Mihi

Ka tu whera te tatau pounamu o te Ao
E takoto te whariki o te Atua ki mua i a tatou
He honore, he kororia ki te Atua
He maungarongo ki te whenua
He whakaaro pai ki nga tangata katoa
Ka huri te kei o te waka ki te Kingi a Tuheitia
Me te whare Kahui Ariki whanau whanui tonu
Ma te Atua e tiaki, e manaaki i a ratou
Me nga whakaaro tonu ki nga mate o te wa
Takoto mai, moe mai koutou, haere, haere, haere

Kati rato ki a rato, tatou ki a tatou
No reira, he korowai rau whero o te whare Waiora o Waikato

Haere mai, Haere mai,
Nau mai.

The green stone door to the world opens
The whariki of God is laid before us
All honour and glory be to God
May there be peace on Earth
And good will to all people
The keel of our waka turns to King Tuheitia
And the household of the Kahui Ariki
May God care and bless them
Our thoughts turn to those who have passed on recently
Rest in peace sleep in peace depart journey on

Let the dead be separated from us the living
Therefore, to our distinguished guests gathered here

Welcome, welcome,
Welcome.
“Mehemea ka moemoeā ahau
Ko au anake
Mehemea ka moemoeā e tātou, Ka taea e tātou”

“If I am to dream
I dream alone
If we all dream together
Then we will achieve”

Te Puea Herangi (1883-1952)
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The vision for this plan

The barriers and inequities disabled people and their families (whānau hauā) face when accessing health services are eliminated\(^1\).

Key changes that will enable the vision

Moving toward the vision means a shift from current attitudes and practice to a new way of behaving. The Disability Responsiveness Plan recommends a set of activities, but these will only be successful if we work in a way that respects whānau hauā as equal partners in the journey to health and wellbeing.

We need to make positive change in the following areas:

- Address inequities for whānau hauā
- Make information available and accessible to all
- Remove barriers that prevent whānau hauā having full and equitable access
- Provide equitable access to whānau hauā living in rural communities
- Be responsive and timely
- Behave with empathy and respect
- Provide a strength based approach where whānau hauā are at the centre of their care
- Whānau hauā are active participants in their treatment and care

While drafting this plan we consulted with Te Rōpū Tiaki Hunga Hauā and also got advice from Waikato Tainui that whānau hauā was the more appropriate reference to use for disabled people and their whanau. This term has been in use in the Waikato since 2006. Tāngata whaikaha was initially used as it was developed for Whāia Te Ao Mārama 2018-2022: The Māori Disability Action Plan in 2014. We have heeded Waikato Tainui advice and used whānau hauā instead of tāngata whaikaha throughout this plan.

Donny Rangihau (Tuhoe) gifted the term whānau hauā and its description to Te Rōpū Waiora, a Māori disability agency based in South Auckland\(^2\).

Whānau hauā distinct from common understandings of disability is that from this perspective a disability does not define a person. In other words, disability is positioned within a person’s background, coming to the forefront in times of need and compromised ability to achieve or undertake necessary activities. Whānau hauā manage disability as part of their daily life rather than it being central to an individual’s identity or everyday life.

This term has been deliberately used throughout this plan to emphasise that whānau hauā are driven by a collective effort and the cultural obligations and responsibilities that whānau members have to each other and the whānau as a whole, while they strive to achieve balance within an environment of change and institutional barriers.

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\(^1\) Waikato District Health Board Consumer Council Terms Of Reference 2018
Two year plan

The Disability Responsiveness Plan is a two year plan for Waikato District Health Board (DHB). It focuses on addressing the barriers and inequities facing whānau hauā including children, adults, older people who use Waikato DHB services. It is an aspirational plan and will form part of a longer term disability strategy which will be developed in the next two to three years.

Whānau hauā are those who have physical, mental, learning or sensory impairments. There are many who have life-long impairments as well as a growing number who acquire disability later in life, often as a result of long-term health conditions. Disability however, is something that happens when whānau hauā with impairments face barriers in society.

We know that whānau hauā experience poor health outcomes when compared to the general population. Research has identified the multiple barriers faced by whānau hauā of all ages and disability categories when accessing primary and secondary care.\(^3\)

- Māori and Pacific peoples have worse health on average compared with non-Māori and non-Pacific peoples, and have greater unmet needs
- Whānau hauā with intellectual disability often have a lower life expectancy, an increased risk of a range of chronic health conditions, and higher hospitalisation rates
- Whānau hauā with physical disabilities are more likely to have chronic health conditions and secondary health conditions
- Some health risk factors are more common among whānau hauā.

This plan identifies goals and activities that will ensure whānau hauā have access to appropriate and timely services at Waikato DHB which are respectful and mana enhancing.

We acknowledge and thank the whānau hauā who shared their experiences and learning with us.

We also thank Waikato DHB Consumer Council, Te Rōpū Tiaki Hunga Hauā (Māori Disability Forum), Waikato Tainui, Enabling Good Lives and other disability providers who have provided valuable insight.

Over 70 people have given generously of their time to shape the goals and actions in this plan (see appendix 1).

The principles of Te Tiriti o Waitangi of participation, protection and partnership have guided how this plan has been developed. The principles embody what a whānau hauā led approach is and this approach will continue as the plan is put into action and monitored.

The plan will provide clear direction for those working alongside whānau hauā to address inequities to ensure better health outcomes. It will identify a number of key areas of improvement across a defined range of dimensions, and it will set some clear performance measures for the DHB.

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\(^3\) Ministry of Health indicators of people with intellectual disabilities, 2011. Te Pou o te Whakaaro Nui, Improving access to primary care for disabled people, 2013
Why do we need a Disability Responsiveness plan?

There are district, national, and international, imperatives for improving the way we respond to the health and wellbeing needs of whānau hauā.

District:
- The New Zealand Public Health and Disability Act 2000 lays out expectations for DHBs to follow regarding disability support. These include improved health, independence, participation and inclusion of whānau hauā in the planning and delivery of health services.
- Waikato Health System Plan, Te Korowai Waiora 2019 commits to “improve health outcomes for our population particularly for Māori and other priority groups”.
- Healthy people. Excellent care, Waikato DHB Strategy 2016 recognises and seeks to address issues impacting on whānau hauā and lays the foundation for a robust approach to addressing health system inequities impacting on the wellbeing of whānau hauā.
- Waikato DHB Consumer Council terms of reference focuses on elevating issues and solutions that remove barriers and eliminate inequities for whānau hauā. To give effect to this vision, the Consumer Council has committed to the strategic imperative of health equity for high needs populations/oranga, such as Māori, and whānau hauā.

National:
- Te Tiriti o Waitangi in health, the treaty is used alongside the current New Zealand Public Health and Disability Act 2000 to ensure equitable health outcomes for Māori.
- The New Zealand Māori Health Strategy, He Korowai Oranga sets the overarching framework that guides the government and the health and disability sector to achieve the best health outcomes for Māori.
- The New Zealand Disability Strategy updated in 2016 states that whānau hauā must have access to mainstream and disability specific services that are high quality, available and accessible.
- Whāia Te Ao Mārama 2018-2022: The Māori Disability Action Plan is a culturally anchored approach to supporting whānau hauā because Māori are more likely to be disabled than the general population.
- Faiva Ora National Pasifika Disability Plan 2016-2021 sets out priorities that guide health providers when working towards the wellbeing of Pacific whānau hauā.
- The Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996 outlines the rights people have when using health services.

International:
- The United Nations Convention on the Rights of Persons with Disabilities states that whānau hauā “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.” New Zealand signed the Convention on Rights of Persons with Disabilities in 2007 and ratified it in 2008.
Who are whānau hauā in the Waikato DHB district?

102,600 estimated whānau hauā in the Waikato (2018)

- 51,300 are estimated to be male
- 51,300 are estimated to be female

- 9500 are estimated to be aged under 15 years
- 26,000 are estimated to be aged 15-44 years
- 28,500 are estimated to be aged 45-65 years
- 38,500 are estimated to be aged 65 years or older

Whānau hauā presented by age and ethnicity

- 24,600 Māori
- 5400 Asian
- 2500 Pacific
- 66,900 European

A higher proportion of the Māori and Pacific whānau hauā are in the younger age groups compared to the European age distribution.

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1 Whānau Hauā Disabled Peoples Health and Wellbeing Profile, Waikato DHB 2019
One in five (19%) of Māori whānau hauā are under the age of 15 years

One in seven (14%) of Pacific whānau hauā are under the age of 15 years

One in 16 (6%) of European whānau hauā are under the age of 15 years

The difference and diversity of whānau hauā needs to be understood, acknowledged and celebrated. Addressing the inequity that Māori and Pacific whānau hauā face is important. Social and economic factors contribute to poorer disability outcomes for Māori and Pacific, including from lower income and poverty, higher unemployment and lack of education.

Twenty-four percent of Māori identified as disabled in 2018. A high proportion of the Māori and Pacific whānau hauā are in the younger age groups (under 45 years). In education 42 percent of Māori at school receive support from the on-going resourcing scheme, one third of Māori whānau hauā receive jobseeker support and a supported living payment. For Pacific the information in the disability profile raised some concern that Pacific whānau hauā are not accessing a lot of additional support in education, in employment, or a supported living payment. Over the coming decades, we will see more cultural and ethnic diversity in the disability community.
How has the plan been developed

Whānau hauā and key stakeholders have been involved in the development of this plan. They have been engaged in discussions to identify issues and priorities for action.

Contributions have been sought through community focus groups, hui and individual feedback. (See appendix 1).

Whānau hauā asked for the plan to focus on actions which will have a positive impact, and for the actions to be aligned with existing documents:

- The Waikato DHB Programme Priority Plan 1.3 Remove barriers for people experiencing disabilities has been a key source document for this plan
- Whāia Te Ao Mārama
- New Zealand Disability Plan;
- New Zealand Disability Strategy;
- Health and Disability Commissioner Code of Rights
- United Nations Convention on the Rights of Persons with Disabilities

The Disability Responsiveness Plan has been developed to sit within the broader context of the Waikato Health System Plan, Te Korowai Waiora. This Plan describes the determinants of health and wellbeing which apply to all people, including those with impairments.

The Disability Responsiveness Plan recognises that certain groups, including whānau hauā, do not achieve health equity due to factors such as discrimination, social and economic factors and barriers to access.

Equality vs equity

Equality

Equity

Diagram adapted from original concept developed by ‘Robert Wood Johnson Foundation 2017’
Goals and actions to achieve the vision
**Goal 1**

*Tāne te wānanga*
*Be whānau hāua centred – listen to and value, our voice and experience*

This will mean
- we get the service that best meets our needs and wishes
- we become active partners with you in our journey to health and wellbeing
- it is easy to give feedback about how services are working for us and our feedback is responded to
- we know how to get support to assist us to resolve issues.

**Action 1.1 Welcome feedback from whānau hauā and act on this to improve responsiveness and service delivery**

**Activities**

Develop and promote a whānau hauā led easy to use, culturally appropriate and accessible feedback process. It is supported by a service improvement programme and information to address improvement priorities.

As part of the development of the DHB engagement framework, whānau hauā will have the ability to engage with the DHB and options are provided to support the range of disabilities. Other communication platforms are also used i.e. social media.

**Action 1.2 Support whānau hauā as a collective**

**Activities**

Ensure front line staff (those that interact with whānau hauā) receive training as part of the learning and development programme so they understand the needs of whānau hauā. This would include cultural training by Māori trainers.

Provide support for whānau hauā using hospital services by using trained kaitiaki and/or hospital volunteers.

**Action 1.3 Inform whānau hauā about their rights when using any of the Waikato DHB services**

**Activities**

Promote the Health and Disability Code of Rights throughout all hospital and community services.

Make resources relating to the rights of whānau hauā when using health services available online in accessible formats including Māori and Pacific languages.

Provide information about the Health and Disability Advocacy Service at all hospital and community venues.
Goal 2

Tāne-toko-i-te-rangi
Give us the information we need in a way we can understand and access

This will mean
- we have increased knowledge and understanding about our own health and wellbeing
- we understand our treatment options and are in control of the choices we make
- we become active partners with you in our journey to health and wellbeing.

Action 2.1 Make all information accessible

<table>
<thead>
<tr>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review all communication channels and materials and develop a plan to improve accessibility using expertise of accessible information specialists and specific impairment groups</td>
</tr>
<tr>
<td>Identify and remove barriers that prevent whānau hauā from independently accessing information</td>
</tr>
<tr>
<td>Implement a plan to make information accessible for all including whānau hauā</td>
</tr>
<tr>
<td>Ensure disability related information is available to Māori and Pacific health services to increase access to disability and health services</td>
</tr>
<tr>
<td>Review all DHB plans to ensure that they are accessible in easy read format</td>
</tr>
</tbody>
</table>
Goal 3
Tāne-toko-i-te-rangi
Barriers to accessing care are eliminated

This will mean
• it is easy and affordable for us to get the care we need
• we do not face barriers that negatively affect our health and wellbeing
• we do not experience disability discrimination due to access barriers.

Action 3.1 Whānau hauā experiencing a high level of difficulty accessing care are prioritised for action

Activities
- People experiencing acute mental distress in rural localities\(^6\) can access crisis response services
- Quality of care for whānau hauā using general and mental health\(^7\) services is improved
- Young adults and adults with Autism Spectrum Disorder and mental health issues receive expert diagnosis and treatment

Action 3.2 Physical spaces are designed to be universally accessible and utilise appropriate equipment and/or technology to ensure they are easy to navigate

Activities
- Input from access experts is sought at design stage for all building projects so that the built environment is fit for all groups irrespective of impairment
- The physical accessibility of the Waikato Hospital campus will be audited and improved
- A pool of specialised equipment is available to whānau hauā, to enable them to easily navigate and access services and facilities

Action 3.3 Innovative solutions are found to reduce barriers that prevent easy access to care

Activities
- A range of virtual health technology options are in place to support engagement with, and access to, information, services and supports
- Define any financial barriers preventing whānau hauā from accessing care are addressed
- There are a range of transport options (public, community and private) that are accessible, affordable and timely
- The limits on medication and other supplies are reduced

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\(^6\) Around 60% of the 394,000 people that live in the Waikato DHB area live rurally, making it difficult to give everyone consistent and appropriate healthcare. (Waikato DHB, 2016)

\(^7\) Systematic challenges in Mental Health and Addictions and Dementia have specific work streams that are currently happening. Meeting the specific needs of these groups of tāngata whaihaka will be addressed in this work
Goal 4
Tāne matua
Help us to achieve our full health and wellbeing potential

This will mean

- We are not discriminated against because of our impairment or culture
- Our wider social needs are considered alongside our health and disability needs
- Care is given early, continues at transition points and is consistently good
- We are in control of decisions about our care
- We are kept safe
- We have ready access to interpreter services.

Action 4.1 There is dedicated disability expertise within Waikato DHB

Activities

- Resources are made available to establish roles which focus specifically on improving outcomes for whānau hauā using Waikato DHB services
- Co-design with whānau hauā a complex care service to coordinate services for whānau hauā with high and complex health needs
- Resources are made available for accessible interpreter services for whānau hauā

Action 4.2 Enable whānau hauā to make informed decisions about their care and wellbeing

Activities

- Improve communication (particularly around transition discharge planning and treatment options) so people can make choices that increase the likelihood of positive outcomes
- Supported decision making is understood and practiced to ensure whānau hauā have their will and preferences taken into account

Action 4.3 Whānau hauā accessing multiple health services and transitioning from one area to another find the process easy and seamless

Activities

- The process for transitioning from child disability/health services to adult services is reviewed and improvements made
- Clinic appointments and surgery bookings are coordinated so people don’t have to come back multiple times
- Innovative solutions are found to reduce barriers that prevent easy access to care, to include kiosks in the hospitals
Action 4.4 The Waikato DHB makes decisions which are informed by robust evidence

<table>
<thead>
<tr>
<th>Activities</th>
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</thead>
<tbody>
<tr>
<td>Disability profiles are completed and include pathway showing how the data will be used to inform decision making and make improvements to health services</td>
</tr>
<tr>
<td>Evidence based and anecdotal information is collected through a variety of mechanisms and is used to guide decisions and practice</td>
</tr>
<tr>
<td>A system is developed to hold essential information about whānau hauā and is universally accessible across the Waikato DHB</td>
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</tbody>
</table>
Goal 5

Tāne te waiora
We are treated with respect and empathy by staff who are knowledgeable about disability

This will mean
- we feel welcome, respected and are treated with empathy
- we are not discriminated against because of our impairment or culture
- we experience staff who demonstrate a positive attitude about disability.

Action 5.1 Educate the workforce so they understand and can work responsively with whānau hauā. This will include training provided by Māori and Pacific disability trainers

Activities

Introduce disability rights and responsiveness training as part of the learning and development programme for all staff. Let’s get real: Disability Workforce Development framework outlines the competencies required to work with whānau hauā

Contract whānau hauā for the co design and delivery of Te Ao Māori cultural and disability responsiveness training

Educate staff about the cultural needs and disability perspectives of Māori and Pacific peoples and other ethnic groups making up the Waikato community

Build internal staff capacity and capability by valuing whānau hauā staff as a key resource and identify opportunities for them to build a network, grow knowledge and expertise and lead change
# Goal 6

**Tāne te waiora**

We are active partners in improving quality, ensuring accountability and monitoring services

This will mean

- we experience improvements in care that are linked directly to our feedback
- resources are used in ways that maximises positive outcomes
- we are recognised and valued for our expertise.

## Action 6.1 Whānau hauā monitor and influence the quality of care and services

**Activities**

- Whānau hauā representatives on the Waikato DHB Consumer Council provide leadership and oversee systems performance and improvement impacting on them
- A disability lens is included on all new and reviewed Waikato DHB plans and policies
- Whānau hauā are involved in service review, co-design of services and quality improvement initiatives
- The Disability Responsiveness Plan is included as part of the overall Waikato DHB quality improvement framework
How this plan will be put into place, monitored and reviewed

Quality and Patient Safety will undertake an accessible journey approach to establish a baseline against which quality improvements will be measured. The accessible journey approach will involve whānau hauā walking through a range of Waikato DHB experiences to identify barriers and solutions.

Quality and Patient Safety and Learning and Development will have significant responsibility for implementing all staff training and will be obligated to deliver or source Māori and Pacific responsiveness training. They will also develop:

- a change framework to measure changes over time and provide reports to the Disability Support Advisory Committee
- an evaluation framework to review progress on implementing the actions in the plan.

As a start we have identified the following key measures of success using the key themes and Waikato DHB values.

**Key measures of success**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tāne te wānanga</strong></td>
<td>- The DHBs engagement approach facilitates the whānau hauā community’s voice in planning and service development</td>
</tr>
<tr>
<td>Mauri Pai</td>
<td>- Progress to remove disabling barriers will be underway and reported</td>
</tr>
<tr>
<td><strong>Tāne-toko-i-te-rangi</strong></td>
<td>- Planned and reportable changes to facilities and the built environment of health facilities will be implemented</td>
</tr>
<tr>
<td>Whakarongo</td>
<td></td>
</tr>
<tr>
<td><strong>Tāne matua</strong></td>
<td>- Purchasing and service development approaches will be driving models of care with reportable equity gain measures for whānau hauā with a particular focus on Māori and Pacific communities</td>
</tr>
<tr>
<td>Whakapakari</td>
<td></td>
</tr>
<tr>
<td><strong>Tāne te waiora</strong></td>
<td>- There will be a culture and capability change across the DHB and its providers</td>
</tr>
<tr>
<td>Whakamana</td>
<td>- Whānau hauā will feel empowered, respected and properly engaged in decisions about their care. Their voices will be central to decision making</td>
</tr>
<tr>
<td>Kotahitanga</td>
<td></td>
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</tbody>
</table>

Disability Support Advisory Committee will be responsible for monitoring the process and overseeing ongoing change. A disability champion will take responsibility for the implementation of the actions in this plan.
Appendices

In the community consultation hui that was held at the end of January 2019, themes were set by the facilitator Ike Rakena. These themes aligned with the key areas identified in all the strategic disability documents noted and reflect the Waikato DHB values.

The themes are based on the Māori legend of the creation with Rangi and Papatūānuku. Tāne god of the forest strategises to separate his parents to allow the children to grow and fulfil their dreams. The themes highlight the key areas of focus for whānau hauā to allow them the opportunity for equity and better health outcomes.

Participants commented on the current situation and what their aspirations are.
## Tāne te Wānanga

### Empowering and engaging people, inclusion and support

- Nothing happening in rural, or smaller towns. Needs to include children, all ethnicities. People with disabilities are tired because the DHB aren’t listening.
- There needs to be a culture change. Practice what you preach. Concern that it’s policy without action.
- Important that services have an understanding of disabilities and what this means in terms of service delivery.
- No services/initiatives for people with disabilities should be done without consultation with the affected group.
- Support holistic wellbeing that is inclusive, and whānau based. Services need to be centred on people and the person.
- The expectation and aspiration of people with disabilities is to have the same health outcomes as everyone else. The services need to make the appropriate accommodations for people with disabilities.
- Fully accessible and meets the physical, emotional, and social needs. There is information readily available and clear communication, mana enhancing, Good coordination/collaboration between primary and secondary/tertiary health providers.
- Celebrate and recognise diversity of people. Health system needs to be simple to navigate and you are able to get your needs met. Seamless.
- Need to be accepted, my voice, your voice, being heard and really understood. I’m not a diagnosis, seeing/knowing the person.
- The right to privacy and informed consent. Equity – equitable with non-disabled, togetherness and co-design.
- We all want to be treated with dignity, having control and choice in their own lives. Integrated system that recognises who you are.
- Tools that can support these aspirations, understanding, empathy, commitment, client-centred services, easier access to specialists consultations.

### Families and whānau of disabled children and young adults:

- There was no follow up after seeing the paediatrician. Multiple specialities involved but no coordination between the specialities. No follow-up or support once we left the hospital.
- No access to speciality services once discharged. No follow-up with GP or advice on medical management or medication management once we left the hospital.
- Couldn’t get through on the phone, left messages no one called back, I had to phone 5 times before my child was seen.
- The dietician never did any of the things she said she would do, and my son just kept losing weight.
- We were treated disrespectfully, the staff found it all very amusing. Discussion of personal issues about the person with whānau in front of them i.e. talking about a non-resuscitation order in front of our daughter.
- Multi-disciplinary meeting held between specialists but whānau not involved. One doctor decided to do something then the next shift came on and reversed the treatment decision. A positive attitude toward my child’s disability. To be treated with respect – parents know their child best.
I have difficulty communicating and the nurses didn’t even have the patience to wait and hear what I have to say.

As a young female adult I was embarrassed when a male nurse came to change my nappy. I told them I wanted a female but they didn’t listen. I complained but never received a response.

I had a male friend visit and the nurse asked him to hold my catheter bag. I was really embarrassed.

**Adults with disabilities:**

Couldn’t they coordinate clinics and surgery – get your ears and teeth done at the same time. There need to be disability alerts on file for people with high vulnerability. Easy to understand information would be great.

It’s a duty of care – you can’t send someone away and refuse to treat them because they haven’t got a legal guardian.

Car parking is challenging and expensive. There are never enough wheelchairs plus mobility aids need to be available everywhere.

Generally staff are welcoming – building a relationship with key people is important. If you say you are in pain they need to listen – not assume you are just complaining. Staff need to tell you what is going to happen every step of the way *(person who is blind)*.

**Tāne-toko-i-te-rangi**

**Environment and facilities. Improved access to services**

More welcoming, less clinical environments and people (attitudes and behaviour).


Interface between mental health services, disability supports, and health services. Fully accessible environments.

Lack of technology to increase access. Design places for people who use them, not staff. Silo approach limits access.

Clinical lead for disabled people with a range of health issues, once they leave paediatric services.

Clinical staff default to support people and step back.

Anxiety increase due to poor sensory accommodations = increased cost (staff, time, $) to manage increased behavioural issues (mainly children).

Planned discharge with information and services in place.
**Tāne te matua**

Eliminating health inequities and improved health outcomes. Re-orientating models of care

- Removing barriers, lack of interpreters including multi languages, language interpretations - e.g. medical terminology is confusing
- Medication instructions need to clearly understand what we’re taking, what it’s for etc. Written instructions needs to be available
- Need to utilise media IT devices in hospital, skype video conference, independence, the same service as everyone else
- Equal opportunity, disability navigators in the hospitals, and community. Māori cultural medication (herbal)
- More funding for aids (hearing aids and wheelchairs) to improve quality of life. Medical files state that the patient needs an interpreter but most of the time no one books one
- Discharge planning with an interpreter. Staff (hospital) learning basic sign language. Hospital staff are of another ethnicity / challenging English is a second language
- Need to understand how to communicate with people who may be deaf or have another disability. They want to be accepted

**Tāne te waiora**

Leadership, strengthening governance and accountability

- Be really driven by the Waikato DHB values and priorities, disability champions, include a person with learning disability on disability consumer council
- We need more welcoming less clinical environments and people (attitudes and behaviour). Disability responsiveness
- Educate the community. Importance of an independent disability consumer council at a governance level
- Educating staff to provide accessible services. Leadership by example, clear chain of communication up and down
- Connectedness at all levels. Clear visibility and voice at all governance levels. Intersectorial collaboration with government agencies. Data repository, can’t advocate without some evidence
- The only good thing I’ve got to say about the disability system is about Enabling Good Lives Waikato McKenzie Centre help parents navigate the system
Appendix 2

People and organisations who contributed to the Disability Responsiveness Plan

- Disabled Persons Assembly NZ
- Disability service providers
- Enabling Good Lives, Ministry of Social Development, Waikato
- McKenzie Centre, early intervention service parent group
- People First NZ
- Personal Advocacy Trust
- Rauawaawa Kaumātua Charitable Trust
- South Waikato Pacific Islands Community Services Trust
- Te Rōpū Tiaki Hunga Hauā
- Waikato DHB Consumer Council
- Waikato DHB staff
- Waikato Tainui
- Whānau haua, including Māori and Pacific peoples, with a range of impairments and complex health needs
- Whangamata Community Services Trust (representing the interests of people experiencing mental illness)
## References

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<tr>
<th>Document name</th>
<th>Date</th>
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<tr>
<td>Health and Disability Commissioner (1996) <em>Code of Health and Disability Services Consumers’ Rights</em></td>
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<tr>
<td>Ministry of Health (2014) <em>He Korowai Oranga: Māori Health Strategy</em></td>
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<td>Ministry of Health (2011) <em>Health Indicators for New Zealanders with Intellectual Disability</em></td>
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<tr>
<td>Ministry of Health (2001) <em>Living a good life</em></td>
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<tr>
<td>Ministry of Social Development (2018) <em>Leading the way in accessible information</em></td>
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<td>Office for Disability Issues (2016) <em>New Zealand Disability Strategy 2016-2026</em></td>
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<td>Statistics New Zealand (2015) <em>He hauā Māori: Findings from the 2013 Disability Survey</em></td>
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<td>Statistics New Zealand (2014) <em>Disability Survey: 2013</em></td>
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<tr>
<td>Te Pou o te Whakaaro Nui (2013) <em>Improving access to primary care for disabled people</em></td>
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<td>Waikato District Health Board (2018) <em>Consumer Council Terms of Reference</em></td>
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<td>Waikato District Health Board (2019) <em>Whānau Hauā Disabled Peoples Health and Wellbeing Profile Waikato DHB 2019</em></td>
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<tr>
<td>Waikato District Health Board (2016) <em>Healthy people. Excellent care, Waikato DHB Strategy</em></td>
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<tr>
<td>Waikato District Health Board (2019) <em>Waikato Health System Plan, Te Korowai Waiora</em></td>
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<tr>
<td>Waikato District Health Board (2019) <em>Programme Priority Plan (draft) 1.3 Remove barriers for people experiencing disabilities</em></td>
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</tr>
<tr>
<td>Wairarapa, Hutt Valley and Capital &amp; Coast district health boards (2017) <em>Sub-Regional Disability Strategy 2017-2022 Enabling Partnerships: Collaboration for effective access to health services</em></td>
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