

HIPOKINGIA KI TE KAHU ĀROHA A TE WHĀNAU

‘He taniwha kei te haere mai - he taniwha tae kuhu, tae huna e kore rawa koutou e kitea, e kore koutou e mohio kua tae mai, kia kitea rano i ngā kanohi a o mokopuna. Ina tae ki tēnā, kua e patua i o mokopuna - engari hipokingia o koutou mokopuna ki te kahu āroha a te whānau.’

These are the words of Aperahama Taonui. They are the foundation of all the Board’s work.

Te Kahu Aroha: addendum report on quality support and service outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers

Executive Summary

This report focuses on opportunities for Oranga Tamariki and the broader children’s system to improve outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers. It is set within the framework of Te Kahu Aroha, which stresses three overarching themes through 28 recommendations. The three core themes of Te Kahu Aroha are 1) the importance of prevention of harm from occurring in the first place through enabling iwi, Māori and communities to lead for their mokopuna and whānau, 2) supporting statutory social work and the work of Oranga Tamariki’s frontline to be as effective as possible in improving outcomes for tamariki, rangatahi and their whānau; and 3) improving organisational culture, including by ensuring relationships of trust and collaboration across the system.

Te Kahu Aroha identifies the necessity of te au o te kanohi Māori in keeping our tamariki at the centre, and the values, resources and strength that whānau need to do this. These same values and Māori ways, models and approaches uphold the mana of everyone, therefore providing the pathway for the care and protection of all tamariki and rangatahi, including tamariki and rangatahi whaikaha. A framework guided by te Ao Māori offers a holistic and integrated approach to supporting tamariki and rangatahi whaikaha within their most appropriate context. We hope that the Oranga Tamariki Disability Strategy that we know is being developed over the coming months will be driven by this outcome. We intend to support this work through our assurance reporting in order to reduce the risk of disability needs being deprioritised in the future, as has happened in the past.

This is because, throughout the Board’s work in preparing Te Kahu Aroha and since, it has become particularly apparent that many of the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers are not being met by Oranga Tamariki or by the broader system. There are significant gaps in provision of support and leadership on responsibilities across the system and this is exacerbating responsiveness and delivery of basic rights, including legal rights, of tamariki and rangatahi whaikaha. Moreover, while the gaps are known within the system, there is no shared view of what a more appropriate response should look like.

Attempts have been made at various times to address gaps, but the system repeatedly defaults to how it has worked, rather than how it could and should work, with settings continuing to deprioritise and side-line the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers. An example of this at a systems level is the lack of responsibility and leadership in addressing the mental health needs of tamariki and rangatahi, which the Board considers is the primary responsibility of the Ministry of Health. An example of the side-lining within Oranga Tamariki is evidenced through the silence on disability in the Future Direction Plan.¹ Addressing the gaps in support for tangata whaikaha should help to reduce the trajectory to a state care and protection response for some tamariki whaikaha. Therefore our first recommendation is that the void in the Future Direction Plan be immediately addressed and, at a systems level, a cross agency response is required. The Oranga Tamariki Action Plan (OTAP)² is the vehicle for this.

The current void in actions and shared responsibility for addressing the needs of tangata whaikaha both negates opportunities for the system to improve outcomes for tamariki, rangatahi, whānau, parents and caregivers, and increases the unrelentless pressure that Oranga Tamariki front-line staff are under.

Through our engagements we heard key themes repeated time and again which reflect the depth of issues and gaps. The intersecting impacts can mean that some individuals and whānau are at risk of experiencing cumulative layers of disadvantage and risk. At the same time, the themes we clearly heard also highlight a range of opportunities to improve outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers. We set out reflections from our engagement in more detail in the body of this report, with the themes centring around:

- the lack of available, accessible and culturally appropriate supports for tamariki and rangatahi whaikaha, their whānau, parents and caregivers, including risk of particular disadvantage to disabled parents
- the impact of the repeal of section 141 of the Oranga Tamariki Act 1989
- the need for specialised disability training for frontline kaimahi
- the lack of specialised care options including placements and therapeutic support for tamariki and rangatahi, as well as a lack of adequate support for care options and placements in general
- the need for better cross-agency collaboration
- the need for better disability data collection, and regular evaluation of impacts from service and programme delivery and changes to legislative and regulatory settings.

Accordingly, we make the following recommendations:

- 1) Reflecting the existing and sometimes unfulfilled legal rights of tamariki and rangatahi whaikaha, their whānau, parents and caregivers, there must be significantly more visible commitment by both Oranga Tamariki and the broader children's system to ensuring the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers are prioritised and supported.

¹ <https://www.orangatamariki.govt.nz/assets/Uploads/About-us/News/2021/MAB-report-action-plan-release/OT-Future-Direction-Action-Plan.pdf>

² <https://www.orangatamariki.govt.nz/about-us/how-we-work/oranga-tamariki-action-plan/>

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- a. More specifically, we recommend:
 - i. The Oranga Tamariki Future Direction Plan is refreshed to explicitly include a disability lens across all relevant actions.
 - ii. That the recommendations of this report are incorporated into the Future Direction Plan, as this will allow the Board to provide the Minister with assurance that the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers are not being deprioritised or side-lined again.
- 2) That the Oranga Tamariki Action Plan states the role of each agency in leading and supporting improvements for tamariki and rangatahi whaikaha, their whānau, parents and caregivers, as this will enable Oranga Tamariki to be clear about its roles and responsibilities within the system.
 - a. More specifically, we recommend:
 - i. Development of a consistent and shared understanding of disability both within Oranga Tamariki and across the system, to include an agreed description of disability that clearly articulates what is included within scope and whose responsibility it is to respond to gaps in support.
 - ii. It is our view that the scope of disability should include neuro-developmental challenges and learning difficulties such as Foetal Alcohol Spectrum Disorder and Attention Deficit Hyperactivity Disorder. Many of the unmet needs of tamariki and rangatahi within the Oranga Tamariki system relate to a lack of agreement between government agencies as to whether the presenting concerns fall within their understanding of what the term disability includes, and which agency is responsible for addressing them.
 - iii. We welcome the development of collective language that reflects current and emerging values framing disability in a rights-based framework rather than a deficit-based approach.
 - iv. At the same time, we consider that mental health concerns should be clarified as primarily a matter for the health sector to lead the response on. We state this in the hope that this support can be unblocked quickly as we are hearing desperate need for it from tamariki and rangatahi whaikaha, their whānau, parents and caregivers, and from Oranga Tamariki frontline kaimahi. Oranga Tamariki kaimahi are already stretched but are still expected to be the default service provider for mental health needs, having to try to find appropriate support for mental health needs in the absence of a systemic and specialist response.
- 3) A cross agency plan is urgently needed to address the lack of specialised care support and the lack of appropriate placement options for tamariki and rangatahi whaikaha. The plan should also provide options for more support for carers so that they can appropriately provide for the needs of the tamariki and rangatahi whaikaha in their care, and to support the provision of more care options, including placement options.

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- a. There is an urgent need for more, and more appropriately tailored, support to be provided to caregivers so they can sustainably meet the needs of tamariki and rangatahi whaikaha in their care.
 - b. A review of the process for implementing agreed caregiver support plans is needed, to ensure that carers are receiving the support that has been identified and agreed.
- 4) There needs to be provision for specific induction on Oranga Tamariki's role for disability for new frontline kaimahi, and provision of ongoing training and resources to support kaimahi to deliver effectively for the tamariki and rangatahi whaikaha, their whānau, parents and caregivers kaimahi are supporting.
- 5) Comprehensive and up to date information and guidance on disability issues needs to be regularly updated, with feedback from frontline kaimahi incorporated to ensure it remains fit for purpose. This also needs to be made more accessible and easier to find for frontline kaimahi. It should include information on the supports and services available in the communities they serve, and resources that can be provided to whānau and caregivers.
- 6) There should be commitment to evaluating outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers from service and programme delivery by Oranga Tamariki. Furthermore, legislative and regulatory changes, and particularly whether their actual impacts meet their intended impacts, should be routinely evaluated. Had this been in place, we assert some of the unintended impacts of the repeal of section 141, for example, would have been identified and potentially addressed at least in part by now.
- 7) There needs to be a plan to improve the collection of disability data within Oranga Tamariki to better inform service design and delivery.

Te Kahu Aroha: addendum report on quality support and service outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers

Ministerial Advisory Board and Te Kahu Aroha

The Oranga Tamariki Ministerial Advisory Board (the Board) was established in early 2021 to provide the Minister for Children with advice and assurance in relation to the current operations and performance of Oranga Tamariki. The key areas set out in the Board's terms of reference are:

- relationships between Oranga Tamariki and families, whānau, hapū, iwi, and Māori;
- professional social work practices; and
- organisational culture.

The Board's initial report, Te Kahu Aroha, is the foundation of this report. Its 28 recommendations for change were accepted and agreed by Cabinet. Oranga Tamariki's Future Direction Plan is the mechanism that gives life to those recommendations.

Te Kahu Aroha highlights a profound need to build partnerships that empower Māori and communities in order to lead prevention of harm. In parallel, Te Kahu Aroha says Oranga Tamariki should strengthen its own ability to provide effective and excellent interventions when the state does need to step in in the lives of tamariki, rangatahi and their whānau.

In terms of future priorities, Te Kahu Aroha signalled that the Board's next priority would include a focus on opportunities to improve outcomes for tamariki with disability impairments and needs. Through our preparation for Te Kahu Aroha, we regularly heard that tamariki and rangatahi whaikaha are likely to experience cumulative disadvantage through multiple layers of accessibility challenges and disparity in support and services. Therefore, we undertook to engage further to explore agency responsiveness and hear views on the quality of services for tamariki and rangatahi whaikaha, their whānau, parents and caregivers. This report reflects what we have heard and learned.

Scope of this report

In this report, we use the term tamariki and rangatahi whaikaha throughout, as whaikaha means to have strength, to have ability and to be enabled. We believe this term appropriately recognises the potential of the child or young person.

The recently established Ministry of Disabled People, itself called Whaikaha, is expected to take a strong leadership and coordination role across the disability sector. It is important to note here that while the disability directorate has been transferred from the Ministry of Health to Whaikaha, responsibility for mental health needs and support for addressing drug and alcohol abuse remains with Health.

We are mindful of leaving room for Whaikaha to start to build momentum in their work and we understand that the new ministry will not have a specific focus on the needs of tamariki and rangatahi as Oranga Tamariki does. However, inevitably there is a need for consideration and agreement of the intersection, and the shared and individual responsibilities of the work of Whaikaha, Oranga Tamariki, and other relevant government agencies. We understand that both Health and Oranga Tamariki acknowledge that there needs to be a stronger connection between their systems, and while we know that comprehensive alignment across the system will take time to agree and settle, we expect this work to be a priority.

Within these broad parameters of taking a strength-based approach and ensuring room for Whaikaha to take its lead role, this report seeks to identify both the positive initiatives underway within Oranga Tamariki, and the barriers within Oranga Tamariki and across the system.

As a Board appointed to look at how Oranga Tamariki is delivering, we focus our recommendations on actions that Oranga Tamariki should lead on and can practically take, but we are mindful of the need for a cross government systems' approach. This is particularly because, from what we have heard, it is clear that at best the system does not consistently deliver for tamariki and rangatahi whaikaha and at worst, is negligent in meeting sometimes even the basic needs of tamariki and rangatahi whaikaha, their whānau, parents and carers. This can, we are told, lead to unmet needs escalating to care and protection concerns and impacts that can require an Oranga Tamariki response which may not have been needed had an appropriate response been available in the first order. When unmet disability needs do require a statutory response from Oranga Tamariki, kaimahi have told us they are often unable to provide what is needed. This is because in addition to having already stretched workloads, they are not specialised to provide physical or mental health responses and have not always received adequate induction or training to appropriately support the needs of tamariki and rangatahi whaikaha. As we have been told, these are inevitable outcomes from unexpectedly becoming the sole agency with legislative responsibility for providing out of home care, as happened – likely as an unintended consequence – with the repeal of section 141.

To address these gaps, there is a critical need for a cross agency response with clearly defined roles, increased capacity for delivering holistic mechanisms, and agreed responsibilities for each agency. We are hopeful that the newly published Oranga Tamariki Action Plan will be the vehicle to enable this to occur. This shared approach is needed to complement the work underway within Oranga Tamariki to develop a purposeful Disability Strategy that specifies what Oranga Tamariki will lead on, and how it will support and enable improved outcomes.

Disability in Aotearoa New Zealand

Aotearoa has an obligation to implement the range of children's rights as set out in the United Nations Convention on the Rights of Children (UNCRC). It is important that these rights are applied to all children regardless of disability, as children are children first. In addition, Aotearoa has an obligation to realise the full range of human rights as set out in the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD). These rights apply to disabled children, adults and encompass, in some areas, broader whānau also.

We know that tamariki and rangatahi whaikaha experience greater inequalities and are more likely to experience abuse than other population groups. In fact, the New Zealand Human Rights Commission report *Acting now for a violence and abuse free future*³ states that global studies, based on meta-analyses, estimate that disabled children are 3.7 times more likely to experience violence than non-disabled children, and children with intellectual or psychosocial impairments are at even higher risk.

Work is needed to build an inclusive, strengths and rights-based description of disability for Aotearoa and, as we said in Te Kahu Aroha, that preferences te au o te kano Māori. There needs to be a consistent understanding of disability across all government and non-government organisations, including the scope of what comes under the disability umbrella and whose responsibility it is to respond and provide supports and services. We hope that the new ministry, Whaikaha, will lead in the development of an inclusive and strengths-based description of what is in scope, while the Oranga Tamariki Disability Strategy being developed over the coming months will clarify the scope of what Oranga Tamariki leads on for tamariki and rangatahi whaikaha and for their whānau, parents and caregivers.

Enabling Good Lives

Tamariki and rangatahi whaikaha have the unique challenge of ableism; this is the process of treating people differently purely because they are disabled. This is experienced by tangata whaikaha everyday in many different forms. Work to address these daily impacts and transform the disability system has been ongoing for a long time and is underpinned by the Enabling Good Lives (EGL) vision that all disabled people and their families have greater choice and control over their own lives and the supports they receive.

The EGL approach has been tested and evaluated through three demonstration projects in Christchurch, Waikato and the Midcentral DHB, with the outcomes from this approach being positive for disabled people and their whānau. The lead agency responsible for the EGL approach is Whaikaha, having taken this over from the Ministry of Health this year. While Whaikaha is responsible for implementing the EGL approach nationally, a range of agencies including Oranga Tamariki have specific responsibilities for ensuring the EGL vision is achieved.

Oranga Tamariki Disability Strategy and the Future Direction Plan

Previous reviews, reports and research into Oranga Tamariki have highlighted the need for the organisation to have a stronger, purposefully planned disability response that is actually implemented. This needs to reflect a greater understanding of the experiences of tamariki and rangatahi whaikaha in care and the issues that impact them and their whānau, parents and caregivers. There is also a need for a focus on disabled parents whose children may enter the care system as a result of their parenting needs not being supported, as opposed to care and protection issues.

³ 'Acting now for a violence-free future: violence and abuse of disabled people in Aotearoa New Zealand, Evidence and recommendations', Te Kahui Tika Tangata Human Rights Commission, December 2021, available at [Acting_now_for_a_violence_and_abuse_free_future_FINAL.pdf](https://www.hrc.co.nz/publications/Acting_now_for_a_violence_and_abuse_free_future_FINAL.pdf) ([hrc.co.nz](https://www.hrc.co.nz))

In February this year the Oranga Tamariki leadership team approved the development of an Oranga Tamariki Disability Strategy to set out a clear vision for how Oranga Tamariki thinks about and applies the social and rights-based model of disability for tamariki and rangatahi whaikaha, their whānau, parents and caregivers. We understand Oranga Tamariki is aiming to have the Disability Strategy completed by May 2023. The development of a Disability Strategy reflects a level of commitment to achieving traction on disability that has not been achieved in the past. It also reflects a commitment to raising awareness of disability responsiveness within the organisation, and is an acknowledgement of the fundamental need to build capability and understanding in this space. We welcome this commitment and encourage the continued development of the strategy to proceed at pace, as the need is pressing already. We note also that the strategy will need to be accompanied by a strong implementation plan that draws out the links with other priority work programmes, together with dedicated budget and resourcing so that the strategy has the best chance of success.

We consider that, for the strategy to be successful, it must be underpinned by Te Tiriti and UNCRPD principles. It must also have achieving better outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers at the front and centre of its purpose. Te Kahu Aroha identifies the necessity of te au o te kanohi Māori in keeping our tamariki at the centre, and the values, resources and strength that whānau need to do this. These same values and Māori ways, models and approaches uphold the mana of everyone, therefore providing the pathway for the care and protection of all tamariki and rangatahi, including tamariki and rangatahi whaikaha. A framework guided by te ao Māori offers a holistic and integrated approach to supporting tamariki and rangatahi whaikaha within their most appropriate context and we hope that the Oranga Tamariki Disability Strategy will be driven by this outcome.

The promise of the Disability Strategy should be complemented by including specific actions to improve outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers within the Future Direction Plan, as this plan sets out the critical forward path for Oranga Tamariki. The plan, however, is silent on disability issues which we find concerning. As well as the need for a disability lens to be applied to all actions of the plan, there are particular themes and individual actions within the plan which should reflect a specific disability focus. We intend to support this inclusion through our assurance reporting in order to reduce the risk of it being deprioritised in the future as we believe has happened in the past.

Themes from engagement and research

The Board has engaged with disabled people, disability organisations, VOYCE Whakarongo Mai, caregivers for tamariki and rangatahi whaikaha, and Oranga Tamariki national office and frontline kaimahi. In addition to the disability-specific engagements, we also heard disability challenges being raised throughout engagements for all of our workstreams. To ensure we had evidence to support what we were hearing, we collected and reviewed information from briefings, reports, reviews, and research both within and outside Oranga Tamariki. This next section outlines the key themes that were identified throughout our engagement and research.

There is a lack of available, accessible and culturally-appropriate supports for tamariki and rangatahi whaikaha, their whānau and caregivers, and disabled parents

This was one of the most prevalent themes throughout our engagement. Almost everyone we spoke with talked about how the lack of early support for tamariki, rangatahi, parents and whānau is a potential reason for tamariki and rangatahi whaikaha entering care. We heard of parents caring for children with complex support needs who experience burnout due to a lack of respite options or sustainable supports. This can lead to parents not being able to see any option but to relinquish their child into care which, with the right supports available early on, could have been prevented.

“So many children come into OT because their disability isn’t supported and not because of care and protection issues”

“Most of our parents are broken by the time they come to us – the system is broken for them and they are tired”

We also heard of disabled parents whose children enter the care system as a result of their support needs, to be able to parent, not being addressed. If appropriate supports to help them with parenting capacity were available early on, this could have been prevented.

“Parents often have disabilities that are undiagnosed and if they’d been able to receive the support they needed, their children may not have come to our attention at all”

This issue is not down to Oranga Tamariki alone. System failures across Health, Education and other agencies are contributing to families reaching breaking point, with the only option left is for Oranga Tamariki to step in.

The Board consider that it is not acceptable for tamariki and rangatahi whaikaha and their whānau to have to wait for their needs to hit crisis levels and escalate to care and protection concerns in order for them to receive support. Now that OTAP has been published, it is promising to see that this includes a focus on tamariki and rangatahi whaikaha across the system, and we hope this will go some way to addressing the system failures across government.

“There’s a sea of unmet need out there”

Once tamariki and rangatahi whaikaha are in the care of Oranga Tamariki, there needs to be a strong focus on getting whānau access to the wraparound support and services they need to enable te tamaiti to return to the care of their whānau. Should this not be possible, even with the best supports in place, there should be a focus on at least maintaining strong connections to whānau and to whakapapa. The goal must be long-term support to ensure these tamariki and rangatahi do not need to re-enter care nor to have court orders to access support. To achieve this, frontline kaimahi need to know what supports and services are available in the regions they serve, and how to access these.

Oranga Tamariki has a Senior Advisor Education and Health in each region to support social workers through liaising with the Ministries of Education and Health to broker access to services for tamariki and rangatahi with complex needs. An evaluation of this role in 2020 found that it had significantly improved access to services and brought about positive changes for both internal and external stakeholders. While this is a helpful resource for social workers, there are limits to what they can achieve on their own. A systems response is needed to

ensure the right supports and services are available when they are needed and that these supports are coordinated and effective.

The Donald Beasley Literature Review into Good Practice for Disabled Tamariki and Rangatahi in care found that it was noted globally that a lack of disability supports and services meant that tamariki and rangatahi whaikaha were much less likely to achieve reunification with their families. This was particularly true for those with complex learning (intellectual) and psychosocial disabilities. For those who were reunited with whānau, or placed in an alternative permanent arrangement, the process took much longer than it did for other non-disabled children in care settings. Further to this, the Donald Beasley report says that care workers often fail to provide accessible planning and information to enable reunification in a timely manner. As a result, re-entry into care following reunification with family is disproportionately high for tamariki and rangatahi whaikaha.

The Donald Beasley report suggests three actions to support tamariki and rangatahi whaikaha to return home following out-of-home care these are:

- early health and disability supports for tamariki whaikaha in out-of-home care (in preparation for reunification)
- supports for out-of-home care workers to enable them to understand their responsibilities as duty bearers under the UNCRPD
- the implementation of supports and services for whānau-carers as they prepare to reunite with their tamaiti whaikaha (such as financial, psychosocial, safety, and respite supports and services).

Difficulties with obtaining assessments for diagnosis

Another issue we heard repeated often during our engagement with the frontline was the difficulties they face getting assessments through the Ministry of Health for tamariki and rangatahi who present with a disability but who have not had this formally diagnosed prior to contact with Oranga Tamariki. We are told that the older the child is, the longer the wait for an assessment and diagnosis, let alone a response, is. While they wait, older tamariki and rangatahi are going without their needs being met.

“If were trying to access disability services and support, or even find out what services are available, we are told we have to pay for an assessment and assessments can take a long time 6-18 months. It’s a difficult position as everything gets worse for people and you know they need an assessment but it can’t happen quickly”

“We often have tamariki and even rangatahi coming into care that have unmet need which turns out to be disability – seems like they’ve missed all the opportunities to be assessed through the right spaces and early intervention. Because they are in the older age group, they are not seen as a priority in our child development services, so they do wait much longer”

Support for caregivers

During our engagement, we were able to speak to a group of Oranga Tamariki caregivers who currently have tamariki and rangatahi whaikaha in their care. While this was only a small group

in one region of the motu, there were some clear and consistent issues raised. The most predominant was the lack of support caregivers are receiving when trying to meet the needs of the tamariki and rangatahi. We heard that caregivers were often being told that due to financial constraints they were unable to get the supports they required. We also heard that processes to get support, such as the caregiver allowance, were complicated and time consuming and could often take weeks or months to be approved. Meanwhile life goes on while these decisions are being made, and caregivers continue to struggle. The impact of these delays for tangata whaikaha is placement disruption.

“It’s taken weeks for one of three children to be approved for higher foster care allowance. We have been told that our children would be eligible for more if they weren’t in care”

“Carers that have children with disabilities should be able to access the support they need and be able to request things and not feel bad about it”

“Funding should not be a barrier to children with disabilities accessing the support they need”

Another issue we heard from caregivers was the lack of information they were receiving about te tamaiti before they come into their care. We heard that in some cases, significant information was withheld from caregivers that would have helped them better meet the needs of te tamaiti. We heard that gateway assessments were taking place six months after a tamaiti was placed with a caregiver, and during this time further trauma could be placed on te tamaiti due to caregivers not knowing enough about their needs.

“We don’t get full disclosure of information before we take children on which means we could be making their trauma worse if we don’t know certain bits of information”

“Gateway assessments happen too late; it took 6 months and we find things out we didn’t know – we were probably interacting in the wrong way but didn’t know”

“A lot of information is kept from us as it is confidential. Without knowing this, how do we know if we are the best people for the job?”

The repeal of section 141 of the Oranga Tamariki Act 1989 has had a significant impact

From 1 July 2019, section 141 of the Oranga Tamariki Act 1989 (the Act) was repealed to ensure that all tamariki and rangatahi whaikaha have the same rights, protections, and safeguards as all children are entitled to in out-of-home care.

Section 141 created a separate pathway into out-of-home care for tamariki and rangatahi whaikaha on the basis of their disability. Under this legislation, the decision for a child to live in out-of-home care was made by the Ministry of Health. Oranga Tamariki’s only involvement would be to enable a care agreement to be signed via a Family Group Conference (FGC). There would be no assessments undertaken by social workers.

We understand that the repeal of section 141 was intended to support a rights-based approach as required by the UNCRPD. However, we have heard repeatedly that this repeal has had a

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substantial negative impact on tamariki and rangatahi whaikaha and their whānau. We believe that this is a situation where the significant unintended consequences should have been monitored and addressed where possible.

With no specific replacement for section 141 of the Act, we are told that social workers are struggling to find appropriate disability supports, services and placements for the tamariki and rangatahi they are working with. This, we keep hearing, can result in additional trauma for te tamaiti or rangatahi and can escalate their needs further.

Furthermore, parents of tamariki and rangatahi whaikaha who have reached breaking point due to a lack of support are, we are told, seeing their children enter the care and protection system via a court order as there is currently no alternative. This is concerning, but we acknowledge that Oranga Tamariki is in the early stages of considering alternatives to the family court process for extended care orders and agree this is an important area of work that we look forward to seeing progress with.

“We’ve been struggling since the section 141 repeal. Some children have had to come into care due to their disability that their parent’s couldn’t deal with. Whānau need support not statutory intervention”

“Parents that have children with disabilities are immediately coming into an organisation that deals with neglect and abuse, so they feel like they are bad parents. Not sure we are the best organisation to be leading this work”

The repeal has also left many social workers feeling inadequately trained and unable to access the services tamariki and rangatahi whaikaha need, reinforcing the message from Te Kahu Aroha that there remains a pressing need to support the continuing professional development of social workers at Oranga Tamariki, and that actions to improve induction and training processes for frontline kaimahi remain a priority.

Oranga Tamariki has acknowledged that at the time of the repeal of section 141, there was advocacy for organisation-wide disability training to provide the specialised skills needed to work with tamariki and rangatahi whaikaha in lieu of section 141. We are told that this was not possible due to the timing of so many legislative changes coming in at the same time and needing training for, so see this as an example of where disability needs were not adequately prioritised.

“Greatest challenge was that prior to the repeal Health were mandated and now we feel like we have been left alone. Prior to the repeal we had some really good FGC plans under 141 where we had our health partners there and they supported placements with specialised caregivers”

“We knew it was coming but we just wasn’t prepared for it and we’re still not”

“The system is like a lottery for tamariki whaikaha”

Oranga Tamariki has provided us with information on the work they have done to try to mitigate the impacts of the section 141 repeal. This includes designing and enacting a new Memorandum of Understanding (MoU) with the Ministry of Health. This MoU states that

Oranga Tamariki and the disability directorate of the Ministry of Health (now under Whaikaha - the Ministry of Disabled People) will work together to support tamariki and rangatahi who are eligible for disability support services and their whānau. While the MoU clearly sets out the roles of each agency, we are hearing that it is not always being adhered to.

The MoU is a positive step in ensuring an effective working relationship between Oranga Tamariki and the disability directorate to improve outcomes for tamariki and rangatahi whaikaha, however, it is not without limitations. The MoU only covers tamariki and rangatahi who are eligible for disability support services, and these have narrow and proscriptive criteria that exclude mental health issues and Foetal Alcohol Spectrum Disorder (FASD) and other neuro-developmental disabilities. This risks a significant gap in support, considering the likely prevalence of these challenges for tamariki and rangatahi entering the care system. Moreover, as above, we are told that many have not had their needs diagnosed prior to entering the system and once a diagnosis is made, there is no guarantee that the care system will be able to readily address needs that have been finally identified at this point.

There is a need for specialised disability training for frontline kaimahi

Another theme throughout our engagement was the need for specialised disability training for Oranga Tamariki kaimahi and, in particular, for frontline kaimahi. Many social workers have limited to no specific disability training, and a number told us they feel they do not have the necessary knowledge, supports and resources to deliver the best outcomes for tamariki and rangatahi whaikaha. We have heard that disability is not included in the induction programme, and there is also a lack of guidance and information to support social workers when working with tamariki and rangatahi whaikaha. The frontline has expressed that there is a need for there to be clear pathways within Oranga Tamariki to help them navigate the system when working with tamariki and rangatahi whaikaha, as well as specialised disability training so they can be more effective for the needs of tamariki and rangatahi.

“It would help if there was a clear pathway within Oranga Tamariki for when we do work with tamariki who might have disabilities, to guide social workers and upskill us”

“Social workers are not getting specialised training in disabilities, and services outside are not meeting the needs. We need to start with the education of our frontline. There is a bit of a fear amongst frontline as they don’t know what they don’t know. Need to upskill staff in things like FASD and ASD”

“Information on the practice centre is really lacking for disability”

“There needs to be more education around disability. Social workers need to understand more about overlapping and intersecting needs”

A particular concern expressed by frontline kaimahi is the prevalence of FASD. Kaimahi are working with increasing numbers of tamariki and rangatahi who are either diagnosed with, or show a range of symptoms that suggest, FASD. This is not surprising, as studies suggest that 30-50% of tamariki and rangatahi in care are likely to have FASD. We note that the practice centre has some useful guidance on FASD but how widely communicated this has been with the frontline is unclear. A lack of purposeful communications between national office and the

frontline is an issue the Board has observed throughout our work and that we have highlighted in our assurance reports to date.

When engaging with whānau of tamariki and rangatahi whaikaha, it would be beneficial for social workers to have the knowledge needed to be able to refer whānau directly to networks and services which could prevent escalation into care. Once tamariki and rangatahi whaikaha enter the care system, social workers need to have an understanding of disability to be able to support caregivers to meet their needs.

We have heard from many of the frontline that they find the Regional Disability Advisors an asset but that this resource is limited to one person per region and this is just not enough. The Regional Disability Advisors do their best to support social workers and provide advice and training where needed but they are spread thin. This can lead to social workers having to make key decisions about a child's needs without a comprehensive understanding of their disability and how it can best be supported.

"We appreciate disability advisors but there needs to be more of them as they are really busy and we need them to be able to upskill us and spend more time with us"

"We work hard to keep disability at the front of peoples' mind. When we do visit sites we get lots of questions from social workers about disability. I did a training on site this morning, by the afternoon I have been contacted by another four social workers wanting to have a discussion with me regarding a child on their case load"

As outlined previously, we know that the Senior Advisors Education and Health are a useful resource to support social workers with access to services but again this resource is limited to one per region. This clearly appears to be insufficient to meet the demand for support. It seems to us that there needs to be both more of this resource, and an increase in the capability of social workers to support disability needs through provision of tailored training, following effective induction.

In parallel with this, we have heard that there are various levels of understanding across the organisation of the EGL approach, noting also that implementation of the EGL approach is at different levels of implementation in different regions. There should be regular and mandatory disability responsiveness training for all Oranga Tamariki kaimahi. This should include the alignment of EGL principles to best practice. In addition, specialised and comprehensive disability training should be available for all frontline kaimahi as part of their induction programme, with yearly refresher courses to ensure the content is up to date. The induction programme should include an overview of the roles of the Regional Disability Advisors and Senior Advisors Education and Health. This will ensure frontline kaimahi are aware of the supports available to them when working with tamariki and rangatahi whaikaha. The design of the induction programme would benefit from regular input from frontline kaimahi, Regional Disability Advisors and the Chief Advisor Disability to ensure continuous improvement.

"There are various levels of understanding across the agency of EGL. No systematic roll out of training across agency. We would like to take the opportunity to get some consistent understanding and use of EGL principles"

“All OT staff should have mandated treaty training and mandated disability training. It is 25 percent of the population. This will shift the approach to a strength based one. OT are likely dealing with a larger proportion of this population”

Meanwhile, we are pleased to learn that there is work underway to develop a specific disability page on the Practice Centre, to contain guidance for the frontline. We are told this will lay the foundation for inclusive and rights-based practice and will cover the social model of disability as well as te ao Māori concepts of disability. We understand that guidance on supporting tamariki and rangatahi with FASD and neurodiversity is also in progress and will ground the existing FASD material into the Practice Framework. We also understand there will be specific guidance for the frontline in supporting parents with mental health and addiction needs, and also those with learning and intellectual disabilities.

There is a lack of available specialised care options, including placements

The lack of available specialised care options, including placements, is an issue that was raised many times throughout our engagement with the frontline. This affects all tamariki and rangatahi but it is especially hard to find suitable care options for tamariki and rangatahi who experience multiple layers of need – we use the term ‘multi-layered’ to recognise that combinations of disability, emotional and behavioural, mental health and social needs create a complexity that require tailored and systemic responses to need. We are regularly hearing that motels are being used as an emergency option, and that sometimes social workers are having to resort to staying overnight at site offices to accompany young people they have not been able to find an appropriate placement for. We heard that there is a lack of care options with the appropriate environment and necessary policies in place to manage challenging behaviours, and so even if an option is identified it may not be suitable.

“We don’t have placements to fit complex disability needs. There are some living in motels with staff. We don’t have any better options”

“The ministry as a whole is under resourced and underprepared for the amount of tamariki we are seeing with disabilities”

We know from our review of Oranga Tamariki residences that these places almost always operate at full capacity and are not able to readily flex to meet urgent demand. It is also likely that these residences would not be suitable for many tamariki and rangatahi whaikaha, as these institutions do not have the necessary and appropriate supports to meet their needs, nor are the workforce adequately trained to work with tangata whaikaha within the specific environment.

It is clear there is a need for a significant increase in specialised care and placement options for tamariki and rangatahi whaikaha. This is an example of where a cross agency and multi-disciplinary approach needs to be in place.

“The organisation being focused on long-term change is great, but the right here and now is really important. What we have right now is not enough”

“We need to build the right environments for these children from the ground up”

There is a need for better cross-agency collaboration

Meeting the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers is not the responsibility of Oranga Tamariki alone. System failures across the whole of government are resulting in some tamariki and rangatahi whaikaha entering the care system due to no other option, but once in care their needs continue to be unmet. It seems clear to us that there is a desperate need for a cross agency response to address the unmet need.

“Oranga Tamariki can’t do it all alone there are other systems that need to come to the party”

“There is no trust from the disabled community in government agencies, everything is very slow and agencies are always passing the buck. Nobody takes responsibility”

We have heard from the frontline that they often experience push back from other agencies, particularly when it comes to who should fund what support. We were told that there is an increasing expectation from other agencies that Oranga Tamariki is solely responsible for providing all services to tamariki and rangatahi whaikaha who are in the care and protection system. But our view is that the responsibilities of agencies for meeting the needs of tamariki and rangatahi whaikaha do not change because te tamaiti or rangatahi has entered the care and protection system. All children have the right to have their needs met from responsible agencies, and in coordinated and holistic ways.

We were told by caregivers that they had similar experiences of being passed back and forth between agencies when trying to access services and supports for the tamariki and rangatahi whaikaha in their care.

“We get told it’s not an MOE problem, it’s an Oranga Tamariki problem. We get ping ponged between agencies. The minute schools hear they are Oranga Tamariki children, we are told to go through Oranga Tamariki for everything”

Support from other agencies on a consistent basis can really help improve outcomes for tamariki and rangatahi whaikaha, and where this is not available it can leave a significant gap. Moreover, early support from other agencies for whānau and disabled parents could prevent tamariki and rangatahi coming into care in the first place.

“We have to get better at working across Government to prevent tamariki entering care”

The High and Complex Needs Unit (HCN) was established by Cabinet in 2001 and is made up of a small team working across Oranga Tamariki, the Ministry of Education and the Ministry of Health. Its aim is to improve outcomes for tamariki and rangatahi with high and complex needs through effective interagency collaboration. The HCN supports whānau and caregivers by working with multiple government and non-government agencies to develop plans and coordinate intensive services around their tamariki and rangatahi. While this unit has gone some way to addressing interagency service gaps, the criteria for referral is very narrow, and the team is only able to work with a limited number of tamariki and rangatahi.

With OTAP now published, we are pleased to see that it includes a focus on tamariki and rangatahi whaikaha and intends to take into consideration how this group can be better

supported. We believe that opportunities to increase the range of, and support for, specialised care options including placements and therapeutic services for this group should be explored through OTAP as a priority. We hope that shared commitment to OTAP will quickly lead to improved outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers.

There is a need for better disability data collection and recording, for regular evaluation of impacts from service and programme delivery and from changes to legislative and regulatory settings

“We are missing data, we can’t say with any confidence how many children in care are disabled. We need to know the scope so we can provide the right supports. Children and families are paying for the gap”

A challenge the Board has faced while consolidating information for this report has been the lack of meaningful disability data available from Oranga Tamariki. This is an issue that needs to be addressed as a priority. Oranga Tamariki is unable to provide an accurate number of tamariki and rangatahi whaikaha in either the care and protection or youth justice systems as data on disability is not collected or recorded in a manner that can easily be counted or reported. (The figure stated in OTAP is between 10 and 25 percent, noting this is an estimate based only on the number of children receiving DSS.)

While Oranga Tamariki does not have a robust current-state picture of disability across all tamariki it works with, some recent analyses provide an indication of what this may be:

- In an analysis of 700 sampled tamariki in care, it was found that 20 percent of these were eligible for DSS. (This figure should be understood as caveated by the fact that the DSS definition is narrow, and this analysis was only focussed on tamariki in care, so does not include thousands of tamariki who have had a Report of Concern or have been assessed, but not entered care.)
- In an analysis of population-level data using Statistics NZ’s Integrated Data Infrastructure (IDI - this brings together data from across public sector agencies), it was found that one in ten tamariki with current or previous involvement with Oranga Tamariki had some indication of disability. Again, a tight definition of disability was used, based on engagement with services or qualifying for the Ministry of Social Development Child Disability Allowance.

Taking the limitations of the above two analyses into account, the true number of tamariki and rangatahi whaikaha in the Oranga Tamariki system is likely to be much higher, and many have told us throughout our engagement over the last 18 months that they think the figure, particularly taking FASD and neuro-disabilities into account, is much higher. For example, VOYCE Whakarongo Mai tell us that their estimate is that 70-80 percent of the tamariki and rangatahi they work with present with a disability of some kind.

The point is twofold. Firstly, there is a significant amount of unidentified, and so unmet, demand. Second, without clear and accurate data, it is difficult for Oranga Tamariki to be able

to establish the types of supports and services needed across the motu or know that they are delivering the impact intended.

The Oranga Tamariki Ministerial Advisory Board looks forward to a refreshed Future Direction Plan that is inclusive of tangata whaikaha, their whānau, parents and caregivers. We also await the positive contribution that OTAP will have for tangata whaikaha and their whānau.

Recommendations

Taking into account what we have heard through extensive engagement and what we know from information provided to us by Oranga Tamariki, we have made 15 recommendations in total (this is made up of seven main recommendations, of which three incorporate eight more specific recommendations within them). These are designed to complement the ongoing work to develop and implement a Disability Strategy within Oranga Tamariki. We believe that, taken together, they will go at least some way to support better outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers.

Accordingly, we make the following recommendations:

- 1) Reflecting the existing and sometimes unfulfilled legal rights of tamariki and rangatahi whaikaha, their whānau, parents and caregivers, there must be significantly more visible commitment by both Oranga Tamariki and the broader children's system to ensuring the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers are prioritised and supported.
 - a. More specifically, we recommend:
 - i. The Oranga Tamariki Future Direction Plan is refreshed to explicitly include a disability lens across all relevant actions.
 - ii. That the recommendations of this report are incorporated into the Future Direction Plan, as this will allow the Board to provide the Minister with assurance that the needs of tamariki and rangatahi whaikaha, their whānau, parents and caregivers are not being deprioritised or side-lined again.
- 2) That the Oranga Tamariki Action Plan states the role of each agency in leading and supporting improvements for tamariki and rangatahi whaikaha, their whānau, parents and caregivers, as this will enable Oranga Tamariki to be clear about its roles and responsibilities within the system.
 - a. More specifically, we recommend:
 - i. Development of a consistent and shared understanding of disability both within Oranga Tamariki and across the system, to include an agreed description of disability that clearly articulates what is included within scope and whose responsibility it is to respond to gaps in support.
 - ii. It is our view that the scope of disability should include neuro-developmental challenges and learning difficulties such as Foetal Alcohol Spectrum Disorder and Attention Deficit Hyperactivity Disorder. Many of the unmet needs of tamariki and rangatahi within the Oranga

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Tamariki system relate to a lack of agreement between government agencies as to whether the presenting concerns fall within their understanding of what the term disability includes, and which agency is responsible for addressing them.

- iii. We welcome the development of collective language that reflects current and emerging values framing disability in a rights-based framework rather than a deficit-based approach.
 - iv. At the same time, we consider that mental health concerns should be clarified as primarily a matter for the health sector to lead the response on. We state this in the hope that this support can be unblocked quickly as we are hearing desperate need for it from tamariki and rangatahi whaikaha, their whānau, parents and caregivers, and from Oranga Tamariki frontline kaimahi. Oranga Tamariki kaimahi are already stretched but are still expected to be the default service provider for mental health needs, having to try to find appropriate support for mental health needs in the absence of a systemic and specialist response.
- 3) A cross agency plan is urgently needed to address the lack of specialised care support and the lack of appropriate placement options for tamariki and rangatahi whaikaha. The plan should also provide options for more support for carers so that they can appropriately provide for the needs of the tamariki and rangatahi whaikaha in their care, and to support the provision of more care options, including placement options.
- a. There is an urgent need for more, and more appropriately tailored, support to be provided to caregivers so they can sustainably meet the needs of tamariki and rangatahi whaikaha in their care.
 - b. A review of the process for implementing agreed caregiver support plans is needed, to ensure that carers are receiving the support that has been identified and agreed.
- 4) There needs to be provision for specific induction on Oranga Tamariki's role for disability for new frontline kaimahi, and provision of ongoing training and resources to support kaimahi to deliver effectively for the tamariki and rangatahi whaikaha, their whānau, parents and caregivers kaimahi are supporting.
- 5) Comprehensive and up to date information and guidance on disability issues needs to be regularly updated, with feedback from frontline kaimahi incorporated to ensure it remains fit for purpose. This also needs to be made more accessible and easier to find for frontline kaimahi. It should include information on the supports and services available in the communities they serve, and resources that can be provided to whānau and caregivers.
- 6) There should be commitment to evaluating outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers from service and programme delivery by Oranga Tamariki. Furthermore, legislative and regulatory changes, and particularly whether their actual impacts meet their intended impacts, should be routinely evaluated. Had this been in place, we assert some of the unintended impacts of the

repeal of section 141, for example, would have been identified and potentially addressed at least in part by now.

- 7) There needs to be a plan to improve the collection of disability data within Oranga Tamariki to better inform service design and delivery.

Future Work

This report focuses on the care and protection system for tamariki and rangatahi whaikaha, their whānau, parents and caregivers. We acknowledge that there is a need to explore outcomes for specific cohorts of tamariki and rangatahi whaikaha that we have not had the capacity to consider in this report.

Specifically, we are aware that there is a disproportionate number of rangatahi whaikaha in the Youth Justice system, particularly those presenting with FASD and other neuro-disabilities, and believe that this is an area that needs to be explored further. Additionally, we think that there are opportunities to improve outcomes for tamariki and rangatahi whaikaha from Pacific communities. While the Board was unable to give the attention needed to these areas in the time available for this phase of work, we do feel that they should be a focus for Oranga Tamariki in the future.

Disability does not discriminate; it impacts on all communities and there are multiple voices that need to be heard and documented. Therefore, work on the intersectionality of tamariki and rangatahi whaikaha and the multiple levels of discrimination that can attach to them needs to be surfaced. We suggest that this work should be considered in collaboration with other government agencies to ensure sustainable positive impacts for tamariki and rangatahi whaikaha.

Through our quarterly assurance reports, we will meanwhile continue to provide assurance on Oranga Tamariki's work to improve outcomes for tamariki and rangatahi whaikaha, their whānau, parents and caregivers. This is to ensure that it remains in focus while the system settles in.