) schedule⁵ and captures limited data on disability. This work includes specific screening of hearing and vision at each of the core contacts and making referrals as necessary. We also document family history where mother or father have any relevant developmental history including hearing and vision impairment.

The Pae Ora Act (2022)⁶ paves a new way for the Health and Disability system, with the potential to effect transformational changes for disabled tamariki, and their carers. We hope the process for developing Locality Plans will include gathering the voices of disabled children and their caregivers so that they are able to co-design services that better meet their needs.

It is also important to note that disability is multi-dimensional and requires a multi-sectorial approach. This was highlighted in the NZ Disability Strategy 2016-2026⁷ and the Disability Action Plan. Whānau Āwhina Plunket supports the newly established Office of Disability Issues⁸ to lead and co-ordinate sector-wide approaches for the disabled community.

³ <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>

⁴ <https://www.stats.govt.nz/reports/supporting-disabled-people-2013>

⁵ At every core contact with the whānau, the practitioner will complete the universal WCTO health and development assessments covered by the schedule. They will also cover family/whānau care and support and health education activities with the whānau to improve child health outcomes. These include referrals for additional services. Most importantly, providers will respond to concerns expressed by parents or caregivers (eg, parenting, safety or health issues).

⁶ <https://www.legislation.govt.nz/act/public/2022/0030/latest/versions.aspx>

⁷ <https://www.odi.govt.nz/nz-disability-strategy/>

⁸ <https://www.odi.govt.nz/about-us/>

Building on these recent changes in the health system, in this submission we will focus on:

- a. Systematic Challenges
- b. Priority Populations
- c. Workforce Development

Section A. Systematic Challenges

Screening and Diagnosis

“If children are not diagnosed, nothing happens.”⁹

1. **Screening** - Early screening can facilitate early diagnosis. According to the *Briefing to the Incoming Minister from CCS Disability Action Group in 2017*, getting ‘formal diagnoses’ will assist whānau to gain financial assistance. The same report noted the many challenges of raising children of disability, such as
 - the additional costs incurred to accommodate the children, like re-modification of the house¹⁰, transportation costs.
 - the difficulty of accessing mainstream services and often facing discrimination; an example would be early childhood centres reluctant to enrol a disabled child – as they will require additional resources.
2. Screening tools for some ‘invisible impairments’ (such as autism spectrum disorder) are validated and are used routinely overseas to screen toddlers¹¹. Whānau Āwhina Plunket believes screening and assessments should be more accessible for neurodevelopmental disorders. There is opportunity to embed such assessments as part of the new Kahu Taurima (Maternity and the early years) model of care¹². Further policy and research are also needed to identify culturally appropriate screening tools that respond to our diverse population.
3. **Diagnosis** – Diagnosis is equally difficult for these invisible disabilities. One of the challenges, especially for carers, is finding evidence to justify the diagnosis in order to meet the threshold to get support and assistance. There are also long wait lists for diagnosis. Early diagnosis facilitates early intervention. Early intervention optimises the effectiveness of treatment for some types of disabilities^{13,14} (such as autism)^{15,16}.

A delay in diagnosis might be a missed opportunity to provide services at a critical time that can transform a child's overall quality of life.

⁹ Child Poverty Action Group (2015). “It shouldn’t be this hard”: Children, Poverty, and Disability.

¹⁰ The role of healthy and secure housing for disabled person is particularly important, as they might spend more time at home due to their disability and mobility. New housing designs programme, such as ‘LifeMarks’ can use design to help adapt to disability. It is also important that the Strategy links up with other key pieces of housing legislations such as the Residential Tenancies Amendment Act 1986.

¹¹ Johnson C.P. & Myers S.M. (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics* 120: 1183–1215

¹² Te Pae Tata: Interim NZ Health Plan 2022

¹³ An example would be children with autism spectrum, early intervention helps reduce symptoms severity and improve quality of life.

Johnson C.P. & Myers, S.M. (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics*, 120, 1183-1215.

¹⁴ Llewellyn, G., McConnell, D., & Bye, R. (1998). Perception of Service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities*, 19, 245-260.

¹⁵ Vismara, L.A., & Rogers, S.J. (2010). Behavioural Treatments in Autism Spectrum Disorder: What Do We Know? *Annual Review of Clinical Psychology*, 6, 447-468

¹⁶ Seida, J.K. et. al., (2009). Systematic reviews of psychosocial interventions for autism: an umbrella review. *Developmental Medicine & Child Neurology*, February 2009, Vol.51 (2), pp.95-104.

Accessibility

4. Whānau Āwhina Plunket supports and advocates for carers to help them connect to, and navigate through, a fragmented system. Our role is not just referring them to get diagnosed, but also, supporting carers to access other services. It is important for this Strategy to improve access as identified in the Disability Strategy 2016-2026.
5. **Access to healthcare** is difficult for people with disability. Medical equipment and clinics are not often built to be accessible for people with limited mobility and other sensory challenges^{17,18}. Using platforms like telehealth, such as PlunketLine, or virtual health consultation can help bypass many barriers that are experienced by families with disabilities.
6. **Access to childcare** - Accessibility to support childcare and flexible working arrangements is also important for carers. Many parents find formal childcare is rare and, in many cases, almost non-existent. They rely on informal childcare, such as family, to provide instrumental care and respite¹⁹. Better support is also needed for early childhood education for children with disability^{20,21}.

'Things' that work

7. Whānau Āwhina Plunket works with disability-specific organisations. These organisations provide expertise to health professionals about the relevant disability. They are instrumental in helping whānau navigate the system. An example of working with an organisation of this kind is when Whānau Āwhina Plunket had the opportunity to partner with Autism NZ on a pilot that assisted a cohort of nurses on diagnosing autism²².
8. We believe the Strategy should target the crucial role that these organisations play in the disability sector. These organisations are often run by a group of enthusiastic individuals or whānau who have lived experience and require support to sustain their services to the community.
9. Telehealth services, artificial intelligence and technology, are some of the platforms that can assist disabled people to access healthcare and improve their quality of life. Online communications such as webinars and forums are also effective channels for carers to seek social support and receive educational information.

In order for tamariki to be well, they need the whānau to be well.

System 'change' principles

10. We believe this Strategy is an opportunity to focus on children under five with a disability, especially those that are living in poverty. The system needs better monitoring of indicators for disabled children, improved transparency of reporting and greater accountability for delivering outcomes. This might require linking in with other indicators and measures used by other legislation or strategies, such as the Child Poverty Reduction Bill and the Child and Youth Wellbeing Strategy.

¹⁷ Valdez, R. S., Rogers, C. C., Claypool, H., Trieshmann, L., Frye, O., Wellbeloved-Stone, C., & Kushalnagar, P. (2021). Ensuring full participation of people with disabilities in an era of telehealth. *Journal of the American Medical Informatics Association*, 28(2), 389-392.

¹⁸ Gajjarawala, S. N., & Pelkowski, J. N. (2021). Telehealth benefits and barriers. *The Journal for Nurse Practitioners*, 17(2), 218-221.

¹⁹ Kagan C., et. al., (1999). Enabled or disabled? Working parents of disabled children and the provision of child-care. *Journal of Community and Applied Social Psychology*, 9(5), 369-381.

²⁰ Guralnick, M. J. (2001). *Early Childhood Inclusion: Focus on Change*. Paul H. Brookes Publishing Company, PO Box 10624, Baltimore, MD 21285-0624.

²¹ World Health Organization. (2012). Early childhood development and disability: A discussion paper.

²² <https://www.tvnz.co.nz/one-news/new-zealand/new-zealand-first-sees-post-natal-nurses-trained-diagnose-autism>

11. Further to this, the Strategy must commit to achieving equity of outcomes, with a cultural focus explicit throughout. A disabled person must be seen in the wider context of their family, community, and environment. The Strategy also needs to acknowledge the intersectionality of disability, acknowledging that people with a disability have different identities including ethnicity, gender, and other demographic and social variables.
12. Whānau Āwhina Plunket supports a long-term focus on improving wellbeing for disabled people that is maintained by successive governments. For this to be achieved, there needs to be a system in place that guarantees this long-term, non-partisan commitment.

Section C. Priority Populations

Disability through a Population Health lens

13. Equity should be at the forefront of the Health of Disabled People Strategy. Culture is an important component of well-being and it is important that this Strategy provides culturally specific, appropriate and acceptable actions and support.
14. If equity is at the forefront of this Strategy, it needs to look at disability through the various lenses of these population groups. Tangata whenua of Aotearoa have long acknowledged that health and wellbeing is multi-dimensional. Mason Durie's *Te Whare Tata Wha*²³ model addresses the different aspect of health – amongst it, spiritual health and cultural health. Similarly, the Fonofale model for Pacifica considers this broader definition of health.
15. Māori and Pasifika children are disproportionately represented among those with a disability and the Strategy needs to address the social determinants of health (such as poor housing, education and poverty) to prevent further inequities in health and economic outcomes.
16. The Strategy also needs to set out the criticality of working in partnership with population groups to ensure that cultural beliefs about disability are responded to in a safe and respectful way²⁴. General and universal health services should specifically include Māori philosophies, policies and practices.
17. For example, disability is strongly stigmatised in some cultures. This affects whānau in accessing the necessary services in a timely manner. Delay in seeking help can result in many missed opportunities to get appropriate assistance.
18. Whānau experiences are crucial in developing effective intervention across the full spectrum of services. Their voices need to be heard (such as in the development of Locality Plans) so that both equity and population lenses are included in decision making.
19. The right to health is a basic human right. The *Code of Health and Disability Services Consumers' Rights* and *Code of Consumer Participation* should be the basis for people to access health services. It is vital that Government should not use resource constraint to bypass access to health or quality of health services to vulnerable groups in achieving equity²⁵.

A cultural focus must be explicit throughout the Strategy.

Resource constraints cannot and should not be used as a compromise to downplay the right to quality health services.

²³ Mason Durie, Whaiora: Māori Health Development. Oxford University Press 1998: Mason Durie, "An Indigenous model of health promotion", Health Promotion Journal of Australia, 15 no. 3 (2004), 181-185.

²⁴ CPAG. "Living well?" Children with disability need for greater income support in Aotearoa.

²⁵ Human Rights Commission. (2010). Human Rights in New Zealand: 11. Right to health. Auckland: Human Rights Commission. https://www.hrc.co.nz/files/9714/2388/0506/HRNZ_10_Right_to_health.pdf

Section D. Workforce Development

20. **A diverse workforce** – the Strategy must acknowledge the importance of a diverse workforce that reflects the population of the communities it serves. The Māori and Pacific health workforce are currently under-represented²⁶ to achieve equitable health outcomes for populations' priorities.
21. **Training for primary care professionals** - There needs to be specific training for primary health care professionals on identifying certain types of disability. It has been found that some disabilities, such as autism, can benefit from early intervention to reduce symptom severity and improve quality of life²⁷. This, in turn, can also reduce carer distress. As early intervention proves to be valuable, we believe upskilling primary care practitioners on some of the early signs would be beneficial.

Conclusion

Whānau Āwhina Plunket's key recommendation for the Health of Disabled Peoples Strategy is to prioritise the diagnosis and support of disabled children under five years old. The early years are a golden opportunity to focus on screening, diagnosis, and to provide intervention so that outcomes can be optimised, before it is too late.

We believe this Strategy should focus on the following overarching principles and priorities:

1. The early years are critical for the long-term wellbeing of disabled people.
2. Acknowledgement of Māori as tangata whenua and the importance of cultural perspectives in achieving equity for all.
3. The Strategy must commit to achieving equity for disabled people and in a non-disabling society²⁸.
4. Children with disability must be seen in the wider context of their family, community, and environment.
5. There must be a bipartisan, long-term commitment to improving disabled children's wellbeing.

Investment in early years is important. But for children with disability, it is crucial.

²⁶ The Māori and Pacific populations are not well represented in the health and disability workforce or within DHBs. Māori are about 15% of our population but only 8% of the DHB workforce. Pacific peoples are about 8% of our population and just 4% of the DHB workforce. The Cost and Value of Employment in the Health and Disability Sector report. Ministry of Health

²⁷ Daniels, A.M. & Mandell, D.S. (2013). Children's compliance with American Academy of Paediatrics' Well-Child care visits guidelines and the early detection of Autism. *Journal of Autism Developmental Disorder*, 43, 2844-854.

²⁸ New Zealand Disability Strategy 2016-2026.