

# Submission to Whaikaha – Ministry of Disabled People on the Refresh of the New Zealand Disability Strategy

## Introducing Mana Mokopuna – Children's Commissioner

Mana Mokopuna – Children's Commissioner (Mana Mokopuna) is the independent Crown entity with the statutory responsibility to advocate for the rights, interests, participation and well-being of mokopuna<sup>1</sup> (all children and young people) under 18 years old in Aotearoa New Zealand, including young persons aged over 18 but under 25 years of age if they are, or have been, in care or custody. The Children's Commissioner is Dr Claire Achmad.

We independently advocate for and with mokopuna within the context of their families, whānau, hapū, iwi and communities, based on evidence, data and research, including the perspectives of mokopuna.

Our work is grounded in the United Nations Convention on the Rights of the Child (the Children's Convention), Te Tiriti o Waitangi and other international human rights instruments. We are a National Preventative Mechanism under the Optional Protocol to the Convention Against Torture, meaning we monitor places where mokopuna are deprived of their liberty, including in the care and protection, youth justice, youth mental health and intellectual disability spaces.

We have a statutory mandate to promote the Children's Convention and monitor the Government's implementation of its duties under the Convention, and to work in ways that uphold the rights of mokopuna Māori including under Te Tiriti o Waitangi. We place a focus on

advocating for and with mokopuna who are experiencing disadvantage, and we recognise and celebrate the diversity of mokopuna in all its forms.

Our moemoeā (vision) is *Kia kuru pounamu te rongo – All mokopuna live their best lives*, which we see as a collective vision and challenge for Aotearoa New Zealand.

When it comes to the rights of mokopuna whaikaha (children and young people with disabilities), our advocacy for their rights, and with mokopuna whaikaha, is a focus across our four strategic advocacy areas:

- A strong start in life (first 2000 days)
- Growing up safe and well (free of all forms of child maltreatment in all circumstances; thriving mental health and wellbeing)
- Thriving families and whānau (living free of poverty, with resources needed to support mokopuna to thrive), and
- Participating in what matters to me (mokopuna have told us, for example, about the importance of participating in their education, culture and identity, sport and recreation, and caring for the natural environment).

<sup>&</sup>lt;sup>1</sup> At Mana Mokopuna we have adopted the term 'mokopuna' to describe all children and young people in Aotearoa New Zealand. 'Mokopuna' brings together 'moko' (imprint or tattoo) and 'puna' (spring of water). Mokopuna describes that we are descendants, and or grandchildren, and how we need to think across generations for a better present and future. We acknowledge the special status held by mokopuna in their families, whānau, hapū and iwi and reflect that in all we do. Referring to children and young people we advocate for as mokopuna draws them closer to us and reminds us that who they are, and where they come from, matters for their identity, belonging and well-being at every stage of their lives.



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Across all of these areas, the rights of mokopuna whaikaha in Aotearoa New Zealand still require greater respect and protection. The Children's Commissioner, through the course of her tenure, has been placing a specific focus on engaging with mokopuna whaikaha – including those with invisible disabilities – and with whānau whaikaha throughout Aotearoa New Zealand, to understand the living experiences of mokopuna whaikaha and amplify their advocacy.

It is clear that urgent systemic change is needed to fulfil the rights of mokopuna whaikaha, and alleviate toxic stress in the lives of whānau whaikaha. The Disability Strategy should reflect and give effect to this. This submission is informed by Mana Mokopuna - Children's Commissioner's engagement with mokopuna whaikaha, with whānau whaikaha, and includes direct quotes from mokopuna whaikaha. In addition, we have specifically engaged with I.Lead to inform this submission.

### **Summary and recommendations**



"One thing we learned from our health, education and disability services is the need to talk to the individual and ask them what they need, don't treat disabilities as one experience, we are individuals with different needs."

(Disabled young person, I. Lead. Children's rights Symposium 2024)<sup>2</sup>

- 1. Mokopuna whaikaha are rights-holders under the Children's Convention, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and, for Māori mokopuna whaikaha, Te Tiriti o Waitangi. These instruments collectively affirm their rights to protection, active participation, inclusion, and equitable access to services. While the draft NZ Disability Strategy (draft Strategy) acknowledges disabled children (mokopuna whaikaha³), it is the strong view of Mana Mokopuna Children's Commissioner that further measures should be included in this Strategy to ensure the rights, needs and perspectives of mokopuna whaikaha (including mokopuna whaikaha in care and/or youth justice) are central to legislation, policy and practice, and we are available to assist in this strengthening.
- 2. Across all areas of the draft Strategy, it is crucial the Crown's Te Tiriti o Waitangi obligations are fully realised. This includes supporting tino rangatiratanga, ensuring equitable outcomes for mokopuna whaikaha Māori, and integrating culturally grounded practices in policy design, data collection, and service delivery.
- 3. The United Nations Committee on the Rights of the Child in its most recent Concluding Observations to New Zealand recommended a focus on the rights of mokopuna whaikaha as one of the seven areas in need of urgent attention. This focus on mokopuna whaikaha and their rights needs to be more strongly reflected in the Strategy. Further, the Committee has recommended that Aotearoa New Zealand strengthen the integration of a human rights-based approach to disability in implementing the previous Disability Strategy. While the draft Strategy's five priority areas (education, health, housing, employment, and justice) show some alignment with this approach, significant gaps remain. In particular, we note gaps in the draft Strategy regarding the urgent need to address poverty that disproportionately affects mokopuna whaikaha, the rights of mokopuna whaikaha in care and youth justice, and wider priorities identified by mokopuna whaikaha as requiring significant attention to uphold their rights.

<sup>&</sup>lt;sup>3</sup> Throughout this submission we refer to disabled children and young people as mokopuna whaikaha. IHC notes "disabled" is referred to as "whaikaha", meaning to have strength, to have ability, otherly abled, enabled.



<sup>&</sup>lt;sup>2</sup> <u>Discussion Doc - CMG Symposium</u>

- 4. Mokopuna whaikaha in care or youth justice are more likely to experience exclusion, abuse, and inequitable outcomes.<sup>4</sup> The draft Strategy must safeguard their rights, and ensure access to appropriate support, education, healthcare and cultural activities.
- 5. To strengthen the draft Strategy, Mana Mokopuna recommends that Whaikaha Ministry of Disabled People (Whaikaha) considers the following overarching recommendations.
  - a) Implement robust data collection and monitoring systems, including disaggregated data for mokopuna whaikaha in care and youth justice, to measure progress and enable transparent reporting.
  - b) Ensure mokopuna whaikaha perspectives are reflected throughout the draft Strategy, and in the implementation of actions that impact them, ensuring their right to participation is supported, including for those in care and/or youth justice.
  - c) Require cross-agency actions to give effect to the Strategy and prevent agencies working in isolation. This needs to be underpinned by making explicit in the Strategy the interconnections and interdependencies with other key strategies, including the Government's Child and Youth Strategy and Te Aorerekura.
  - d) Ensure all actions are adequately resourced with financial and human capacity to achieve intended outcomes.
- 6. Mokopuna whaikaha have highlighted the need to extend the draft Strategy beyond the existing five priority areas. Key gaps include mental health, sport and recreation, transport, emergency management, and the rights and wellbeing of mokopuna whaikaha in State care and/or youth justice. Mana Mokopuna advocates for these areas to be explicitly recognised as additional priorities in the Strategy, to ensure a rights-based approach and align more closely with what mokopuna whaikaha themselves are advocating for.
- 7. Greater focus must also be placed on the draft Strategy's education priority, as gaps persist in inclusive practices, accessibility, and support for mokopuna whaikaha to fully experience their education rights. Many mokopuna whaikaha experience exclusion, inconsistent teacher knowledge and understanding of disability and inclusion, insufficient learning support, limited whānau involvement, and barriers for those in State care and/or youth justice. Addressing these gaps requires compulsory and continual disability awareness and inclusion training for educators, beginning in teacher training, and backed up by ongoing teacher education, improved support systems, accessible mechanisms for mokopuna whaikaha to share their views and participate in decision-making, and annual reporting on learner outcomes.
- 8. Mana Mokopuna is pleased to see the progress noted in the draft Strategy, however more work is needed to embed a human rights-based, Te Tiriti o Waitangi-aligned approach that centres mokopuna whaikaha and their whānau, and the rights of mokopuna whaikaha that are protected under the Children's Convention, United Nations Convention on the Rights of Persons with Disabilities, and New Zealand domestic laws. Strengthening resourcing, data collection, active participation, and extending priority areas will ensure the draft Strategy improves outcomes, equity, and inclusion for all mokopuna whaikaha.

#### Recommendations to strengthen the draft Disability Strategy 2026-2030

Mana Mokopuna – Children's Commissioner makes the following recommendations:

1. Ensure mokopuna whaikaha are explicitly prioritised in the draft Strategy.



PAGE | 3

<sup>&</sup>lt;sup>4</sup> "Institutions are places of abuse" - The experiences of disabled children and adults in State care .docx

<sup>&</sup>lt;sup>5</sup> https://evidence.ero.govt.nz/documents/thriving-at-school-education-for-disabled-learners-in-schools

- 2. Update the draft Strategy to make the language strengths-based and understandable for everyone and explain terms used to support transparency.
  - a) Simplify use of language and outline if there are links to other key disability documents such as Enabling Good Lives, and human rights obligations like the UN Convention on the Rights of Persons with Disabilities, the Children's Convention and Te Tiriti o Waitangi.
- 3. Consider overarching recommendations which support the Government to implement the General Measures of Implementation under the Children's Convention.
  - a) Ensure all actions are adequately resourced with financial and human capacity to achieve intended outcomes.
  - b) Implement robust data collection and monitoring systems, including disaggregated data for mokopuna whaikaha in care and youth justice, to measure progress and enable transparent reporting.
  - c) Embed mokopuna whaikaha perspectives across the draft Strategy and in the implementation of actions that impact them, ensuring their right to participation is supported, including for those in care and/or youth justice.
- 4. Give effect to Te Tiriti o Waitangi to achieve equitable outcomes for mokopuna whaikaha Māori by making the following changes to the draft Strategy.
  - a) Referring to Te Tiriti o Waitangi as they key rights instrument rather than the Treaty of Waitangi
  - b) Strengthening Māori governance, including the perspectives of mokopuna whaikaha Māori, through leadership, co-design, and active monitoring of the draft Strategy.
  - c) Actively support the right to self-determination by investing in and supporting Māori-led services, resourcing Māori practitioners, and prioritising culturally responsive interventions designed by mokopuna whaikaha Māori and their whānau to address disparities.
  - d) Increasing the focus placed on achieving equity for mokopuna whaikaha Māori and their whānau, hapū and iwi.
  - e) Integrating Māori worldviews and strengthen wairuatanga in services, supporting connection to whānau, iwi, and whenua.
- 5. Improve how the draft Strategy connects to other government work and ensure that it aligns with other key changes such as the NCEA reforms or other disability action plans.
  - a) Provide for cross-agency actions which ensure the rights of mokopuna whaikaha in a collaborative manner, rather than working in isolation.
  - b) Make much clearer the interconnections and interdependencies between the Strategy and other key strategies including the Government's Child and Youth Strategy (specifically the interconnections between the three priorities: Supporting children and their families and whānau in the first 2,000 days; Reducing child material hardship; Preventing child harm), and Te Aorerekura.
- 6. Reflect more clearly in the Strategy focus and actions to implement the most recent recommendations from the UN Committee on the Rights of the Child and the UN Committee on the Rights of Persons with Disabilities.
- 7. Include actions from the I. Lead report cards (2024) and add the following priorities areas to the draft Strategy, as informed by I. Lead:
  - a) Mental health
  - b) Sport and recreation



- c) Transport, and
- d) Emergency management.

Consult with I.Lead directly to ensure that the recommendations of the 2025 Report Cards (put together by mokopuna whaikaha at the 2025 I.Lead Conference are further informing the Strategy, noting, for example, the new area of focus of Arts).

- 8. Focus the Strategy on addressing systemic issues that impact mokopuna whaikaha and their whānau, including to following.
  - a) Reducing poverty and material hardship through targeted support that addresses the social determinants of wellbeing for mokopuna whaikaha and their whānau (noting that material hardship disproportionately impacts mokopuna whaikaha, and reducing child material hardship is one of the three priorities of the Government's Child and Youth Strategy).
  - b) Establishing clear, consistent, and timely disability definitions and diagnostic processes, coupled with increased financial resources, to ensure early access to appropriate supports.
  - c) Ensuring disability assessments occur as early as possible to enable tailored planning and prevent inappropriate placements in care, education, and justice settings.
  - d) Formally recognising Fetal Alcohol Spectrum Disorder (FASD) as a disability so mokopuna receive equitable access to health, education, justice, and social services.
  - e) Reforming disability funding models and services so they are child-centred, flexible, culturally responsive, and focused on long-term outcomes.
  - f) Explicitly prioritising the prevention of violence against mokopuna whaikaha by embedding stronger safeguarding, reporting, and trauma-informed practice, with clearer interconnections to Te Aorerekura.
  - g) Protecting the rights of mokopuna whaikaha in youth in-patient units by ending harmful practices such as seclusion, reviewing and replacing the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, and investing in safe, therapeutic environments to uphold the rights of mokopuna whaikaha.
  - h) Reducing over-representation of mokopuna whaikaha in State care and youth justice, prioritising early disability assessments and improving facilities to be fit-for-purpose.

#### Introduction



"If you were a young disabled person in a wheelchair and there wasn't a ramp at the front of a building, [you would have to] go around the back entrance just to get in. As much as you have the accessibility it's almost dehumanising to be forced to go through that back entrance."

(Disabled young person. What Makes a Good Life? OCC, 2021)<sup>6</sup>

9. Mana Mokopuna – Children's Commissioner welcomes the opportunity to submit on the Refresh of the New Zealand Disability Strategy (the draft Strategy). Under our statutory mandate to monitor the United Nations Convention on the Rights of the Child (the Children's Convention) and to advocate for its implementation, our submission is grounded in a children's rights approach and guided by Article 23 of the Children's

<sup>&</sup>lt;sup>6</sup> <u>A summary report in the What Makes a Good Life? Children and Young People's views on wellbeing series. Published by the Office of the Children's Commissioner, September 2021.</u>



Convention, which establishes the right of mokopuna whaikaha to enjoy a full and decent life. This is underpinned by all of the other substantive rights in the Children's Convention, which mokopuna whaikaha should experience fully, at all times, in all circumstances.

- 10. Mokopuna whaikaha are diverse in their identities and we acknowledge all disabilities in all of their forms, noting there are vast individual lived experiences of disability and a multitude of issues impacting mokopuna whaikaha and their whānau. The draft Strategy must harness the strengths and diversity of all mokopuna whaikaha, supporting them to reach their full potential, achieve their aspirations and experience full inclusion at all times.
- 11. We are pleased to see one of the principles proposed for the draft Strategy is human rights and includes reference to international rights instruments such as the Children's Convention. However, this principle should be more strongly interwoven throughout the Strategy, and can be practically strengthened by linking each of the priority areas to key rights under each instrument. Mana Mokopuna – Children's Commissioner is available to Whaikaha to support this to be reflected from a children's rights perspective, as the draft Strategy is further refined and finalised.
- 12. One of our key functions is encouraging the active participation of mokopuna, to uphold their right to participation (Article 12 of the Children's Convention). On these grounds, Mana Mokopuna amplifies the perspectives of mokopuna and rangatahi whaikaha who have shared their experiences, aspirations and ideas with us, including through direct conversations and engagements with their Children's Commissioner, and with the Mana Mokopuna team through various projects. We acknowledge and thank the mokopuna of I.Lead who have helped to inform this submission, and we champion the wider advocacy of mokopuna whaikaha who are advocating for positive change throughout our country.

## Upholding the rights of mokopuna whaikaha in the Strategy



"The biggest barrier causing discrimination within our systems is the lack of open-mindedness by the people running those organisations. It is about learning, being open to make mistakes and involving disability at all levels of decision making."

(Disabled young person, I. Lead. Children's rights Symposium 2024)<sup>8</sup>

- 13. Mokopuna whaikaha are rights-holders under the Children's Convention and the United Nations Convention on the Rights of Persons with Disabilities (the UNCRPD), with mokopuna whaikaha Māori holding rights under Te Tiriti o Waitangi. As a States Party to the Children's Convention and UNCRPD, and as the Crown is one of the two parties to Te Tiriti o Waitangi, the New Zealand Government is duty-bound to uphold these rights by ensuring dignity, promoting self-reliance, and enabling the active participation of mokopuna in their lives and communities.9
- 14. As a country, we still have a long way to go in achieving equitable outcomes for mokopuna whaikaha and realising all of their rights. For example, a Growing Up in New Zealand (GUiNZ) study found mokopuna whaikaha tend to have poorer outcomes in health, wellbeing, education, relationships, and sense of safety. 10 Official child poverty



<sup>&</sup>lt;sup>7</sup> Section 22, Children's Commissioner Act 2022.

<sup>&</sup>lt;sup>8</sup> Discussion Doc - CMG Symposium

https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#Article-23

<sup>&</sup>lt;sup>10</sup> Growing Up in New Zealand, 2021. Now We Are 12: <u>The impact of disability on young people and their family</u>

- statistics highlight that mokopuna whaikaha are disproportionately experiencing poverty. 11
- 15. The draft Strategy is a step towards safeguarding and realising the rights of mokopuna whaikaha. However, more must be done to improve outcomes for them and their whānau. We are pleased that there is a focus on mokopuna whaikaha in the draft Strategy, but to ensure a good start in life for mokopuna whaikaha they must be more strongly and explicitly made central and prioritised in the Strategy. This is crucial given the significant progress that is still required to uphold the rights of mokopuna whaikaha across many facets of their lives.

#### Considerations from a children's rights perspective for the draft Strategy

- 16. The 2023 Concluding Observations of the United Nations Committee on the Rights of the Child (UNCRC Committee) urgently recommend the New Zealand Government takes urgent measures to protect the rights of mokopuna whaikaha. As one of the seven urgent areas of concern specified by the UNCRC Committee, Mana Mokopuna expects the Government to prioritise and respond to the recommendations made by the UNCRC Committee regarding the rights of mokopuna whaikaha. The Strategy is a primary vehicle for this.
- 17. The UNCRC Committee recommends the Government acts urgently and implements the following recommendations.
  - a) **Poverty reduction and family support:** Strengthen community-based services, respite provision, and access to affordable housing for low-income families of mokopuna whaikaha.
  - b) **Eliminating stigma and violence:** Implement sustained public campaigns to challenge discrimination, ensure zero tolerance of abuse, and provide accessible, child-friendly reporting mechanisms.
  - c) **Education and employment pathways:** Remove barriers to education completion, enhance the quality of vocational training, and facilitate effective transitions from school to employment.
  - d) **Protection of bodily integrity:** Prohibit non-consensual sterilisation and promote awareness of children's rights to bodily autonomy among families, caregivers, and professionals.
  - e) **Active participation in decision-making:** Ensure mokopuna whaikaha are empowered to be involved in policy development, including throughout the work of Whaikaha and renewal of the Disability Action Plan.
  - f) **Improved data and monitoring:** Conduct the Disability Survey every five years to strengthen evidence for inclusive policymaking and to enhance equitable access to services, particularly in rural areas.<sup>13</sup>
- 18. The UNCRC Committee has recommended Aotearoa New Zealand strengthens the integration of a human rights-based approach to disability in implementing the previous Disability Strategy<sup>14</sup>. While the draft Strategy's five priority areas show some alignment with such an approach, this should be further strengthened by following international guidance from the UNCRC Committee outlined in its General Comment No.9 on the rights of children with disabilities.<sup>15</sup>

<sup>&</sup>lt;sup>11</sup> See: No movement in child poverty rates for year ended June 2024 | Stats NZ

 $<sup>^{12}\,\</sup>text{CRC/C/NZL/CO/6, 2023.}\,\underline{\text{The UN's Concluding Observations to Aotearoa New Zealand}},\,\text{at para 4.}$ 

<sup>&</sup>lt;sup>13</sup> CRC/C/NZL/CO/6, 2023. The UN's Concluding Observations to Aotearoa New Zealand.

<sup>&</sup>lt;sup>14</sup> CRC/C/NZL/CO/5, 2016. The UN's Concluding Observations to Aotearoa New Zealand.

<sup>&</sup>lt;sup>15</sup> See: tbinternet.ohchr.org/ layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2FC%2FGC%2F9&Lang=en

- 19. Mokopuna whaikaha in youth in-patient units (i.e. youth mental health, intellectual disability) and youth justice settings face systemic breaches of their rights under the Children's Convention and UNCRPD. Under our designation as part of New Zealand's National Preventative Mechanism under the Optional Protocol to the Convention Against Torture, Mana Mokopuna has documented serious concerns, including prolonged seclusion, unsafe placements, and inadequate facilities that fail to provide therapeutic or child-centred care. <sup>16</sup> Injustices and breaches of the rights of mokopuna whaikaha in places where they are deprived of their liberty are compounded by the over-representation of mokopuna whaikaha in State care and youth justice, where disability is often under-identified and poorly supported.
- 20. Mokopuna whaikaha have advocated for improvements to give effect to their human rights that go beyond the five priority areas identified in the draft Strategy. These include crucial areas of focus including mental health, sport and recreation, transport and emergency management.<sup>17</sup> Mana Mokopuna amplifies their advocacy, and strongly advocates for the draft Strategy to be strengthened by adding these specific areas as additional priorities, with a strong focus on the rights of mokopuna whaikaha.

## The Convention on the Rights of Persons with Disabilities with a specific focus on mokopuna whaikaha

- 21. Both the UNCRC and UNCRPD Committees urge Aotearoa New Zealand to address inequities for mokopuna whaikaha and consider their best interests. <sup>18</sup> Essential steps to make good on these recommendations include reducing poverty, preventing violence, strengthening inclusive education and employment pathways, ensuring the active participation of mokopuna whaikaha in decision-making affecting them, and improving disaggregated data to support accountability and a consistent human-rights-based approach. <sup>19,20</sup>
- 22. As noted in the UNCRPD Concluding Observations, the UNCRPD Committee is concerned about persistent inequities for tangata whaikaha, including "the disproportionate levels of poverty among persons with disabilities, who are twice as likely to live in poverty than the general population, and for Māori persons with disabilities, who are three times as likely to live in poverty."<sup>21</sup>
- 23. As informed by the New Zealand Independent Monitoring Mechanism under the UNCRPD, Mana Mokopuna highlights the following key disability rights issues which have a compounding effect on mokopuna whaikaha.
  - **Poverty:** Over-representation of disabled people, particularly mokopuna whaikaha Māori, in poverty due to inadequate welfare, housing, and employment systems.
  - **Humanitarian crises:** Loss of essential services, inaccessible information, and lack of inclusion of mokopuna whaikaha in emergency planning and response.
  - **Integrity of the person:** Exposure to violence, abuse, seclusion, restraint, and non-consensual medical procedures, with limited supported decision-making.

<sup>16 2022/23</sup> Annual report of activities under the Optional Protocol to the Convention against Torture (OPCAT) | Mana Mokopuna

<sup>&</sup>lt;sup>17</sup> Report Cards – I.Lead

<sup>&</sup>lt;sup>18</sup> <u>Article 7 of the UNCRPD</u> outlines that the best interests of the child shall be a primary consideration and that mokopuna whaikaha have the right to express their views freely on all matters affecting them.

<sup>&</sup>lt;sup>19</sup> CRC/C/NZL/CO/6, 2023. The UN's Concluding Observations to Aotearoa New Zealand,

<sup>&</sup>lt;sup>20</sup> Concluding observations on the combined 2nd and 3rd periodic reports of New Zealand

<sup>&</sup>lt;sup>21</sup> <u>Ibid:</u> at para 53(a)

- **Equality and justice:** Persistent systemic discrimination, outdated laws undermining autonomy, and disproportionate representation of mokopuna whaikaha Māori in care and justice systems.
- Accessibility and independence: Ongoing barriers to housing, education, digital access, and support services, despite some progress through accessibility legislation and Enabling Good Lives.<sup>22</sup>

### Amplifying the voices of mokopuna whaikaha



"Being included and knowing our voice matters - that's our mahi, making sure disabled people are included in the conversation."

(Disabled young person, I. Lead, presentation at the Children's rights Symposium,

- 24. As previously noted, the active participation and voices of tangata whalkaha are fundamental to a human-rights-based approach to the draft Strategy. Mana Mokopuna advocates for active, sustained and empowered participation of mokopuna whaikaha and their whānau in the draft Strategy's implementation, governance, decision-making, and ongoing oversight and monitoring of impact and outcomes.
- 25. It is essential that mokopuna whaikaha perspectives are embedded at every level of policymaking, service design, implementation and evaluation – through age-appropriate and accessible formats, and intentional participatory mechanisms on an ongoing basis.
- 26. The Children's Commissioner regularly engages with mokopuna whaikaha and their whānau in their communities, at disability events and in spaces that are led by rangatahi whaikaha, for mokopuna whaikaha. The Children's Commissioner has heard about the issues directly impacting mokopuna such as barriers to education, inclusion in the things that matter to them such as sport, recreation, culture and community, large financial pressures, health inequities and the lack of appropriate and accessible forms of participation for mokopuna whaikaha across many aspects of their lives. Mokopuna whaikaha have emphasised to the Children's Commissioner that the decisions taken at a strategic level should involve them – nothing about them without them – which we fully support. The Disability Strategy provides a crucial opportunity to have a positive intergenerational impact for mokopuna whaikaha, and they should be involved on an ongoing basis in its implementation and monitoring, and it should reflect and respond to their lived realities.

## What mokopuna whaikaha and their whānau have said about some the of issues impacting them

27. On the following pages of our submission, we have outlined a series of insights that are shaped by I. Lead, a disabled youth movement led by youth, for youth, and the voices of mokopuna whaikaha who have shared their views with Mana Mokopuna through surveys, events and informal korero with the Children's Commissioner and Mana Mokopuna team. We have structured these findings under the 8 priorities identified by I. Lead for their report cards produced by rangatahi whaikaha during their Disabled Youth Conference in 2024.<sup>24</sup> We advocate to Whaikaha to ensure these are reflected in the Strategy. We further note that the report cards from the 2025 I.Lead Conference are not yet published,



PAGE | 9

<sup>&</sup>lt;sup>22</sup> Independent Monitoring Mechanism. Disability Rights: How is New Zealand doing? An update report about the state of disability rights in New Zealand. June 2022.

<sup>&</sup>lt;sup>23</sup> Discussion Doc - CMG Symposium

<sup>&</sup>lt;sup>24</sup> Each priority area has been hyperlinked to direct you to the report card on I. Lead's website.

and include a wider focus, including on what mokopuna whaikaha say needs to change in areas such as the Arts. We urge Whaikaha to engage with I.Lead to ensure the 2025 report card recommendations inform the Strategy, too.



Some Mokopuna
Whaikaha Perspectives
shared with Mana
Mokopuna – Children's
Commissioner

#### **Evidence / Key Issues**

#### Recommendations from I. Lead

#### **Health**

"The well-being of fellow youth and the importance they have support in both mental and physical health, and spaces where they can open up and be guided by mentors."

(Mokopuna whaikaha, 12 -17 years old. What matters most? Mana Mokopuna, 2023)<sup>25</sup> Mokopuna whaikaha face persistent barriers to accessing healthcare in Aotearoa New Zealand, despite their right under Article 24 of the Children's Convention to the highest attainable standard of health. <sup>26</sup> This right is not being upheld, even though mokopuna whaikaha engage with the health system more frequently than their peers. <sup>27</sup>

It is important that the draft Strategy works to make long-term improvements to the health sector and streamlines the health and disability sector including inconsistencies with funding across Te Whatu Ora and ACC.

I.Lead has highlighted barriers such as overcrowded and inaccessible facilities, short and unaffordable appointments, limited support for complex needs, high costs of private care, long waitlists, stressed professionals, and poor communication with neurodiverse patients. These issues leave many mokopuna without the timely and appropriate care they need.<sup>28</sup>

- Establish scholarships, internships, and work experience programmes for disabled youth to allow more disabled youth to become employed within the health sector.
- Investigate medication access so that we can access medications quickly and have specialised medications funded for us.
- Develop training for the health sector on how to communicate with disabled people.

#### **Mental Health**

"Mental illness. Too much work and pressure at school and not enough help from school."

Mokopuna whaikaha experience clear inequities in access to mental health and wellbeing services. Support is often not designed with their needs in mind, leaving many feeling excluded, misunderstood, or unable to access timely help. These inequities mean mokopuna whaikaha are at greater risk of poor mental health outcomes compared with their peers.<sup>30</sup> While the draft Strategy identifies health as

 Training and ongoing professional development for mental health workers to be able to understand disabled youth to ensure that they feel connected and supported.



<sup>&</sup>lt;sup>25</sup> Voices of mokopuna | Mana Mokopuna

 $<sup>^{26} \, \</sup>underline{\text{https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child\#Article-24} \\$ 

<sup>&</sup>lt;sup>27</sup> Disabled people experiencing poorer health and wellbeing than non-disabled people | Whaikaha - Ministry of Disabled People

<sup>&</sup>lt;sup>28</sup> Workshop 3 I.Lead Slides - Symposium Aug 2024.pdf

<sup>&</sup>lt;sup>30</sup> Child disability health data available for the first time | Whaikaha - Ministry of Disabled People

(Mokopuna whaikaha, 12 - 17 years old. What matters most? Mana Mokopuna, 2023)<sup>29</sup> a priority, it does not include specific actions to improve mental health outcomes. I.Lead has highlighted mental health as a standalone priority, and Mana Mokopuna therefore calls for a stronger focus in the draft Strategy.

- Hire people with lived experience of disability and mental health concerns.
- Nationwide campaign using young people with disabilities.

#### **Employment**

"Without sort of being scared that they are going to apply to this work and just be rejected based on the fact that they've got this physical disability."

(Disabled young person. What Makes a Good Life? OCC, 2021)<sup>31</sup>

Employment offers mokopuna whaikaha the opportunity to contribute their skills, gain independence, and thrive in their communities. Under the UNCRPD, mokopuna whaikaha have the right to work on an equal basis with others.<sup>32</sup> Realising this right requires removing barriers to employment and creating environments where mokopuna whaikaha can succeed.

While the draft Strategy identifies employment as a priority outcome, more deliberate focus is needed on creating equitable opportunities for mokopuna whaikaha to find and maintain employment that is meaningful to them and which supports their full inclusion. The current actions set a strong foundation, particularly around building employer capability and developing accessible job pathways. However, the actions should go further to ensure rangatahi whaikaha are supported into careers that reflect their strengths and aspirations.

- Create an accreditation system to ensure that workplaces are accessible and inclusive of people with disabilities, alongside ensuring that there is mandatory training for all staff.
- Reintroduce wage subsidies for employers to be able to give young people with disabilities a chance at gaining employment.
- Develop an app for inclusive jobs.
- Not-for-profits funded by the government are incentivised through their contracts to employ disabled people.

#### **Housing**

"I want everyone to have a nice warm home and as much food as anyone shall need." (Mokopuna whaikaha, 5-11 years old. What matters most? Mana Mokopuna, 2023)<sup>33</sup> Like all other children, mokopuna whaikaha have the right to safe, accessible and inclusive housing, yet many continue to face barriers in securing homes that meet their needs.<sup>34</sup> While housing is recognised in the draft Strategy, stronger action is required to address the lack of accessible housing and to embed universal design across both public and private housing – noting that any guidelines should be mandatory and not voluntary to ensure housing is truly universally accessible.

The draft Strategy insufficiently addresses the specific challenges faced by mokopuna whaikaha and their whānau. Despite protections under Article 27 of the

- Mandatory yearly training on disability inclusion for Realtors, Kainga Ora, Councils and Private Landlords.
- Create design templates for accessibility to ensure that property developers and councils can implement universal design features.
- Establish an accreditation scheme so we know which realtors, housing organisations, and



<sup>&</sup>lt;sup>29</sup> Voices of mokopuna | Mana Mokopuna

<sup>&</sup>lt;sup>31</sup> A summary report in the What Makes a Good Life? Children and Young People's views on wellbeing series. Published by the Office of the Children's Commissioner, September 2021.

<sup>&</sup>lt;sup>32</sup> https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities#article-27

<sup>33</sup> Voices of mokopuna | Mana Mokopuna

<sup>&</sup>lt;sup>34</sup> The Effects of Housing on Health and Well-Being in Aotearoa New Zealand 2021

Children's Convention<sup>35</sup> and Article 28 of the UNCRPD,<sup>36</sup> many mokopuna whaikaha still face barriers to accessible, secure, and affordable homes.

property managers are understanding of inclusivity and accessibility.

#### **Education & Training**

"Being included at school, I'm neuro-diverse. But L don't want to be just present at school, I want to learn in a way that works for me. Because I'm smart and want an interesting job when I grow up. Schools are too loud, and teachers don't explain in a way that works for me. That makes me frustrated, angry and sad." (Mokopuna whaikaha, 12 - 17 years old. What matters most? Mana Mokopuna, 2023)<sup>37</sup>

Many mokopuna whaikaha continue to experience exclusion, inequity, and barriers to participate in early childhood education and schooling across all levels. 38,39 While most disabled ākonga enjoy school, too many are discouraged from enrolling in their local schools, asked to stay home when staffing is short, stood down, or not supported to engage in wider school activities. 40

Mokopuna whaikaha with complex needs often experience poorer outcomes and do not feel accepted or like they belong. Schools and Boards often lack full understanding of their legal obligations under the Children's Convention and New Zealand disability legislation, and policies do not consistently support inclusion.<sup>41</sup> Many educators report low confidence in teaching disabled learners, resulting in learning that does not meet individual needs or provide sufficient challenge.<sup>42</sup>

Parents and whānau often find it difficult to have input in their child's learning goals and pathway plans, and many are unaware of their child's rights or how to raise concerns. 43 Transitions between schools and from school to further education, training, or employment are also poorly coordinated, leaving mokopuna whaikaha at risk of gaps in support. The draft Strategy must ensure consistent inclusion and support for mokopuna whaikaha from early childhood through to tertiary education, so their rights are upheld, and they can thrive at every stage.

- Develop and deliver compulsory disability awareness and inclusion training for teachers (including ECE) that is more than one year and occurs throughout all years of training, qualification, and registration.
- Four key themes for the education sector to focus on:
  - 1. Reduce Bullying
  - 2. Support systems for us to grow and learn
  - 3. Craft co-design partnerships with disabled people
  - 4. Invest in disability awareness and inclusion training for education providers.

#### **Sport & Recreation**



<sup>&</sup>lt;sup>35</sup> https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#Article-27

 $<sup>^{36} \ \</sup>underline{\text{https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities\#article-28}$ 

<sup>&</sup>lt;sup>37</sup> Voices of mokopuna | Mana Mokopuna

<sup>&</sup>lt;sup>38</sup> What is inclusion? A focus on disabled children and their families in early childhood education. | He kupu

<sup>&</sup>lt;sup>39</sup> https://evidence.ero.govt.nz/documents/thriving-at-school-education-for-disabled-learners-in-schools

<sup>&</sup>lt;sup>40</sup> Thriving at school? Education for disabled learners in schools

<sup>41</sup> https://evidence.ero.govt.nz/media/2etf5xbv/education-for-disabled-learners-in-schools-a-guide-for-parents-and-wh%C4%81nau.pdf

<sup>42</sup> Ibid

 $<sup>{}^{43}\</sup>underline{\ https://evidence.ero.govt.nz/media/2etf5xbv/education-for-disabled-learners-in-schools-a-guide-for-parents-and-wh\%C4\%81nau.pdf}$ 

"Safety is important, playing sport and including others, having equipment so everyone can play."

(Mokopuna whaikaha, 10 years old. What matters most for mokopuna at Halberg Games, 2024)<sup>44</sup>

While sport and recreation are not currently identified as a priority in the draft Strategy, access to inclusive physical activity is essential for the health, wellbeing, and social participation of mokopuna whaikaha. Many disabled children and young people face barriers to participating in sport and leisure activities due to inaccessible facilities, limited opportunities, and a lack of trained staff. Ensuring equitable access to cultural activities, the arts, sport and recreation supports physical development, mental health, confidence, and social connection, consistent with the rights of mokopuna under Article 30 of the Children's Convention and Article 31 of the UNCRPD.

- Provide funding to sport and leisure organisations to improve access & participation, so they are fully inclusive and accessible.
- Urgently provide accessible play, sport & recreation spaces (indoor & outdoor) for people with disabilities.
- Mandatory training for PE teachers on disability awareness and inclusion.

#### **Transport**

"Bus drivers are very judgemental and won't help. I almost always get stuck on the ramp into the bus, and 9 times out of 10 another passenger gets out of their seat to help me." (Mokopuna whaikaha, NZTA 2022)<sup>48</sup>

Transport is not currently identified as a priority in the draft Strategy, yet accessible and inclusive transport is crucial for mokopuna whaikaha to fully participate in education, employment, recreation, health, and social life. Having access to accessible transport is often the difference between participating and not participating for mokopuna whaikaha in a range of aspects of their lives in their communities. Barriers to transport limit independence, increase social isolation, and reduce access to essential services, undermining the rights of mokopuna whaikaha under Article 23 of the Children's Convention which outlines that mokopuna whaikaha have the right to special care, assistance, and access to services.<sup>49</sup>

- Public transport staff and drivers must be required to undertake courtesy, etiquette, support and awareness training and education regarding disability.
- Universally accessible public transport nationwide across all forms of transportation.
- Total Mobility assessors need lived experience with disability.

#### **Emergency Management**

"Climate change – the genuine inclusion of disabled children." (Mokopuna whaikaha, Mokopuna whaikaha often face heightened risks in times of emergency due to a lack of accessible planning, communication, and infrastructure. These gaps leave

 National emergency management campaign that champions accessibility while also targeting the disabled community.



<sup>&</sup>lt;sup>44</sup> This was an answer that a mokopuna whaikaha wrote on one of our 'What Matters Most?' postcards at the Halberg Games in 2024. For more mokopuna voices at the 2024 Halberg Games, please refer here: <a href="https://www.facebook.com/watch/?v=8970771326357215">https://www.facebook.com/watch/?v=8970771326357215</a>

<sup>45</sup> Exploring Physical Activity in Children and Adolescents with Disabilities: A Bibliometric Review of Current Status, Guidelines, Perceived Barriers, and Facilitators and Future Directions - PMC

<sup>&</sup>lt;sup>46</sup> https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#Article-31

 $<sup>^{47} \</sup>underline{\text{https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities\#article-30} \\$ 

<sup>&</sup>lt;sup>48</sup> Research Report 690 Transport experiences of disabled people in Aotearoa New Zealand - summary

 $<sup>{}^{49}\</sup>underline{\text{https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child\#Article-23}}$ 

Mokopuna, 2023) <sup>50</sup>	many mokopuna and their whānau without the support they need to stay safe, connected, and informed during crises. <sup>51</sup> The draft Strategy does not currently give enough attention to the unique needs of disabled children and young people in emergency management planning.	Develop an emergency management app.  Create spaces to be utilised during an emergency that are accessible to all people.
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<sup>&</sup>lt;sup>50</sup> Voices of mokopuna | Mana Mokopuna

<sup>&</sup>lt;sup>51</sup> Are we included in your plan? Report on Auckland disability community hui on planning for emergencies



## Giving effect to Te Tiriti o Waitangi and achieving equity for mokopuna whaikaha Māori

- 28. Ensuring equity for mokopuna whaikaha Māori requires giving effect to Te Tiriti o Waitangi. While the draft Strategy acknowledges the Crown's obligations, more focus is needed on addressing ongoing inequities in health, education, housing, justice, and social services. It is essential the draft Strategy refers to Te Tiriti o Waitangi as the spirit and intent of the English text does not reflect the provisions outlined in Te Tiriti o Waitangi.<sup>52</sup>
- 29. A Te Tiriti o Waitangi-based analysis of the draft Strategy reveals both strengths and gaps in meeting the needs of mokopuna whaikaha Māori. Persistent historical and contemporary inequities in health, education and housing are highlighted in Came et al.'s (2022) review of the 2016–2026 New Zealand Disability Strategy.<sup>53</sup>
- 30. The principle of kāwanatanga recognises the Crown's duty to govern while safeguarding Māori rights. The draft Strategy acknowledges Te Tiriti o Waitangi but limits engagement with mokopuna whaikaha Māori and their whānau in governance. Strengthening governance through Māori leadership, co-design, and active monitoring will improve accountability and ensure the Crown's commitments are realised.
- 31. Tino rangatiratanga affirms Māori authority and control over their own affairs. For mokopuna whaikaha Māori, this includes decision-making about health, education, and social support that is culturally responsive and aligns with whānau aspirations. Research highlights ongoing disparities in service access and outcomes for Māori with disabilities, exacerbated by systemic inequities. The draft Strategy must support self-determination by enabling Māori-led services, ensuring resourcing for Māori practitioners, and prioritising interventions designed by tangata whaikaha Māori and their whānau to address their distinctive needs and lived experiences.
- 32. Tangata whaikaha Māori experience higher rates of disability (32% compared to 24% for non-Māori) and often face significant social, economic, and educational inequities.<sup>55,56</sup> Further work must be done to actively address these disparities to uphold Article 3 ngā tikanga katoa rite tahi. The draft Strategy must increase the focus placed on achieving equity for mokopuna whaikaha Māori and their whānau, hapū and iwi.
- 33. Wairuatanga recognises the spiritual, relational, and cultural dimensions of wellbeing, which are central to Māori models of health and development, such as Te Whare Tapa Whā. Strengthening wairuatanga in the draft Strategy requires integrating Māori worldviews, supporting connection to whānau, iwi, and whenua, and designing services that respect the holistic wellbeing of mokopuna whaikaha Māori.
- 34. A Te Tiriti o Waitangi-based approach across these principles will better address inequities, centre the voices of mokopuna whaikaha Māori, and ensure the Crown responds to inequitable outcomes for tangata whaikaha Māori. Embedding Te Tiriti o Waitangi provisions will help policies be culturally responsive, equitable, and supportive of mokopuna whaikaha Māori thriving.



<sup>&</sup>lt;sup>52</sup> It is important to raise the Contra Proferentem which in international law, dictates that when interpreting a treaty or agreement, if there is any ambiguity or uncertainty, the indigenous or those against the proposer is preferred. Therefore, Te Tiriti o Waitangi must be prioritised in the draft Strategy and when referring to the Treaty, we recommend using Te Tiriti o Waitangi and the provisions in the te reo text.

<sup>53</sup> View of Critical Te Tiriti o Waitangi analysis of the New Zealand Disability Strategy 2016-2026

<sup>54</sup> The Multidimensional Impacts of Inequities for Tangata Whaikaha Māori (Indigenous Māori with Lived Experience of Disability) in Aotearoa, New Zealand - PMC

<sup>55 &</sup>lt;u>Disability-Rights-How-is-New-Zealand-doing.pdf</u>

<sup>&</sup>lt;sup>56</sup> Towards20a20non-disabling20New20Zealand20-20January202024.pdf

## Addressing discrimination and systemic inequities for mokopuna whaikaha



"It feels like there is a whole system that isn't made for young people with multiple things going on."

(Rainbow Youth Advisor with a disability or chronic condition. Youth19, 2021)

35. In addition to the priority areas identified by I. Lead, Mana Mokopuna highlights the following systemic issues which cut across a number of sectors and have compounding effects for mokopuna whaikaha, especially those with intersecting identities. We advocate for Whaikaha to strengthen a focus on these addressing these systemic issues in the Strategy.

#### Reducing poverty and material hardship for mokopuna whaikaha

- 36. Mokopuna whaikaha and their whānau experience disproportionate levels of poverty and material hardship, which can exacerbate existing inequalities and limit opportunities for participation, learning, and wellbeing.<sup>57</sup> Addressing these inequities requires targeted, sustained interventions that support access to adequate welfare benefits, housing, nutritious food, education, and essential health and disability services.
- 37. The draft Strategy should prioritise financial support, whānau-centred assistance, and policies that reduce barriers to participation and inclusion. By addressing the social determinants of health and wellbeing, the draft Strategy can help ensure mokopuna whaikaha have the resources and opportunities they need to thrive and fully engage in their communities.
- 38. While housing and employment are identified as priority areas in the draft Strategy, Mana Mokopuna notes that far more action is needed to address the disproportionate rates of poverty and material hardship experienced by mokopuna whaikaha and their whānau, which continue to limit opportunities for wellbeing, learning, and active participation. We advocate for a much stronger interconnection between the Strategy and the Child and Youth Strategy's priority focus on reducing child material hardship.

#### Preventing violence against mokopuna whaikaha

- 39. Mokopuna whaikaha experience disproportionately high rates of violence, including physical, emotional, and sexual abuse, both within families and in institutional settings. <sup>58,59</sup> Current protections are often insufficient, and many incidents go unreported or inadequately addressed, due to gaps in systems, oversight, and culturally responsive practices. <sup>60</sup> With the greater risks of harm to mokopuna whaikaha, there has been a clear failure to uphold their rights to protection, safety, wellbeing, and participation.
- 40. Mana Mokopuna recommends that the draft Strategy explicitly prioritises the prevention of violence against mokopuna whaikaha. This should include strengthening safeguarding frameworks, improving reporting and monitoring mechanisms, ensuring trauma-informed and culturally grounded responses, and equipping the workforce with the skills and accountability measures needed to protect mokopuna whaikaha in all settings. Stronger systemic measures are needed to reduce the high rates of violence and uphold the rights



<sup>57</sup> Samuel Murray. Breaking the Link Between Disability and Child and Whānau Poverty. Policy Quarterly – Volume 14, Issue 4 – November 2018

<sup>&</sup>lt;sup>58</sup> Neglect of Children with Disabilities: A Scoping Review - PMC

<sup>&</sup>lt;sup>59</sup> Summary of key findings | Abuse in Care - Royal Commission of Inquiry

<sup>60</sup> Neglect of Children with Disabilities: A Scoping Review - PMC

and dignity of mokopuna whaikaha. The Strategy should more strongly outline the interconnections with how this focus connects to both the Child and Youth Strategy priority focus on preventing child harm, and with Te Aorerekura.

#### **Defining and diagnosing disabilities**

41. Identifying and diagnosing disabilities is a key challenge for the disability community in Aotearoa New Zealand. Inconsistent definitions and delays in assessments due to lack of capacity in the sector, mean many mokopuna whaikaha miss out on early support and tailored services. <sup>61</sup> Clear and timely processes are needed to ensure all mokopuna receive the help and protections they need. Mokopuna and whānau whaikaha often tell us about the barriers to diagnosis due to long wait times, as well as high-cost barriers.

#### Ensuring disability assessments are occurring as early as possible

- 42. Early disability assessments are critical to providing mokopuna whaikaha with the support they need before challenges escalate. Delays in assessment can mean that children enter alternative education, care, detention, or specialist facilities without appropriate services in place, which can have long-term impacts on their wellbeing, development, and participation. 62
- 43. Ensuring assessments happen as early as possible allows whānau and professionals to identify strengths, abilities, and support the holistic needs of individual mokopuna whaikaha. Early understanding enables tailored planning and access to resources that help mokopuna whaikaha thrive, participate fully, and reach their fullest potential.<sup>63</sup>

## Extending Government definitions of disabilities to include mokopuna with Fetal Alcohol Spectrum Disorder (FASD)

- 44. FASD should be formally recognised as a disability to ensure mokopuna whaikaha living with its impacts have access to appropriate supports across health, education, justice, and social services. Early identification, prevention, and tailored interventions are essential to improve outcomes and uphold the rights of these mokopuna. <sup>64</sup> Recognition of FASD, and better understanding the implications of this disability, also allows for accurate diagnosis and support that respond to the individual needs of mokopuna whaikaha with FASD.
- 45. Formal recognition is particularly important given the over-representation of mokopuna with FASD in the youth justice system. <sup>65</sup> Extending disability definitions ensures services can respond appropriately, provide trauma-informed and culturally grounded support, and uphold the rights and dignity of mokopuna whaikaha, while validating their lived experiences and enabling their voices to guide systemic improvements.

#### Disaggregating disability data and ensuring rigorous data collection

46. Effective planning, resourcing, and monitoring of services for mokopuna whaikaha requires robust and disaggregated data on disability. <sup>66,67</sup> Current systems often fail to capture the full range of impairments, meaning the prevalence and specific needs of

<sup>&</sup>lt;sup>61</sup> Counting what matters: Valuing and making visible the lives of children with disabilities, ACYA, 2016.

<sup>&</sup>lt;sup>62</sup> It's never too early, never too late: A discussion paper on preventing youth offending in New Zealand, Office of the Prime Minister's Chief Science Advisor, 12 June 2018.

 $<sup>{\</sup>small ^{63}}\,\underline{Appendix-Five-Understanding-children-with-disabilities-in-the-Family-Start-programme.pdf}$ 

<sup>&</sup>lt;sup>64</sup> FASD-community-engagement-insights-report.pdf

<sup>65</sup> Fallen by the wayside: Young people with fetal alcohol spectrum disorder (FASD) in New Zealand's youth justice system - University of Otago

<sup>&</sup>lt;sup>66</sup> **Disaggregated Data** refers to data that is broken down into smaller, more detailed categories or subgroups, typically by characteristics such as age, gender, race, disability status, or other demographic variables.

<sup>&</sup>lt;sup>67</sup> Critical Issues and Challenges - Review of Disability Support Services

- mokopuna whaikaha are under-recognised.<sup>68</sup> Disaggregating data by type of disability, age, gender, ethnicity, and care setting is essential to identify gaps in service provision, highlight inequities, and ensure targeted support reaches those who need it most.
- 47. Rigorous data collection must also include information on outcomes, service accessibility, and lived experiences. This enables evidence-informed decision-making, allows for evaluation of interventions, and ensures accountability across health, education, justice, and social services. Collecting and reporting this data consistently will supply the evidence required to target appropriate supports that help prevent the ongoing marginalisation of mokopuna whaikaha and support the development of inclusive, equitable policies and practices.<sup>69</sup>

#### Improving disability funding models and services

- 48. Current disability funding models and service provision fall short of meeting the diverse needs of mokopuna whaikaha, particularly those with complex or intersecting impairments. The funding structures can be inflexible, siloed, or focused on short-term outputs rather than long-term outcomes, limiting the ability of whānau and service providers to deliver tailored, holistic support. Ensuring funding models are responsive, equitable, and needs-based is critical to enabling mokopuna to thrive. Greater funding must be made available for diagnosis related costs, to reduce barriers to disability diagnosis and funding that may flow as a result of diagnosis.
- 49. Services must be child-centred, culturally responsive, and developmentally appropriate, with an emphasis on early intervention, wraparound supports, and continuity of care across health, education, social services, and justice systems.
- 50. Investment in workforce capability, accessible infrastructure, and innovative service models will strengthen the quality and reach of supports, ensuring mokopuna whaikaha have access to the resources they need to reach their full potential.

### Ensuring that youth in-patient units realise the rights of mokopuna whaikaha

- 51. As a National Preventive Mechanism under the Optional Protocol to the Convention against Torture. Mana Mokopuna monitors places where mokopuna are deprived of their liberty. This includes mokopuna assessed with an intellectual disability and subject to compulsory care orders under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR), as well as mokopuna detained under the Mental Health (Compulsory Assessment and Treatment) Act 1992.<sup>73</sup>
- 52. Our monitoring has identified breaches of the Children's Convention in youth in-patient units, including a particularly concerning case where a mokopuna was kept in seclusion for over 60 days.<sup>74</sup> It is clear that most of these facilities are not fit for purpose, lack safe staffing capacity, and continue to use harmful seclusion and isolation practices.<sup>75,76</sup>

<sup>&</sup>lt;sup>68</sup> UNICEF Fact Sheet: Children with Disabilities

<sup>&</sup>lt;sup>69</sup> Oranga-Tamariki-Disability-Data-Project-2023.pdf

<sup>&</sup>lt;sup>70</sup> IHC | Woefully underfunded disability allowances failing intellectually disabled New Zealanders

<sup>&</sup>lt;sup>71</sup> Shifting the Discourse on Disability: Moving to an Inclusive, Intersectional Focus - PMC

<sup>&</sup>lt;sup>72</sup> Long-Issues-consultation-findings-18-Feb-for-publication.pdf

<sup>&</sup>lt;sup>73</sup> For this submission, youth in-patient units refer to the facilities where mokopuna are deprived of their liberty under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, as well as the Mental Health (Compulsory Assessment and Treatment) Act 1992.

<sup>&</sup>lt;sup>74</sup> Mana Mokopuna, November 2024. OPCAT Monitoring Follow-Up Report: <u>Hikitia te Wairua Final.pdf</u>

<sup>&</sup>lt;sup>75</sup> Ibid.

<sup>&</sup>lt;sup>76</sup> 2022/23 Annual report of activities under the Optional Protocol to the Convention against Torture (OPCAT) | Mana Mokopuna

- 53. While health is identified as a priority in the draft Strategy, Mana Mokopuna has observed significant gaps in actions to safeguard mokopuna whaikaha deprived of their liberty. We therefore recommend that Whaikaha consider the following priorities in finalising the draft Strategy:
  - Protect rights and dignity of mokopuna whaikaha in youth in-patient units: Eliminate harmful practices such as seclusion and inappropriate placement of mokopuna in adult facilities, ensuring all care upholds human rights standards.
  - **Review and replace the IDCCR Act:** Ensure child-centred legal framework that explicitly recognises mokopuna, upholds supported decision-making, ensures therapeutic care, and supports whānau connection.
  - **Enable therapeutic, individualised care:** Develop models of care that are responsive to the needs of each and every mokopuna, including those with intellectual disabilities, neurodiversity or oppositional defiant disorder, rather than relying on one-size-fits-all approaches.
  - Build safe, skilled services: Invest in purpose-built therapeutic environments, fill
    specialist vacancies, and provide kaimahi with ongoing training in traumainformed and culturally grounded practice.

## Addressing discrimination and over-representation of mokopuna whaikaha in State care and the justice system

- 54. Mokopuna whaikaha are significantly over-represented in both State care and the justice system, reflecting systemic discrimination and a lack of appropriate support. Despite this, Oranga Tamariki has limited visibility over disability within its care population and cannot reliably identify which children and young people in care are living with impairments.<sup>77</sup>
- 55. According to the 2023 household disability survey, 10% of mokopuna have disabilities in the general population.<sup>78</sup> Research has reported much higher estimates for mokopuna in care, however, due to definitional issues, undetected disabilities, and reliance on formal diagnoses this number is not conclusive.<sup>79</sup> A 2018 transitions cohort study based on interviews with 120 high-needs rangatahi– suggested disability prevalence could be as high as 75% when psychosocial disability was included.<sup>80</sup>
- 56. These findings highlight serious gaps in how disability is defined, recognised, recorded, and responded to within State care and youth justice. The under-identification of mokopuna whaikaha risks their rights being overlooked, their needs going unmet, and their over-representation in care and justice settings being perpetuated.
- 57. Although justice is recognised as a priority in the draft Strategy, Mana Mokopuna has identified persistent gaps in protections for mokopuna whaikaha, especially those disproportionately represented in State care and the justice system. Greater focus and targeted action are needed to ensure responses are child-centred, disability-informed, and effectively safeguard their rights.
- 58. It is essential that mokopuna whaikaha who must be placed in the care of the State are supported in fit-for-purpose facilities that are accessible, appropriate, and responsive to their full range of needs. Current environments often fall short of these standards, placing mokopuna at further risk of harm and discrimination.

<sup>&</sup>lt;sup>77</sup> Donald Beasley Institute (2022a), Good practice review for disabled tamariki and rangatahi in care.

<sup>&</sup>lt;sup>78</sup> Disability statistics: 2023 | Stats NZ

<sup>&</sup>lt;sup>79</sup> Oranga-Tamariki-Disability-Data-Project-2023.pdf

<sup>&</sup>lt;sup>80</sup> Evidence-Brief-Primary-care-needs-of-disabled-children-in-care.pdf

59. Early intervention is critical to ensure appropriate support for mokopuna with disabilities.<sup>81</sup> Disability assessments should be conducted as early as possible, ideally during initial contact with services or systems that may lead to care, detention, or forensic facilities. While it may not always be possible to predict those who will need care, proactive screening and early identification by families, communities, and frontline workers can help flag those at risk. This helps prevent avoidable placements in unsuitable environments and ensures timely support.

#### Conclusion



"Making sure they [wheelchair users] feel like they are like everyone else [...] they're feeling like they are less than everyone else because they're finding it so much harder to go to the places where they want to go."

(Disabled young person. What Makes a Good Life? OCC, 2021)

- 60. The draft Strategy makes important steps toward recognising the rights of mokopuna whaikaha, but substantial gaps remain in ensuring equitable outcomes and active participation for mokopuna whaikaha across all aspects of their lives. Without targeted action, these gaps risk perpetuating exclusion, inequities, and barriers to full participation in society for mokopuna whaikaha. We urge Whaikaha to take the Strategy further to focus more strongly on the rights and needs of mokopuna whaikaha, as outlined in this submission, and as advocated for by mokopuna whaikaha themselves. We are available to help with this.
- 61. The submission has highlighted priority areas where the draft Strategy can be strengthened, including education, mental health, housing, sport and recreation, and transport, as well as the need to more strongly focus on the rights and needs of mokopuna whaikaha in State care and youth justice. Across these areas, key recommendations include embedding disability awareness and inclusion training, developing accessible systems and infrastructure, ensuring active participation of mokopuna in decision-making, and improving data collection and monitoring. These measures align with international guidance, including **General Comment No.9 on the rights of children with disabilities**, and are essential to fully realise the full range of rights that mokopuna whaikaha are entitled to in all circumstances, as rights-holders.
- 62. Finally, Mana Mokopuna emphasises that meaningful progress will require sustained commitment from the current Government and successive governments, sufficient resourcing, and genuine and ongoing partnership with mokopuna whaikaha and their whānau grounded in transparency and trust. The insights and recommendations provided by the mokopuna of I. Lead, detailed throughout this submission, provide a roadmap for ensuring the draft Strategy is not only inclusive in intention but effective in action. By prioritising mokopuna whaikaha, Aotearoa New Zealand can take significant steps toward a more equitable, accessible, and rights-based future for all children.

<sup>81</sup> Ministry of Health. (2019). Disability Support Services: Early Intervention Guidelines. Wellington: Ministry of Health.