

Whāia Te Ao Mārama:

The Māori Disability

Action Plan for

Disability Support Services

2012 to 2017

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MANATŪ HAUORA

Foreword

Whāia Te Ao Mārama literally translated means pursuing the world of enlightenment. It is an apt title for this document, which outlines a pathway towards supporting Māori with disabilities to achieve overall wellbeing, and bringing both them and our communities into a place of shared understanding and action.

Culture is an important component of our overall wellbeing, and providing culturally specific action plans such as this recognises the diverse contexts from which we all come, and the unique responses that are required to address the needs of the Māori disabled community.

One in five Māori are living with some sort of disability, and this represents a large proportion of our whānau, hapū and iwi. Each of these whānau will have different expectations and needs in terms of their health and wellbeing, although all tangata whenua have shared values and beliefs that underpin our respective aspirations.

This action plan provides a strong foundation and a clear direction for providing the support that Māori disabled people and their whānau require. It also outlines key principles that those of us working within the disability support sector need to acknowledge. In developing this action plan, we hope that we have created a resource which weaves us closer together as communities who are respectful and supportive of diversity.



This action plan was developed by Māori disabled people, their whānau, and those who work in the disability support sector; with support from the Ministry of Health. The collaborative approach used to bring this plan together outlines the importance that we place on bringing key stakeholders, particularly those who live with disabilities, into the process of developing shared solutions, and responses.

Helen Keller once said, 'No pessimist ever discovered the secret of the stars, or sailed to an uncharted land, or opened a new doorway for the human spirit.'

This Māori Disability Action Plan operates from an attitude of optimism – it is essentially encouraging us all to dare to be powerful, to operate from a position of strength. Our strength is inherent in our whakapapa; in whakawhanaungatanga; in our kaupapa, our tikanga.

Knowing our collective strength helps us to move us closer towards Te Ao Mārama and closer towards reaching a shared awareness about the needs of Māori disabled people.

Tikanga, after all, is about doing the right thing, at the right time for the right reason, and this is the essence that has been captured in this action plan.

Tēnā koutou katoa

Hon Tariana Turia
Associate Minister of Health

Acknowledgements

E kore e hekeheke he kakano rangatira

I will never be lost for I am the product of chiefs.

The development of this document was driven by the Associate Minister of Health Hon Tariana Turia, and led by the Māori Disability Leadership Group.

Over 200 Māori individuals who participated in hui, focus groups and interviews, and organisations such as Te Piringa, NASCA, NZFDIC and disability support services providers contributed to the content of this over an 18-month period.

The consultation process was supported by the New Zealand Federation of Disability Information Centres. The individual stories and art work for Te Tōrino were produced by Te Rau Matatini.

The development of this document was led by the Disability Support Services Group of the National Services Purchasing Unit within the National Health Board.

Thanks to all the staff who contributed to this work from across the Ministry of Health and Te Puni Kōkiri.

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Introduction

Why an action plan?

A number of factors determine the outcomes for Māori disabled and their whānau. Some directly relate to how their needs are supported to participate in their own lives, communities and cultural worlds. This participation can shape their chances of attaining a quality of life that matches their aspirations.

The aim of *Whāia Te Ao Mārama: Māori Disability Action Plan 2012 to 2017* is to establish priority areas of action for achieving these aspirations, and to reduce barriers that may impede Māori disabled and their whānau from gaining better outcomes.

‘Whāia te ao mārama’ means to pursue and enable a good life that is self-determined, through enlightened supports. The tōrino double spiral diagram in the plan illustrates

the four core elements needed for supports to be effective for Māori disabled:

- > te ao Māori
- > te ao hurihuri
- > te rangatira
- > tūhonohono.

Each element is interwoven and interdependent. Their purpose is to support Māori disabled to uphold their own mana and strong self-determination within their whānau, hapū, iwi and wider communities.



Māori disabled

Disability is a significant issue for Māori. One in five Māori report having a disability, and due to the youthfulness of Māori communities and the higher susceptibility of Māori to disabling health conditions as they age, the incidence of disability is expected to increase.

It is widely acknowledged that culture and health are closely linked, and that those services that fail to take account of the significance of culture in the assessment and support of Māori disabled have the potential to create a greater likelihood of poor outcomes and reduced health gains.

Māori aspirations

Māori disabled are clear about what will make a positive difference to their lives. They want:

- > every opportunity to have leadership, choice and control over their lives (te rangatira)
- > to be supported as both Māori and as disabled to thrive, flourish and live the life they want
- > to be able to participate in te ao Māori (the Māori world)
- > to have their whānau valued as their primary support system
- > to be connected to natural support networks, including Māori and disability communities
- > a holistic approach to their disability that also values the beneficial effects of Māori cultural views and practices on spiritual, mental, physical, emotional and whānau wellbeing.

Government priorities

The Ministry of Health's *Disability Support Services Strategic Plan 2010–2014* outlines the overall purchasing strategy and actions for providing disability support services to eligible New Zealanders. It continues the Ministry's move towards a needs- and outcomes-based approach to purchasing national disability services.

Whāia te Ao Mārama provides direction over the next five years for actions to address the needs and priorities of Māori disabled. It has been informed by community and stakeholder consultations with a Māori Disability Leadership Group comprising Māori disabled from across the disability sector, who provided leadership and peer review for the development of the plan.

Whāia te Ao Mārama is based on three principles from te Tiriti o Waitangi: Māori participation at all levels, partnership in service delivery, and protection and improvement of Māori wellbeing. *Whāia Te Ao Mārama* also reflects New Zealand's obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (2007), and as a nation that has stated its support for the United Nations Declaration on the Rights of Indigenous Peoples (2010).

The five-year action plan is aligned closely with:

- > the New Zealand Disability Strategy (2001)
- > Disability Support Services' new initiatives designed to supporting disabled people and their whānau
- > cross-Ministry of Health initiatives such as the Uia Tonutia: Māori Disability Research Agenda
- > intersectoral initiatives, particularly those related to the Government's Whānau Ora programme.

Reducing barriers

Māori disabled can experience discrimination and face significant barriers, both in everyday living and in accessing health, disability and other services. As a result of their disability experiences, Māori have reported feeling disconnected from their whānau, communities of choice and culture.

Reducing barriers to ensure Māori disabled and their whānau get disability information, resources and services is a key strategic challenge in supporting Māori disabled to achieve better outcomes.

Disability support services

Anecdotal evidence indicates that Māori whānau commonly take care of their disabled whānau members without accessing the supports by the Ministry of Health-funded disability support services. Effective disability services are seen as critical to achieving improved disability outcomes for Māori, and these services are expected to be responsive to Māori needs and priorities. A key strategic challenge is to achieve better Māori access to effective disability support services that are appropriate at both the population and individual levels of need.

Supporting New Zealanders with disabilities to receive better disability supports contributes to the Ministry's outcome to promote and protect the good health and independence of New Zealanders.

The Ministry is introducing new ways of supporting clients of disability support

services. These initiatives recognise that disabled people and their whānau are the best people to determine how they want to live and develop goals that will meet their needs. The Ministry is developing initiatives to take account of the diverse needs and concerns of Māori, and will play an important role in supporting Māori clients to achieve good outcomes from disability support services. The shift to increasing disabled people's choice and control is consistent with what Māori communities have said they want from the Ministry's disability support services.

Māori data

Some of the following information has been sourced from the Ministry of Health's Disability Support Services database.

The 2006 New Zealand Household Disability Survey indicated that disability was a significant issue for Māori, with close to one in five Māori (approximately 96,700) reporting they had a disability.



Māori disabled make up approximately 5400 (16%) of people who access the Ministry of Health-funded disability support services. As a group, Māori disabled are predominantly youthful, with over a third (37.8%) under 15 years of age and 49% aged under 25 years. Maori disabled mainly have intellectual disability (50.9%) or physical disability (32.2%), and some Māori disabled have significant support needs, with 23% having very high levels of need.

Most live in the Auckland (26.4%), Waikato (12.3%) and Northland (10.6%) regions. Māori disabled predominantly live in urban areas (89%) rather than rural areas (11%). Those living in rural regions are mainly based in Northland (45.2%), Bay of Plenty (24.1%) and Gisborne (25.6%).

As at June 2011, almost two-thirds (64%) of disability support services funding from the Ministry of Health for Māori disabled was allocated to residential care, followed by home support (19.7%) and day programmes (5.2%).

Future changes to disability support services

After talking with disabled people, their families, providers and the wider disability sector, the Ministry of Health has developed, and is testing, a new model for supporting disabled people. The aim of the new model is for disabled people and their families to lead good everyday lives. It will increase people's control and choice, and the flexibility of their supports, as well as ensuring information and support are available in their local communities.

The new model incorporates work to enhance Individualised Funding and Choice in Community Living. The current support services model lends itself more to someone else making the decisions about what, and when, support is given.

Whāia Te Ao Mārama requires Māori disabled and their whānau to be fully involved in the planning and implementation of current and future development programmes to improve the disability support system.



Strategic response

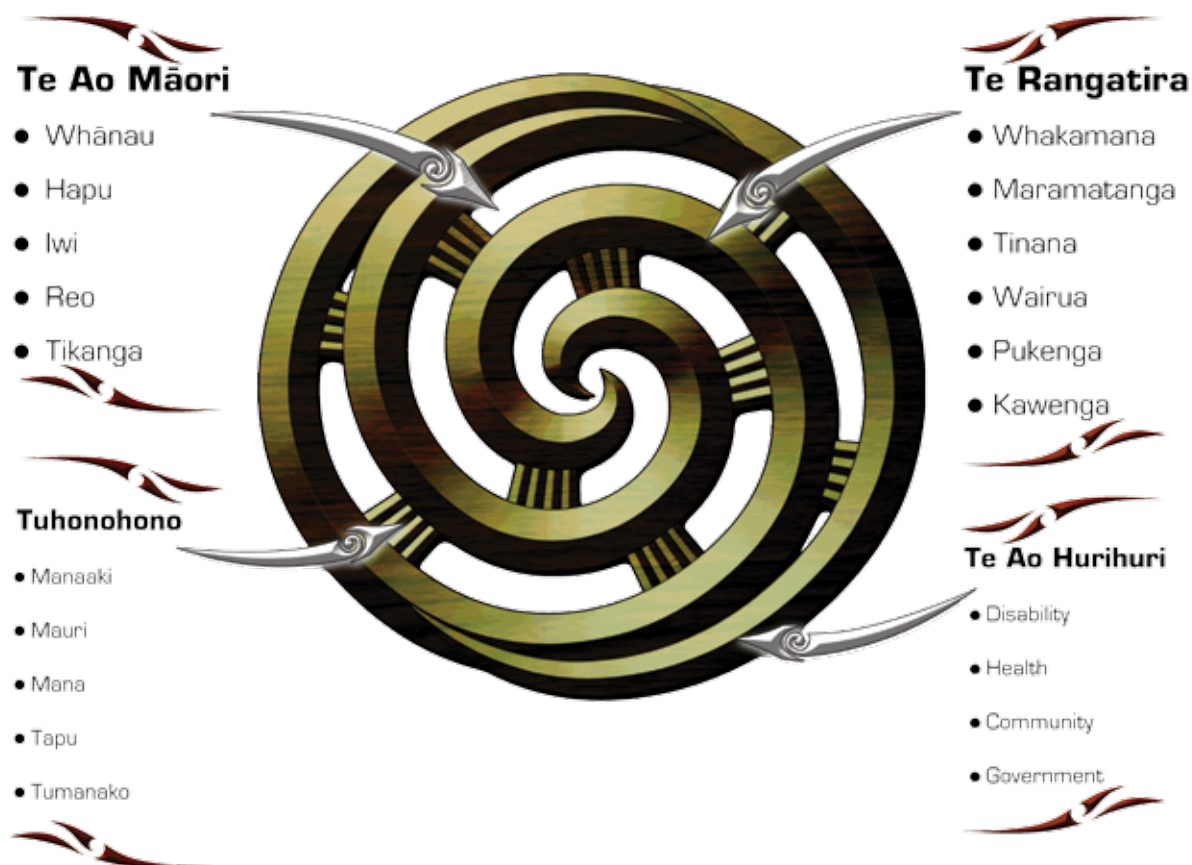
Whāia Te Ao Mārama responds to the wish expressed by Māori disabled and whānau for them to be able to live a good life, participate in te ao Māori and take part in their communities as other New Zealanders do.

There is no definitive word or description of disability in te reo Māori. Commonly te reo refers to a person's ability to flourish or function in relation to their ability to contribute to either their own, or others, wellbeing.

Whāia Te Ao Mārama's vision, kaupapa, guiding principles and priority areas have been developed in collaboration with Māori

disabled, key stakeholders and the Māori Disability Leadership Group (see Table 1). It is a culturally anchored approach to supporting Māori disabled and their whānau through Ministry of Health-funded disability support services. The approach has been developed from a Māori world view which also recognises that Māori disabled know what works for them.

Figure 1: Whāia Te Ao Mārama: To pursue a good life with enlightened support



Whāia Te Ao Mārama reflects the four core elements needed for supports to be effective for Māori disabled. Close relationships with and between Māori disabled, their whānau, hapū, iwi and communities, and the Ministry are essential to make a positive difference for Māori disabled. Included alongside the core elements discussed below are excerpts from the stories of Māori disabled who have generously guided and blended their experiences into this action plan.

Te ao Māori

Te ao Māori (the Māori world) is represented by the space between the spirals, shown in Figure 1. This space represents a person's ability to participate in their own whānau, hapū and iwi, and as a Māori New Zealander. The person is included, and is able to draw on the support and opportunities, within whānau and the Māori community through te reo, whakapapa, whanaungatanga, manaaki and wairua.

‘For example, a taonga for Ngāti Kāpō might be the ability to make choices and the right to be Māori and access cultural resources. ‘It’s the balance – active participation. Not even my mum and dad would have thought that I would become one of the leaders in health and disability services in Tairāwhiti, or that I would have a major influence in terms of indigenous issues around the world!’

‘I would have laughed at it myself, but it is about a vision. Ka pū te ruha, ka hao te rangatahi; mate atu he tetekura, ara ake he tētēkura – beautiful. So that’s what our old people were thinking.’

– Maaka, Ngāti Porou me Te Whānau ā Apanui)

Te rangatira

The te rangatira spiral represents Māori disabled as individuals living life and having the whakamana to take up their various roles as they have a right to do within their whānau, te ao Māori and society as a whole, and who are responsible for their own lives.

‘One of the concepts in Maoridom, which is so vitally important, is about applying tino rangatiratanga, which means that I can take control of my life and destination. We all want that – what’s important to give you a good life is the foundation and the legacy that we leave for others. Self-advocacy is also important. It’s that notion that talks about we can, ka taea mātau, ahakoa te aha, ka taea tonu e mātau. And then the other one is, mehemea kei kōrero koe mōku, māku anō au he kōrero, so if it’s about us,



then don't talk about it without asking us. These are internally understood principles, which have been translated into Māori kupu.'

– Maaka, Ngāti Porou me Te Whānau ā Apanui)

Tuhonohono

This is the solid link between the spirals, which represents the points in a person's life where both the spirals and the space between them must connect to provide balance and harmony. These connecting points are important and represent personal milestones and relationships that Māori disabled have with their whānau, hapū, iwi and caregivers, who are in turn supported through Disability Support Services or other agencies.

'We're still using the same old institutions. Why can't we join the dots together to show that perhaps there is a different way to achieve the outcomes that we all needed to achieve? The imported system can't be working for our people, and there's some indigenous ways which could be working maybe a lot better.'

– Gary, Ngāti Porou)

'Basically we go to people's houses that have ramps that we can access. Or we sit outside – we've sat outside in the rain with an umbrella, or if it's hot. So it really restricts you from doing the social things that you want to do with whānau. You sort of lose contact. And so of course contact with marae and wider whānau is also limited. We've had a lot of tangi and stuff. If I go, Tyler has to sit outside. So we can't do that, can't see the cuddies or things'

–Andrea and Tyler, Ngāti Mutunga me Moriori)

Te ao hurihuri

This is the spiral surrounding the disabled person. This spiral represents services, and the political, economic, social and environmental trends that support, influence and affect Māori disabled.

'Sometimes I do get labelled, and I don't like it. I look at myself as being treated like anyone else in the community. I don't have to go, "How come you're this handicapped fellow?" No, I'm a normal person just like you. I don't care if I've got a disability. I'm just a normal and loving person like you, and you should awahi it..'

–Rainus, Ngāti Awa)

Sylvia says she has been able to express her needs to disability services and have her needs met. But she says some other disabled people are not so able to do so.

'They're not speaking up for what they want, 'cause some of them don't know how. Staff should also develop better skills in listening and speaking simple language to encourage disabled people to speak up. They've been shut up, like shut down or "shut out". Sometimes it's because they might bear a grudge against a person or a service, or vice versa..'

– Sylvia, Whakatōhea

A focus for action

Table one contains key features of the plan that have been developed through extensive consultation. These include:

- > a **vision for Māori disabled and their whānau**
- > the **kaupapa**
- > **guiding principles** that underpin the vision
- > the **priority actions** which state how these elements will be accomplished.

Table 1: Māori disabled and their whānau

Vision for Māori disabled and their whānau	
<ul style="list-style-type: none"> > To achieve a good quality of life and wellbeing > To participate in and contribute to te ao Māori > To participate in their communities as other New Zealanders do 	
Kaupapa	
Māori disabled will achieve a good quality of life through whānau support and high-quality disability support services	
Guiding principles	
Enabling Māori disabled <ul style="list-style-type: none"> > Greater personal leadership, choice and control over disability supports accessed > Acceptance of Māori diversity and disability experience > Respect for Māori cultural values and preferences > Māori disabled have roles within their whānau and their communities of choice 	Respecting community <ul style="list-style-type: none"> > Good partnerships with whānau, hapū, iwi, and Māori communities > Full Māori participation in planning and delivering disability support services > Change the attitudes of whānau, hapū, iwi and communities to support the vision for Māori disabled
Valuing whānau <ul style="list-style-type: none"> > Whānau as the principal source of support for many Māori disabled > Whānau assisted to support disabled family members > Socioeconomic solutions for Māori disabled 	Delivering high-quality, effective disability support services <ul style="list-style-type: none"> > Culturally safe and trustworthy disability support services > A high strategic priority placed on improving Māori disability outcomes > Better Māori knowledge of and access to disability support services > Equitable resource allocation for Māori-focused disability support services
Priority actions	
1.1	Require providers to ensure that personal plans to support Māori disabled are culturally appropriate and specifically identify and address the individual's cultural needs (2012–17)
1.2	Provide a range of new and innovative support options for supporting disabled people that offer Māori disabled and their whānau more personalised support arrangements and greater choice and control over the supports they use (2013–14)
2.1	Improve caregiver training to ensure whānau have access to culturally appropriate training to address the needs of Māori disabled (2013–17)
2.2	Develop the New Model for Supporting Disabled People to respond to whānau needs and priorities (2012–13)
3.1	Improve the quality, reliability and comparability of national information about the demographics of, and disability supports provided to, Māori disabled (2012–17)
3.2	Improve the quality of the community engagement process with Māori, particularly with hapū, iwi, and community leaders and groups (2012–17)
4.1	Strengthen the cultural competencies of workers in the disability sector through the development and delivery of Māori cultural training (2012–17)
4.2	Support the Māori disability workforce to develop leadership skills and career pathways (2012–17)

The action plan

Priorities for *Whāia Te Ao Mārama* have been informed by:

- > available Māori disability and needs data
- > feedback from Māori consumers and whānau hui
- > guidance from the Māori Disabled Leadership Group
- > consultation with Te Piringa, the Māori Disability Provider Network
- > special focus groups and Māori disability experience-gathering exercises in 2011
- > the current difficult economic climate, which will mean that all actions will be resourced within existing funding.

Priority 1:

Improved outcomes for Māori disabled

1.1

Require providers to ensure that personal plans to support Māori disabled are culturally appropriate and specifically identify and address the individual's cultural needs (2012–17)

1.2

Provide a range of new and innovative support options for supporting disabled people that offer Māori disabled and their whānau more personalised support arrangements and greater choice and control over the supports they use (2013–14)

Priority 2:

Better support for whānau

2.1

Improve caregiver training to ensure whānau have access to culturally appropriate training to address the needs of Māori disabled (2013–17)

2.2

Develop the New Model for Supporting Disabled People to respond to whānau needs and priorities (2012–13)

Priority 3:

Good partnerships with Māori

3.1

Improve the quality, reliability and comparability of national information about the demographics of, and disability supports provided to, Māori disabled (2012–17)

3.2

Improve the quality of the community engagement process with Māori, particularly with hapū, iwi, and community leaders and groups (2012–17)

Priority 4:

Responsive disability services for Māori

4.1

Strengthen the cultural competencies of workers in the disability sector through the development and delivery of Māori cultural training (2012–17)

4.2

Support the Māori disability workforce to develop leadership skills and career pathways (2012–17)

Monitoring and reporting on the implementation of *Whāia Te Ao Mārama*

The high-level actions in *Whāia Te Ao Mārama* are supported by a detailed Ministry of Health Disability Support Services action plan, incorporating accountabilities, time frames and outcome measures.

Internal monitoring and reporting of the implementation of *Whāia Te Ao Mārama* will occur on a quarterly basis, alongside Disability Support Services' quarterly reporting on achievement of its annual service plan.

The *Whāia Te Ao Mārama* Monitoring and Advisory Group – a new external group of Māori disabled – will meet six-monthly to review implementation progress and provide advice to the Ministry.



Appendix 1: Additional actions for future reference

The following actions were identified by the Māori Disability Leadership Group but were not included in Whāia Te Ao Mārama. These may inform future service planning for Māori disabled.

Priority 1:

Improved outcomes for Māori disabled

- > Develop learning and leadership training and development opportunities for Māori disabled, including tamariki (children) and taiohi (young people)

Priority 2:

Better support for whānau

- > Develop indicators to measure whānau outcomes
- > Support parents with disabled children, particularly in the areas of behaviour support and whānau-centred respite care
- > Ensure whānau are involved in the funding, planning and delivery of disability services, including the development of service specifications
- > Improve Māori provider capacity and capability to participate in Whānau Ora through Te Piringa

Priority 3:

Good partnerships with Māori

- > Additional actions have been identified to enable Māori participation and inclusion in disability service prioritisation, specification and engagement
- > whānau, hapū and iwi relationships are established to better engage disability awareness and supports through iwi health plans and whānau support options on marae

Priority 4:

Responsive disability services for Māori

- > Review the Quality Assurance Outcomes Framework for Māori disabled to guide the approach for Māori receiving disability supports
 - > Use Māori disability research to inform service development for Māori disabled, including from Uia Tonutia: Māori Disability Research Agenda
-

Appendix 2: Glossary

Hapū	Māori sub-tribe, clan or kinship group
Iwi	Māori tribe or clan
Mana	Spiritual power, authority, integrity, prestige or group
Manaaki	To support
Marae	Central area of a village and its buildings
Māramatanga	Understanding
Pūkenga	Skills
Rangatira	Leadership
Rangatira-tanga	Influence and control over life
Taiohi	Adolescent
Tamariki	Child
Tangata Whenua	Māori as indigenous people to this land
Te ao hurihuri	Contemporary society, including Disability Support Services and other services and factors that affect the individual
Te ao Māori	The Māori world in which the individual has a role within whānau and hapū, and is able to draw on the support and opportunities of whānau and also take up their role within whānau
Te rangatira	Disabled individual Māori living life and taking up their various roles within whānau, te ao Māori, and society as a whole
Te reo	Māori language
Tikanga	Customs, practices and protocols that reflect Māori knowledge and traditions
Tinana	Physical; bodily
Tūhonohono	Connectedness and relationships that Māori disabled have with their whānau, hapū, iwi and caregivers which provide balance and harmony in their lives
Wairua	Spirituality or spiritual health, which encompasses dignity and respect, cultural identity, personal contentment, and non-physical spirituality