

# Briefing

## Overview on neurodiversity

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<b>To:</b> Hon Matt Dooney, Associate Minister of Health	
<b>Consulted:</b> Health New Zealand: <input type="checkbox"/> Māori Health Authority: <input type="checkbox"/>	

## Contact for telephone discussion

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## Minister's office to complete:

- |   |                                    |  |
|---|------------------------------------|--|
| <input type="checkbox"/> Approved             | <input type="checkbox"/> Decline   | <input type="checkbox"/> Noted               |
| <input type="checkbox"/> Needs change         | <input type="checkbox"/> Seen      | <input type="checkbox"/> Overtaken by events |
| <input type="checkbox"/> See Minister's Notes | <input type="checkbox"/> Withdrawn |  |

**Comment:**

# Overview on neurodiversity

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**Security level:** IN CONFIDENCE      **Date:** 18 March 2024

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**To:** Hon Matt Doocoy, Associate Minister of Health

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## Purpose of report

1. This briefing provides a high-level overview of neurodiversity in support of your Ministerial portfolio responsibility in this area. This information is to assist your preparation for a meeting with officials on 18 March 2024 about the breadth of your delegation topics.

## Summary

2. The term “neurodiversity” can cover many different conditions, including autism, Attention Deficit Hyperactivity Disorder (ADHD), traumatic brain injury, learning disability (e.g., Dyslexia) and a wide range of neurological disabilities and neurodevelopmental conditions such as Fetal Alcohol Spectrum Disorder (FASD).
3. Some neurodiverse groups (e.g. FASD, ADHD) are known to experience barriers in accessing diagnostics and specialist assessments, services and supports, have unmet needs and worse health, disability, education and justice outcomes.
4. The Government's response to neurodiversity is spread across many Ministerial portfolios, government agencies and Crown health entities in the health, disability, education, justice, children and social development sectors.
5. The health sector has a central role in the Government’s response to those with neurodiverse conditions. The Ministry of Health | Manatū Hauora (the Ministry) is government’s primary advisor on neurodiversity in the health context. Health New Zealand funds most of the health services and some support services for this group.
6. Key issues are:
  - varied definitions and understandings about neurodiversity
  - data and evidence limitations in some contexts (e.g. Pacific neurodiversity)
  - workforce capability in neurodiversity
  - lack of access to, and cost of, diagnostics and specialist interventions
  - underfunded, fragmented and inconsistent service delivery
  - need for better cross-government coordination on neurodiversity.

7. Further work would be required to provide more detailed advice on the neurodiversity-related work underway in the health system and to explore opportunities for a cross-government response to neurodiversity. This would need to be prioritised against other work programme areas.



Maree Roberts  
Deputy Director-General  
**Strategy, Policy and Legislation | Te Pou  
Rautaki**

Date: 15 March 2024

Hon Matt Doocey  
**Associate Minister of Health**

Date:

PROACTIVELY RELEASED

# Overview of Neurodiversity

## What is Neurodiversity?

8. The term neurodiversity was first coined to describe autism characteristics but is now used to recognise the natural variability of how our brains engage in learning, perceive information, and organise and communicate thinking.
9. From a clinical perspective, neurodiverse conditions can also be diagnosed as neurological disorders or neurodevelopmental disorders. These disorders comprise a very broad range of conditions where dysfunction of the brain or nervous system can affect a person's behaviour, memory or ability to learn. Common disorders from this group include autism, Attention Deficit and Hyperactivity Disorder (ADHD), traumatic brain injury, learning disability (e.g., Dyslexia), epilepsy, Fetal Alcohol Spectrum Disorder (FASD),<sup>1</sup> brain tumours, Tourette's syndrome, Motor Neurone Disease and Multiple Sclerosis.
10. Neurodiverse conditions are often viewed by those who experience them as a range of natural variations in the human brain. In some circumstances neurodiverse conditions may be preventable (e.g. FASD) or treated, and with support all people can be enabled to live their best life in the community. There has been a shift away from the idea of pathology toward a more nuanced perspective with variations of what is "normal."

## Neurodiversity data and research

11. New Zealand's data and evidence on neurodiversity/neurodiverse conditions is variable in some contexts. To illustrate:
  - a. There is limited prevalence data available on the whole neurodiverse population in New Zealand, or the proportion of the neurodiverse group in the estimated 1.1 million disabled New Zealanders. The Neurodiversity in Education Coalition has estimated that around one in 5 (or 320,000) young people in New Zealand are neurodiverse.
  - b. There is very little information available on Pacific neurodiverse experience, needs and outcomes.
  - c. New Zealand Health Survey data indicates prevalence of children and young people aged 5 to 14 years diagnosed with ADHD is around 2.9 percent to 4.0 percent. However, this is thought to under-represent the level of need.
  - d. Autism New Zealand has estimated around 1 to 2 percent (93,000) of New Zealanders have autism. Whaikaha estimate around 35 percent (17,402) of disabled people receiving funded disability supports have an autism diagnosis.
  - e. Oranga Tamariki does not collect disaggregated data by impairment type. Research and practice experience suggests that neurodiversity is one of their biggest impairment/disability types for children and young people in care and youth justice. The most common conditions are FASD, ADHD and autism. A 2022 'snapshot' of young people in youth justice residences showed that of the 78 percent with a suspected or confirmed disability and/or mental health condition, nearly 49 per cent

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<sup>1</sup> See The Donald Beasley Institute. "Education counts." Education Counts Education Counts. Last modified 2020. <https://www.educationcounts.govt.nz/publications/learning-support/responding-to-neurodiversity-in-the-education-context>.

had a suspected or diagnosed neuro-disability, including ADHD, FASD, autism and dyslexia.

## Neurodiversity in the health system

12. The key health agencies and entities with responsibilities for neurodiversity are:
  - a. The Ministry is the chief steward of the health system and lead advisor for the Government on matters relating to policy, regulation, and monitoring of the health system (including Pharmac and Medsafe) – this includes how it supports those with neurodiverse conditions.
  - b. HNZ is the lead commissioner and funder of health services and some disability support services for eligible people with long-term health conditions, mental health and age-related disability. This includes services for those with neurodiverse conditions, such as ADHD services, alongside wider health services that support individuals' overall health and wellbeing, such as primary and community health care.

## Neurodiversity across government

13. Government's responsibilities for neurodiversity are spread across different ministerial portfolios and government agencies.
14. In the Health portfolio, your delegated responsibility for neurodiversity overlaps with your other delegation for Youth, Mental Health and Rainbow Health. The Ministry has provided separate advice on these topics (youth health: H2024036868 and rainbow health: H2024034849 refers). This delegation also overlaps with Minister Reti's responsibilities for the health of disabled people and his interests in FASD.
15. Many other ministerial portfolios overlap with yours, particularly those which address significant neurodiversity need, including Education, Social Development, Children, Disability and Justice. These require coordination.
16. Key government agencies with lead responsibilities for neurodiversity are:
  - a. Whaikaha is steward of the disability system across government. Whaikaha is the lead commissioner and funder of national disability support services (DSS) for people with eligible disabilities, including with autism and some neurological conditions.
  - b. Ministry of Education is steward of the education system and the lead commissioner for learning support services for people with neurodiversity in the education context.
  - c. Ministry for Children (Oranga Tamariki) is responsible for the well-being of children where there are care and protection issues, or for young people involved in the Youth Justice system.
17. A range of legislative commitments and conventions combine to guide the government's response to neurodiversity. For example, the Human Rights Act 1993 and the New Zealand Bill of Rights Act 1990 protect the right of disabled people to be free from discrimination (with some exceptions). The Health and Disability Commissioner Code of Rights safeguards the rights of consumers in using health and disability services. The United Nations Convention on the Rights of Persons with Disabilities is about disabled people having full and equal enjoyment of all human rights and fundamental freedoms.

## Key issues

18. Among considerations on how the health and wider support systems can work better for neurodiverse people:
  - a. *Service gaps, unmet need and inequitable outcomes.* Some neurodiverse groups are known to experience barriers in accessing assessment, services, medication and supports and report poorer outcomes. The threshold for accessing disability support services or behavioural supports means that many neurodiverse people struggle to receive adequate supports. These issues have been highlighted by the FASD, ADHD and Tourette syndrome communities.
  - b. *Cross-government coordination on neurodiversity.* Services and supports for those with neurodiversity are widely distributed across government. This can create access barriers and navigation difficulties for people and their whānau families living with neurodiverse conditions. There is a need for better cross-government alignment and coordination on neurodiversity action.
  - c. *Delays in diagnosis.* There are often significant delays and costs that many people experience in seeking specialist assessment due to lack of specialists and services.
  - d. *ADHD risks.* People with ADHD (particularly those with fewer resources and adults) are underserved by mental health services and are at greater risk of under achievement, unemployment, substance use, relationship failure and imprisonment. There is reliance on overseas guidelines for assessment and support, not tailored to New Zealand.
  - e. *Autism risks.* People with Autism are also at greater risk of under achievement and unemployment. This group experiences greater hospitalisation, co-existing medical and mental health conditions, and significantly higher risk of mortality than neurotypical peers.
  - f. *Children and young people with neurodiversity.* As evidenced by the Oranga Tamariki information, not identifying and supporting neurodiverse children and young people puts them at significant risk of worse education, social and justice sector outcomes.
  - g. *Neurodiversity in Māori, Pacific, Women's and Rainbow communities.* Further data collection and research is needed to better understand neurodiverse experience and outcomes for these communities and design more effective responses for these groups in their cultural contexts in the health and disability system.
  - h. *Workforce capability.* There is a general lack of neurodiverse awareness and workforce capability for neurodiverse people in the health and disability workforce.
  - i. *Definition of neurodiversity.* There is a lack of clarity of what is neurodiversity and what is included under the umbrella of neurodiversity across government agencies and communities. This area is likely to be considered in Whaikaha's planned policy work programme to review eligibility to access disability support services – see below.
  - j. *Neurodiversity data.* There is some data on specific conditions such as autism and ADHD. Education has invested in neurodiversity research given the priority of that cohort in the inclusive education framework. However, there is a general lack of systematic data collection on neurodiverse conditions across many contexts, including health. Without prevalence, health needs assessment and outcomes data, it

is difficult to measure level of need within neurodiverse communities, information on which would inform policy planning and commissioning health and disability services.

## Current programmes and initiatives

### Health

19. *New Zealand Health Plan.* The national Health Plan has a priority focus on disabled people who make up nearly a quarter of New Zealand's population. A key goal is that all health services will be accessible, inclusive and equitable for disabled people. A Disabled Peoples' Reference Group is established that includes members of the neurodiverse community, recognising their intersectionality with other impairments or other marginalised groups.
20. *FASD programmes and initiatives.* You received a copy of a briefing to Minister Reti on 7 March 2024 about FASD which details the initiatives to support people with FASD and their whānau (H2024035583).
21. *Improving health outcomes for disabled people.* The Ministry leads on implementing Outcome 3 Health and Wellbeing in New Zealand Disability Strategy 2016-2026. This work is being progressed through the Government's Disability Action Plan and the Provisional Health of Disabled People Strategy (2023). This framework guides health entities in improving health outcomes for disabled New Zealanders and their whānau. It covers those with neurodiverse conditions who may self-identify as disabled.
22. *ADHD New Zealand (ADHD NZ) collaborative forum.*<sup>8</sup> ADHD NZ leads a collaborative network of clinicians, professional associations and government agencies to progress work to improve outcomes for people with ADHD. The network was established following a meeting about ADHD at Parliament in 2022, by Greens MP Chlöe Swarbrick. The network has been focusing on seeking to improve access to ADHD medication, the potential to adapt Australia's new ADHD guidelines, pursuing a greater role of primary care in ADHD care, and commissioning research on ADHD.
23. *ADHD medication access and availability.* Stimulant medications used to treat ADHD are controlled drugs regulated under the Misuse of Drugs Act 1975 and require a Special Authority approval. This involves an assessment and written application from a paediatrician or psychiatrist (or medical or nurse practitioner on the recommendation of a paediatrician or psychiatrist). Pharmac requires the special authority to be renewed every two years to continue access. Pharmac is considering a consultation in 2024 on the potential to remove the requirement to renew Special Authority approvals for ADHD medications every two years.<sup>2</sup> The Royal College of General Practitioners is investigating if primary healthcare practitioners could play a greater role in diagnosis and management of ADHD.
24. *Neurodiversity workforce development.* Te Pou provides neurodiversity e-training modules for the health and disability workforce.

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<sup>2</sup> Changing the Special Authority requires careful consideration, including dialogue with mental health professionals and will involve Pharmac's usual investigation and prioritisation process. Pharmac has assessed an additional medication which better tolerated by some patients and less likely to be diverted for recreational purposes. This medication is currently considered as an option for investment alongside other funding proposals.

## Disability

25. *Review of eligibility for Disability Support Services.* Whaikaha is currently scoping a medium-term policy work programme to review eligibility to access disability support services (DSS). Whaikaha expects to provide advice to the Minister for Disability Issues on the scope of the work programme in due course. The review will consider whether to expand eligibility to cover more groups of disabled people and tāngata whaikaha Māori (disabled Māori), and how DSS functions alongside other government supports.
26. Once the scope of the review of eligibility is confirmed, Whaikaha expects that the review itself will take at least 18-24 months. Any proposed changes to DSS eligibility settings will require a decision from Cabinet in future and will have funding implications.
27. Whaikaha is working with an Advisory Group in scoping the review of DSS eligibility. The Advisory Group represents the needs of people currently not served or underserved by DSS. The Advisory Group includes members from ADHD NZ, Autism New Zealand, Fetal Alcohol Spectrum Disorder – Carers' Action Network, Tourette's Association, Epilepsy New Zealand, Rare Disorders New Zealand, Stroke Foundation, as well as other representative organisations.

## Education

28. *Learning Support Action Plan 2019-2025.* The plan has a priority focus to develop flexible supports for neurodiverse children and young people (Priority 4).

## Oranga Tamariki

29. *Neurodiversity/FASD practice guidance.* Oranga Tamariki has recently developed practice guidance.<sup>3</sup> This provides an overview of FASD and areas for support for individuals and whanau.
30. *Oranga Tamariki Disability Strategy.* This aims to support disabled tamariki (children) and rangatahi (young people). Their prototype definition of disability recognises neurodiverse conditions such as autism, ADHD and FASD.<sup>4</sup>
31. *Review of the Gateway Assessment process.* Oranga Tamariki, health agencies and the Ministry of Education with support from Whaikaha are reviewing the Gateway Assessment process. Gateway is used to identify unmet health and education needs, including screening and potential referrals around neurodiversity.

## Upcoming events

32. *ADHD NZ collaborative network.* A second Parliament meeting of the ADHD NZ collaborative network is scheduled shortly with date to be confirmed. Greens Party co-leader Chlöe Swarbrick will again host the forum and we understand you have been invited to attend. Ministry officials will also attend this meeting.
33. *Neurodiversity Awareness Week.* Neurodiversity Celebration Week aims to give schools, universities, and organisations the opportunity to recognise and the many talents and advantages of being neurodivergent. It is celebrated 18 to 24 March 2024.

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<sup>3</sup> See <https://practice.orangatamariki.govt.nz/our-work/disability/practice-when-working-with-disabled-people/fetal-alcohol-spectrum-disorder-fasd-and-neurodiversity/>

<sup>4</sup> See <https://www.orangatamariki.govt.nz/about-us/supporting-oranga-for-disabled-people/disability-definition/>



34. *Autism Acceptance Week.* World Autism Acceptance Day is a yearly event on the 2nd of April each year. This year it will be celebrated 2 to 8 April 2024. This is the 17th annual World Autism Day, which was declared by the United Nations Council in 2007 and first celebrated in 2008. The theme for World Autism Acceptance Day 2024 is: Colour. Autism New Zealand are hosting a World Autism Awareness Day Breakfast event at Parliament.

## **Opportunities**

35. As indicated above, the health system has a central role in improving health outcomes for people with neurodiverse conditions. However, there is need also to have a well-coordinated whole of government approach to neurodiversity to address the complex and diverse needs of this group.
36. To support improved understanding about how the health could better connect and coordinate across government, you could consider bringing together a forum of experts, consumers and communities to consider how best to improve intersectoral coordination on neurodiversity.

## **Next steps**

37. Minister Reti is due to receive a briefing on the Health of Disabled People on 28 March that provides information on the Health Minister's role in relation to the health of disabled people and seeks his high-level direction on work to improve health outcomes for disabled people.
38. At your request, the Ministry can provide you with further information on any of the neurodiversity work and issues outlined in this briefing.

**END.**