Strengthening Our Voice

Report from the Balance Aotearoa 2021 national hui

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Introduction

On 13 and 14 May 2021, Balance Aotearoa hosted a hui in Whanganui called "Strengthening Our Voice". The hui was attended by people with lived experience of mental distress and/or addiction from around New Zealand. The event was interpreted into New Zealand Sign Language and streamed live online.

The hui had two parts. The first part focused on human rights, especially the United Nations Convention on the Rights of Persons with Disabilities, and the importance of Te Tiriti o Waitangi. The second part focused on considering what a Disabled People's Organisation (DPO) representing people with lived experience of mental distress and/or addiction could look like, and how it could function.

In keeping with the "strengthening our voice" theme, this report uses the voices of attendees. Quotes are used throughout the report as much as possible, and with the consent of those who said them. These quotes were sourced from a transcript of the forum. This transcript, and video recordings of the forum, are available for anyone who would like to access the full discussion.

Balance Aotearoa wishes to thank everyone who attended and supported the hui, especially our pou tikanga Terence Mathews and the Matthews whānau, our guest speaker Sir Robert Martin KNZM, our facilitators Fiona Clapham-Howard, Gemma Griffin, and Nigel Ngahiwi, our NZSL interpreters, staff, support crew, and members of the Board of Trustees. Special thanks also to Ngahina Gardiner (Ngahina Gardiner (Ngā Wairiki, Ngāti Apa, Te Ātihaunui-ā-Pāpārangi) for the artwork on the cover of this report. Ka nui te mihi ki a koutou katoa.

We gratefully acknowledge that the hui was funded by the New Zealand government through the mental health, addictions, and disability workforce development agency Te Pou.

Executive Summary

What is this report about?

It's a summary of what was discussed at a hui that Balance Aotearoa, a Disabled People's Organisation, hosted in Whanganui, Aotearoa New Zealand on 13 and 14 May 2021. The hui was called 'Strengthening Our Voice'. Tāngata whai ora/people with lived experience of mental distress and/or addiction came to the event from across the country.

What did we talk about?

Sir Robert Martin KNZM gave the opening address to the hui. Sir Robert is a human rights advocate and one of the founding members of the self-advocacy movement for people with learning disability in Aotearoa. He spoke about his life in institutional and foster care, his involvement in drafting the United Nations treaty called the Convention on the Rights of Persons with Disabilities (UNCRPD), and his role on the Committee which monitors this Convention.

We spoke about the United Nations and human rights

The United Nations is a global organisation that was set up right after the Second World War to prevent another global war. It aims to maintain peace and security in the world and expects all its members to promote and respect human rights. New Zealand is a founding member.

Shortly after it was set up, the United Nations – for the first time in human history – officially defined what human rights were and got all its members to accept that definition. The document that sets this out is called the Universal Declaration of Human Rights. It lays out the basic civil, political, economic, social and cultural rights that all human beings should enjoy. By signing this declaration, each member of the UN agreed to protect the rights of every individual, everywhere – without exception.

We discussed the UNCRPD and how it fits in Aotearoa New Zealand

The UNCRPD tries to get all of the countries that signed it to give disabled people full equality under the law. In practice, this means creating specific policies to help disabled people and tāngata whaikaha Māori reach full equality, and getting rid of policies that don't. Aotearoa signed up to the convention in 2008 and must work to implement it.

Nigel Ngahiwi of Kāpō Māori Aotearoa facilitated a session for us about Te Tiriti o Waitangi. He talked about it being a partnership between the Crown and Tāngata Whenua, and how it guarantees tūrangawaewae – a standing place, a place to belong – for everybody, without discrimination. Te Tiriti is the umbrella that the UNCRPD should sit under since it is one of the founding documents of Aotearoa.

> *Essentially the power of the UN is the power that resides in the people of the countries. It's only by the people in those countries standing up to their governments and saying, 'You need to fix this because look at what the UN is saying', that's where the power comes from.* – hui participant

We talked about the social model of disability

The medical model of disability sees people as being disabled by an impairment that doctors and health professionals say needs to be cured through treatment. The social model sees people as being disabled by barriers in society, rather than by an impairment. Barriers can be physical things or societal attitudes. The social model of disability links well with the UNCRPD and its human rights framework, since disability is seen as part of human diversity and as something to be accepted.

We also reflected on the discomfort that many people in the mental health sector have with the language of disability. The UNCRPD says that disabled people include those with ‘psychosocial impairments’, or mental health conditions. However, many tāngata whai ora do not use labels like ‘psychosocial impairment/disability’ or ‘disabled people/people with disabilities’.

We exchanged ideas on the best models for DPOs, as well as the difficulties in running them

This was the first discussion of its kind, where participants shared ideas about what an ideal Disabled People’s Organisation for tāngata whai ora could look like in Aotearoa.

While there are different legal ways a DPO can be set up, we didn’t conclude which was the best and agreed we need to talk more about the issue. But we did agree that there are some key things which successful DPOs have:

- a collective voice with a diverse membership
- many ways for people to participate
- good relationships with external organisations
- strong governance and accountability to members.

The main challenge DPOs face is the difficulty in getting funding, especially since it can be expensive to bring people together to talk.

Another issue is that national issues can sometimes dominate regional voices in DPOs.

We also highlighted that DPOs must do a good job of communicating with their members. Communication often tends to be one-way. People said that DPOs should consider communicating more in ways that let people get back in touch easily. This would help them listen to their members more closely and give them space to share.

We concluded that the hui had been a rare opportunity to connect

We all reflected at the end of the two-day hui on a number of issues. People said how rare it is for tāngata whai ora to meet and connect in such a safe and welcoming environment. We concluded that we should all continue our work to build a stronger, larger, more diverse network of tāngata whai ora.

Pōwhiri

Kā nui te mihi me mātou whakaute nui ki a Atihaunui a Paparangi te Iwi, me Ngaa Paerangi te Hapu, me mātou rangatira kō Terence Matthews me te whānau Matthews kātoa. Kā tika mātou hui i roto i te korowai o te aroha me rangimarie i whakatakotoria mo tatou.

Our thanks and respect to Atihaunui a Paparangi te Iwi, to Ngaa Paerangi te Hapu, our rangatira Terence Matthews and the Matthews whānau. Our hui went well within the korowai of aroha and peace laid down for us all.

Opening Address – Sir Robert Martin

The hui was opened by guest speaker, Sir Robert Martin KNZM. Sir Robert is from Whanganui and a former resident of The Kimberley Centre (Kimberley), where he began his journey as a human rights advocate. Sir Robert is one of the founding members of the self-advocacy movement for people with learning disability in New Zealand. He has twice been voted onto the United Nations committee responsible for monitoring the Convention on the Rights of Persons with Disabilities. He remains the first person with learning disability to have held a seat on a UN Human Rights Treaty Body. This, together with his lifelong commitment to championing the rights of disabled people, has earned him a knighthood.

Sir Robert described his journey, starting with being segregated as a young child. He was sent to Kimberley, then foster care, then Lake Alice Hospital (Lake Alice).

“It was the worst part of my life cos I ended up in Villa Eight and you were locked up at night, and you couldn't go out and couldn't do things.”

After Lake Alice, Sir Robert went to community-based services. He recalled that people didn’t have a choice of what clothes they wore, what they got to eat, what time they went to bed, and what they wanted to do.

“I thought, well, this can't be right, how we treat our most vulnerable people in society. So…we created a strike. I think it’s the only strike that has happened for people with learning disabilities.”

Later, Sir Robert was involved in closing down Kimberley. He was involved in a large march through the streets of Wellington to Parliament, where people with learning disability delivered a petition to the then-Minister of Disability Issues.

“People have a right to live in society. People have a right to be part of our community. Nobody has the right to be segregated. We know segregation doesn’t work, so why do we still do it? We’ve done it for all kinds of people in our world we live in. It's never worked, so why do we still do it?”

From 2002 – 2006/7 Sir Robert was involved in drafting the United Nations Convention on the Rights of Persons with Disabilities. Later he was voted on to the Committee on the Rights of Persons with Disabilities, which monitors implementation of the Convention. In 2020 Sir Robert was re-elected for another term on the committee. He received more votes than any other candidate in the election.

Following his address, Sir Robert was asked what he felt the biggest issues for people with mental distress were. He said segregation, being over-medicated and being institutionalised.

> *"They…get people out of institutions, but re-institutionalise them by sending them to a vocational centre. …I just don't get it. We hear from countries like Indonesia, where people are still locked away and things. They're shackled to beds and stuff like that. I mean that's happening around the world, and we need to stop it. That's why I'm also the co-chair of [a committee about] closing all institutions around the world. Yesterday, we had a meeting about the Asia Pacific region. There's lots of issues even in our region that we need to overcome."*

Sir Robert was asked if he had any thoughts for hui attendees, about how people can use the Convention in their own lives in Aotearoa.

> *"Well, it belongs to us. It's a vibrant living thing, and that to me is what this convention is all about. It's about all people with disabilities. It should be in the hearts and minds of everybody, not only people with disabilities, but those without disabilities as well.*
>
> *We are part and parcel of our society, our community, our world."*

In closing, Sir Robert was asked if he would choose to go through all of the painful things in his life, if he had to live his life over again.

> *"Yes, because I don't think I could do the job I'm doing. Sometimes you gotta go through all the crap to get to the other side."*

Section 1

Our Human Rights Framework:

Te Tiriti o Waitangi and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Introduction to Human Rights and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

This section summarises a presentation given about human rights and the UNCRPD (“the Convention”). Some relevant information and updates have been added. In this section you will see headings that include the words “Focus Issue”. These headings show where hui participants were asked to work together on understanding how an Article of the Convention is applied to that focus issue.

What is the UNCRPD?

The UNCRPD is an international agreement that New Zealand ratified in 2008. New Zealand is obliged to implement it.

The UNCRPD did not create new rights for disabled people. There were already several human rights agreements that apply to everyone. The Convention was developed because in countries all over the world, including New Zealand, disabled people were not enjoying the same human rights as everyone else. They were often excluded. Their rights were violated. They were left out and marginalised. The Convention was developed to say that disabled people must have the same human rights as everyone else.

What are human rights?

Human rights are the experiences and things that every human should have access to, because they are a human being. Human rights belong to everyone. They cannot be separated and they depend on each other. They cannot be taken away,

The first international human rights instrument was the Universal Declaration of Human Rights, which was developed in 1948. It was developed in the aftermath of World War II. People were really concerned about the atrocities that happened. They wanted to make sure that it could never happen again, so the declaration outlined fundamental human rights. It said that *all human beings are born free and equal in dignity and rights, and everyone is entitled to all rights and freedoms without distinction of any kind.*

Human rights are held by all people, and it's important to remember that with human rights, come responsibilities. We have a right to be treated with respect, but we also have the responsibility to treat everyone else with respect.

How important is the Convention?

More than one billion people throughout the world experience some form of disability. Currently, 182 countries have signed the convention. Around 24% of New Zealanders experience disability, according to the New Zealand Health Survey.

What does disability mean?

In the preamble to the Convention, it says that disability is an evolving concept. Disability happens when a person has an impairment of some kind, and there are barriers in society that stop the person from being able to participate fully and equally with others. The Convention is very clear in Article 1 that people with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments. In New Zealand, the term ‘disabled people’ is most commonly used.

For some people, this is a significant change. Historically, some people with experience of mental distress have not identified themselves as disabled people. Some may not identify as disabled people now. The Convention is clear that people who've experienced mental distress can be disabled by barriers in society. It calls that type of disability ‘psychosocial disability’.

The Convention demonstrated a significant change in thinking about disability generally. Previously, disabled people were often seen as objects of charity, who needed medical treatment or social protection - people who should just be grateful for whatever they got. Under the Convention, they're seen as subjects with rights - as ‘rights-holders’. They are seen as citizens who are capable of claiming their rights. To go from an object of charity (who should be grateful for whatever you get) to a full citizen (a rights-holder capable of claiming those rights), is a major change in power dynamic and in thinking about disability.

The social model of disability

A significant development that led to this change was the development of the social model of disability. Previously, there was the biomedical model of disability. Under that model, disabled people were seen as having something wrong with them, that needed to be treated or – preferably - cured. Doctors and health professionals were seen as experts, and the solution to disability was to manage or eradicate it through treatment.

Under the social model, disability is something that happens when social and physical environments do not allow for difference - when they are designed for non-disabled people. Disabled people are seen as the experts in what they need and what society needs to do to accommodate them. The solution is to eliminate those barriers and to accommodate people. This social model sits well within a human rights framework. Under a human rights framework, disability is seen as part of human diversity and something to be accepted.

Discussion: Are people who experience mental distress disabled persons?

The group was asked to reflect on the definition of disability in the Convention and the social model of disability and consider whether people who experience mental distress are disabled persons. Many people identified barriers in society that could be disabling to people who experience mental distress.

> *“We got to a place where…we could say, “Your shitty system and structure is disabling me right now,”. So actually starting to name that when we connect with people or structures or systems. That “ I'm seeing you and I'm seeing what you're doing, and you're disabling me”….The*

responsibility goes on to others, cos if we sit with that biomedical model, then we actually excuse the oppression in our communities rather than naming it."

"The system is never regarded as disabled, but the system is disabling, and people are othered or disabled by the system is really what it boils down to."

Some reflected on their initial resistance to identifying with the term disabled, and how that might come from a place of privilege.

"We felt a sense of potential discomfort. Because we don't have a visible disability….We can pass as not having a disability. Do we just leave disability as a term with all of its stigma and stuff for people who can't avoid it so easily?"

"We spoke…about how our able-bodied privilege meant that we had somehow adopted some kind of stigma or prejudice towards the word disabled. It's a bit of a bitter pill to face when you connect with that."

One group suggested that it was important that "disabled" didn't become another label being put on to people.

"People [need] to be able to self-identify or avoid labels that aren't comfortable for them. Otherwise, are we just blanket labelling people in our community in a way that that's happened to us for so long with different labels? We're just putting a different one on us."

Why are disabled people often denied human rights?

Attendees were asked why they thought disabled people were often denied human rights.

Society sees disabled people as being unable to contribute or meet expectations

People get ignored and marginalised

People think we're dumb

[there's a] power imbalance embedded in society

Ableism is valued

[We] don't have a voice

Underpinning a lot of the stigma, discrimination and barriers faced by people who experience mental distress, are myths and folklore that have been held for a long time. These include the beliefs that people are sick, that they're throwaways, they don't have any value, or they're people to be made fun of. There is also a common myth that people with mental illness are dangerous.

“We see it in casual comments, and we also see it in our really high compulsory treatment rates, because that indicates that we have a fear-based system that is almost entirely focused on risk and this idea of danger.” – hui presentation

Language is an important way that people are left out and excluded. Words can make people feel like they're not valued, like they're less than others. Some examples are words like crazy, nuts, and mental.

There are barriers within our society and especially with our laws that can stop us from enjoying our human rights. We see this especially in our current Mental Health Act, which allows people’s rights to liberty and autonomy to be denied because of a perceived impairment or illness.

The environment around us can be another barrier to us enjoying our rights and fully participating in society. For example, a person with a sensory impairment may feel overwhelmed by a large amount of information in a grocery store. People with a trauma history may feel excluded or unable to participate because of the way that buildings and environments are designed.

The United Nations Convention on the Rights of Persons with Disabilities

Purpose

Article 1 states that the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.

Discussion: principles of the UNCRPD

The group discussed each of the principles and considered how they related to people who experience mental distress.

- respect for dignity, autonomy and independence – *“‘Being able to make our own decisions and be able to live the lives we want, not what someone else wants us to.”*

- non-discrimination *“The disparity in physical health and life expectancy for people in mental health services is appalling in this country...[we need to address] overt and covert systemic discrimination, stigma, and abuse of tāngata whaiora.”*

- full and effective participation and inclusion – *“We're not included by those in power, so our voice is never heard or acknowledged.”*

- respect for difference and acceptance - *“Discrimination and stigma is disabling. If all people recognised difference as normal, then I might not be disabled.”*

- equality of opportunity - *"actually [we] need equity and not equality…a lot of the socioeconomic factors with having mental distress means that we lack opportunities that should be open to all of us."*

- Accessibility – *"Accessibility isn't always about having a ramp for the wheelchairs… it means the right connections and a safe environment…why is it so bad in society to access mental health services?"*

- equality between men and women – *"this breaks it down to a very simple equation between men and women when in fact the equation is much bigger and involves other gender identities and non-identities."*

- respect for the evolving capacities of children*. [No specific quote was recorded on this topic.]*

Types of rights

There are four types of rights in the Convention – social rights, economic rights, cultural rights, civil and political rights.

Administering the Convention

The Conference of State Parties is an annual meeting of the countries who have signed the Convention where State Parties discuss their progress on applying the Convention.

Twice a year, the Committee on the Rights of Persons with Disabilities examines the progress of some of the State Parties. Each of the State Parties is subject to an examination approximately every 4 years[1]. The Committee can also conduct inquiries in some circumstances.

The Optional Protocol is an additional document that countries can sign if they choose. New Zealand signed it in 2016. If a country has signed the optional protocol, then citizens of that country can make complaints to the committee.

What the Convention says about monitoring

The Convention also includes information on how progress against the Convention should be monitored.

Article 4.3 of the convention requires countries to actively involve disabled people in all decision-making processes concerning persons with disabilities, through their representative organisations. In New Zealand, a Coalition of Disabled People's Organisations (DPOs) exists for this purpose.

Article 33.3 requires countries to actively involve disabled people in monitoring the convention. In New Zealand, disabled people have been involved in writing monitoring reports about the Convention.

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[1] In September 2022 New Zealand had its third examination, 8 years after the previous one.

The New Zealand monitoring framework

In New Zealand, the Convention is monitored by the Independent Monitoring Mechanism (IMM). The IMM is made up of the Human Rights Commission, Office of the Ombudsman, and the Disabled People's Organisation's Coalition (DPO Coalition). Balance Aotearoa is a member of the DPO Coalition, and so is also a member of the IMM.

The IMM compiles and publishes reports that go to the UN Committee. The most recent report was entitled "Making Disability Rights Real – Te Whakatuturu i Nga Tika Hauātanga". The DPO Coalition produces and publishes its own Disabled-People-Led Monitoring reports, which also go to the UN.

There are also two national policy documents, the Disability Strategy, and the Disability Action Plan. Balance Aotearoa asked for the 2014 Action Plan to include an action that says there needs to be an assessment of the fit between the Mental Health Act, the Bill of Rights Act, and the UNCRPD. That action was completed in 2018. In the 2019 Action Plan, Balance Aotearoa asked for an action to "repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992". That action is currently in progress.

The Disability Rights Commissioner is part of the Human Rights Commission and has a special role in advocating for disability rights and amplifying the voices of disabled people on issues that affect them. This role is closely related to, and supports monitoring of the Convention.

Focus issue: Seclusion/solitary confinement

During the last examination of New Zealand by the UN committee, both the government and civil society provided information about New Zealand's use of seclusion (solitary confinement)[2]. The committee observed that New Zealand continues to allow the use of solitary confinement and restraints in mental health inpatient wards. Although there has been a decline in this practice, the situation is not satisfactory. After observing that, they went on to say: "the Committee recommends that immediate steps be taken to eliminate the use of seclusion and restraints."

> *"There is no room for interpretation. The UN committee have said that New Zealand's use of seclusion is unacceptable under international human rights law, and that it must stop, and it must stop now."* – hui presentation

In 2017, there was an independent report called "Thinking outside the Box? A Review of Seclusion and Restraint Practices in New Zealand". The report was completed by an independent expert, Dr Sharon Shalev. It covered Corrections and Education as well as Health. The report made some very strong recommendations about seclusion and restraint.

Judge Beecroft, the Children's Commissioner at the time, was quoted as saying:

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[2] In this report, we call "seclusion" solitary confinement because we believe that term more accurately reflects the dehumanising and traumatic experience many people have of this practice. Where we are reporting other people's statements we use the words they have used.

“The whole report is a sobering wake-up call. We are out of line. We are in flat out contravention of our human rights obligations.”

In 2020 Dr Shalev released a further report called “Seclusion and Restraint – Time for a Paradigm Shift”, which found inadequate progress had been made. It was noted by some hui participants that there are some good examples of DHBs eliminating seclusion, that others should learn from.

Focus issue: Right to health

Article 25 is the right to the highest attainable standard of health.

Disabled people have the right to enjoy the best standard of health without discrimination, but there is a lot of evidence that, as a group, people with psychosocial disability have poorer health outcomes and shorter lifespans. From the Equally Well project and other similar work it is clear that people with psychosocial disability have poor health outcomes from diabetes, cardiovascular disease, metabolic syndrome, cancer and poor oral health.

Article 25 also includes the right to free and informed consent and to be protected from harms of treatment. This includes harm from the side effects of medications and treatments like Electro Convulsive Therapy (ECT).

There is also an argument that, like mental health systems all over the world, the New Zealand mental health system is underfunded.

“If governments decide to under-invest in mental health compared to physical health, then that is discriminatory, and that violates Article 25.”- hui presentation

Focus issue: Compulsory treatment

Compulsory treatment is an issue of concern as it violates Articles 14 (liberty) and 12 (equal recognition before the law).

“We know that New Zealand's use of community treatment orders is amongst the highest in the world. We also know from research that very few applications for release from the Mental Health Act are successful, so it’s difficult to regain your liberty once you are under the Act.”

– hui presentation

Under the current Act there is no test for mental capacity – whether you can make decisions for yourself. The Act relies instead on a clinician’s opinion that you have disordered thinking and are a risk to yourself or others. In other areas of health, the right to refuse medical treatment can only be over-ridden if you “lack mental capacity” that is, you cannot make decisions for yourself.

There is also a significant issue for people who are accused of a crime and are found not fit to stand trial. They are incarcerated (locked up) on the basis of their disability and don’t go to trial. Often there is no release date, and they may remain in custody longer than if they had been convicted of the crime.

In 2014 the UN Committee was concerned about New Zealand's Mental Health Act. They recommended that New Zealand take "all the immediate necessary legislative, administrative and judicial measures to ensure that no one is detained against their will in any medical facility on the basis of actual or perceived disability."

In 2018 the Ministry of Health released a discussion document, "Mental Health and Human Rights" which considered human rights issues within the Mental Health Act and other laws and regulations that apply. Balance Aotearoa worked with the Ministry of Health and others on this document. The published results of this discussion show that most of the participants agreed the Mental Health Act is outdated and in conflict with Bill of Rights Act and the UNCRPD.

There is one aspect of compulsory treatment where there has been some progress in relation to the UN Convention. A Bill is going through parliament that will mean that treatment orders have to be reviewed regularly and cannot be indefinite. The legislation disclosure statement with the Bill[3] says that the change is being made to "make existing legislation more consistent with obligations under the UN Convention".

Focus issue: Supported decision-making

The Convention promotes supported decision-making over substitute decision-making. Substitute decision-making is where someone else makes a decision for you. Supported decision-making is promoted under Article 12 - disabled people have the right to be treated equally before the law, like everyone else. The UN committee has said that people should get the advocacy and support they need to make their own choices.

> *We know from reports that many people who use services have said that they do not get support to make decisions, especially when they're under the Mental Health Act.*
> – hui presentation.

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[3] The Mental Health (Compulsory Assessment and Treatment) Amendment Act 2021 (2021/41) was passed into law on 29 October 2021.

The relationship between the Convention and Te Tiriti o Waitangi.

This section summarises a conversation between Nigel Ngahiwi of Kāpō Māori Aotearoa and the group.

The conversation refers to *Te Tiriti o Waitangi* rather than The Treaty of Waitangi. It was explained that this was because Te Tiriti is the document that Māori signed and understood. As the indigenous copy it is the legally recognised document, including by the United Nations.

[CHECK SPELLING, CONFIRM WITH NIGEL]

He Whakaputanga o te Rangatiratanga o Nu Tirene

There was a document signed five years before Te Tiriti. That document is known as He Whakaputanga o Nga Rangatiratanga o Nu Tirene, which translates to Te Whakaminenga, or the New Zealand Constitution. This document was actually signed by more rangatira than Te Tiriti, including Pōtatau Te Wherowhero, who later (in 1857) became the first Māori King. He signed Te Whakaminenga. He did not sign Te Tiriti o Waitangi. There were quite a few rangatira who did not sign Te Tiriti o Waitangi.

Te Tiriti o Waitangi and the UNCRPD

Te Tiriti o Waitangi was a partnership between the Crown and Tāngata Whenua. It guaranteed tūrangawaewae for everybody. This means a standing place, or a place to belong.

Article 1 gave an authority to govern in partnership. Article 2 says the Crown was to promise and protect rangatiratanga. Article 3 says that the Crown promised that whānau would participate in their communities without discrimination.

Another relevant document is the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), which New Zealand endorsed in 2010. A Convention is legally binding on the countries who sign it but a Declaration is not.

The relationship between these documents was considered:

> *With Te Tiriti o Waitangi and the UNCRPD, how does that all fit…? Te Tiriti o Waitangi is the umbrella in which the UNCRPD sits underneath…it is one of the founding documents of this country, anything that comes after it should fit underneath it. When we look at it as in Te Tiriti promised turangawaewae for settlers and tāngata whenua, so it should offer its power or mana to the UNCRPD.*
>
> \- hui presenter

Attendees thanked Nigel for telling them about the place and importance of tūrangawaewae:

Thank you for telling us that we have been guaranteed tūrangawaewae, a standing place for our legs, a place to plant our feet, a place to belong, because it tells me that we are connected. We are planted in mother earth, and from mother earth, we grow and we make connections with each other. Through those connections, we realise that we belong, but not only that, that we are never ever alone.

I think in all our pain, we need to remember that, because see others out here who can help us and who support us. We never stand alone, and we can connect with others to help us, so always reach out.
Thank you because I have never heard that before. - hui participant

The meaning of disability in te ao Māori

The meaning of disability was discussed. In Te Ao Māori, disabled people were revered. For many people, being disabled is not their main identity:

In te ao Māori, especially us who's Kāpō Māori, the rōpū, the group, having a disability actually comes down the list. It's not a priority, so for me, first and foremost, I'm a Māori born and bred...... Down the row a bit, I have this thing called blindness. That's the way most of us think in Kāpō Māori, is we're Māori first, somewhere down the way, we've got this impairment. I don't call it a disability, cos the only reason I know I'm disabled is when I bang into something... That's the gentle reminder that that's right, I can't see. Otherwise, most of the time, I carry on like I do. It hasn't become the thing that drives me, and it hasn't become the person that I am.
– hui presenter

Stigma and discrimination around mental distress

Stigma and discrimination in our communities towards experiences called "mental illness" and suicide were considered. It was explained that in many Māori whānau, there was a history of looking after and including those diagnosed with "mental illness". Stigma toward suicide exists because some people don't understand it. There is a general lack of understanding about disability as well.

Society does not understand disability at all. Otherwise, they wouldn't keep closing us out. They wouldn't keep creating things that they think are good for us, but that are a nightmare.- hui presenter

A number of people shared very personal stories about their whānau and history, especially around the stigma of mental illness and suicide.

The historic treatment of Māori within the mental health system and the impact of colonisation on the experience of mental distress was raised. One person recalled their experiences of being treated at Lake Alice:

There was no Māori there that I could remember at that time. It was about 1969/1970/'71. I was there a couple of years, and then I came back about five years later and there was a lot of Māori there then, so something changed in society for an

> *acceptance of psychiatry. Something changed and now we have a lot of Māori being treated or Eurocentric psychiatry and Eurocentric systems, so something changed between 1970 and ’75.* – hui participant

Nigel explained that one reason was that the older generation was lost during this time, so the whānau dynamic changed.

> *“More and more of our people were getting sent to these places or getting transferred to these places. It’s because the whānau dynamics started to change. We started to become, I suppose, for want of a better word, more colonised, because that's the way that was taught to us”* – hui presenter

Learning about the UNCRPD and using it to effect change

Information was shared about other training programmes on the UNCRPD. The Kia Noho Rangatira Ai Tātou programme is funded by Te Pou and available throughout New Zealand. It is a beginner’s course on how to understand and use the articles in the UNCRPD.

In closing, questions were raised about how the UNCRPD is enforced. What does the government have to do if they are found to be breaching the UNCRPD?

> *Essentially the power of the UN is the power that resides in the people of the countries. It’s only by the people in those countries standing up to their governments and saying, “You need to fix this because look at what the UN is saying”, that’s where the power comes from. At the moment, there are huge delays around that, but just the fact that a complaint has been made is something that’s public. Within the country and within the international community, your government is put to shame by you registering that complaint, even if it isn’t resolved, so there is power in the process, even if it takes a long time to get resolved.* – hui participant

> *There is a lot that can be done, but it does take people to be interested and to stand up for their rights and to be talking with each other about it consistently, and to be getting out there and [protesting] about it, if you need to.* – hui participant

Section 2

A Disabled People’s Organisation (DPO) for people with psychosocial disability.

A Disabled People's Organisation (DPO) for people with psychosocial disability.

In this section of the hui, attendees considered how a DPO for people with psychosocial disability could function. The host organisation, Balance Aotearoa, is recognised as a DPO for people with psychosocial disability. Balance Aotearoa was interested in peoples' thoughts about what they would like to see from a DPO, and in building awareness and networks.

> *We've got to make this about trying to reach as far as we can, trying to bring people who are interested and the aroha, the mahi aroha, the mahi wairua that people have to do with their lived experience to make a difference. We've got to try to gather that energy, that ability that we have as a community to effect change by using what's happened to us and what we know from that.* – Balance member

It was made clear that this section of the hui was to support the development of DPOs generally, not just Balance Aotearoa. That is why this report is being published.

> *The idea of having this discussion about how a DPO could be constructed is [for] whoever wants to create a DPO… there's nothing to stop there being multiple DPOs of any kind. This is about doing some thinking about structures based on all that knowledge we've got in this room, the wisdom that you bring from the experiences you've had. Just think about what you've seen working well, and talk about that, and then whatever kind of organisations are out there can learn from that. This is a sharing experience for us. It's not just about what Balance needs.* – Balance member

Discussion of DPO Attributes

The hui considered a document from the DPO Coalition about the attributes required of DPOs to qualify as members of the Coalition. References to "Attributes" are from this document, which is included as appendix one.

Organisational structure

A DPO is a group of individuals with certain rules that bind them to a common purpose or goal (Attribute 1).

To join the DPO Coalition, an organisation generally needs to have a national structure and focus (Attribute 2). It can have a regional focus, but only if there is no other national organisation that also speaks on behalf of the same community.

There's no particular legal structure required. Often organisations in New Zealand are set up as charitable trusts with a board of trustees. There are some that still work as a fully membership-driven organisation like an incorporated society, but often organisations chose a charitable trust structure because it limits their personal liability.

Constitution

A DPO needs to function effectively. It needs to demonstrate that it is putting into practice its constitutional requirements (Attribute 5). It needs to show that it has effective governance and is working to meet its objectives on behalf of its members.

Membership

A DPO must be open to all people who meet the membership criteria (Attribute 6). If the membership criteria is “experience of mental distress or addiction”, it needs to be open to all people who have this experience and wish to join. A significant majority of the members must be disabled people (Attribute 9), so that their voice is the strongest. DPOs can have members who are non-disabled. Many DPOs have associate members or organisations that are allies.

Governance

Attribute 7 suggests that governance and decision-making within DPOs should sit with those members who have a disability. Equally, only disabled people who meet the membership criteria should be entitled to elect and vote for the governing body (Attribute 8).

Collective voice

Attribute 11 says that DPOs must show that they are responsive to, and driven by, the collective voice of their disabled membership. It is suggested that some sort of national meeting could be held, at least every one or two years. Any such meeting should be open to all members and could include representatives from around the country who can speak on behalf of members in their own region.

Attribute 12 says that DPOs must demonstrate strong links to their members throughout the country/region. They must have a variety of ways to ensure that members are informed of key decisions.

Mandate

A DPO must demonstrate that it has a mandate to represent disabled people (Attribute 10). The mandate may be expressed in the organisation’s primary goal, objectives or philosophy.

Balance Aotearoa – an example

Balance Aotearoa is a charitable trust. They have trustees who are required to meet every three months but usually meet every month. Their personal liability is limited. The DPO Coalition accepts that Balance Aotearoa runs democratically and in the spirit of the attributes. Balance Aotearoa has different types of membership. You can be an individual member as a person with lived experience of mental distress or addiction (a disabled person), or you can be an associate member as an organisation or a group. Balance Aotearoa is also a provider of peer support and consumer advisory services.

Sustainable funding

Under article 4.3 of the Convention, DPOs should be sustainably funded. Balance Aotearoa is currently not sustainably funded for its DPO work. Meeting fees are paid for attendance at DPO Coalition events, but there is no funding support for consultation with members to inform that work. Underfunding is a significant barrier to engaging disabled people in the work of DPOs.

DPOs are not funded for all the UNCRPD-related work they do. They're only funded for each piece of work rather than being funded for any infrastructure or admin time as well as, for example, all Balance Aotearoa's contributions to the DPO Coalition.

All disabled people's organisations that are working in this space need to be supported to do that, so we can effectively engage with the constituents that we represent. That's the key from our perspective. – Balance member

Structures – group discussion.

The group had a general discussion about the features of an effective DPO.

People were split up into small groups to discuss potential structures for a DPO.

Attendees were asked to explore structures and consider:

- What works well
- What works well to meet the DPO attributes
- What are the potential barriers or challenges

Discussions focused on:

- Balance Aotearoa's structure and experience.
- Nga Hau e Wha – having regional representatives come together as a decision-making body.
- Multiple regional organisations that feed into a national decision-making organisation.

The following section summarises the feedback sheets from the group discussions. The full text of notes from the feedback sheets are included in appendix B.

Organisational structures and “what works well”.

Legal forms of organisations

Different legal forms were considered including incorporated societies and charitable trusts. While legal form was a topic of discussion, no clear indication emerged of which would be better. It was noted that incorporated societies can be vulnerable to hostile membership takeovers. A further, focused discussion on legal form was recommended.

Networks

Networks were seen to provide opportunities to learn about what is happening in different parts of the country and promote collaboration. Networks can mean that a group is more representative of issues. Relationships are particularly important in networks, and they can be similar to iwi/hapu relationships.

National organisations

National organisations were considered by some to work well, particularly those with a representative board that includes Māori representation. National groups can have strong relationships with members at grassroot levels.

What makes organisations successful

The group discussions suggested some essential elements for success:

- diverse membership
- many ways to participate
- accountability, strong governance, and democratic processes
- strong management and leadership
- good relationships with external stakeholders.

Membership should be inclusive, member-driven, and democratic. Strong representation from tāngata whenua and including whānau and external stakeholders was also suggested. There should be a variety of ways for members to participate in the organisation’s activities. Organisations should be accountable to members and have strong governance and democratic processes including regular elections of governance. Organisations need to grow leaders through succession planning and training. Having a single point of contact with government agencies was seen as a way to build relationships of trust.

What works well to meet the DPO attributes

Many of the groups felt that the areas they identified under the “what works well” question, also applied to this question. Additional points included:

- Collective voice. Having a lived experience mandate.
- Membership and engagement. Being totally membership-driven, engaging meaningfully, and getting regional voices to inform national advocacy.
- Accountability. Measuring performance according to indicators developed by disabled people. Having accountability to a lived experience network.

Potential barriers or challenges

Many participants identified lack of funding as a barrier. There are significant costs involved in bringing people together to discuss issues, and there is often no funding for gathering or sharing information. However, it was also acknowledged that lack of funding can lead to creativity, which may have some positive benefits.

Lack of capacity to do systemic advocacy work can be a barrier, and this is often the result of lack of appropriate funding. People have to try to do advocacy on top of their other work. A lack of resources and investment means that skills are often invested in a handful of people, and there is no ability to train others.

For national organisations, national issues can dominate regional voices. Different regions can have different expectations. There is a risk of under-representation of some areas – there are large regions with few people to represent them.

Challenges with organisation leadership included the potential for trust to be betrayed, a lack of diversity and representativeness, and limited access to leadership opportunities.

We need to put trust in people to speak on our behalf and that gives privilege which is sometimes misused. - Group feedback sheet

Diversity of thought and representation – a membership who is largely 'white' or 'conservative' or 'straight' etc. might elect others like them consistently to roles in the executive team further marginalising the marginalised. – Group feedback sheet

People in positions of power need to be able to make room and invite people in, so those of us that have a platform, that have privilege, have a heavy responsibility to not only make space, but really actively invite others into that space because otherwise, we can end up in this situation …where we're not walking the talk. We find that we're othering others, because we've been othered, and we're leaving someone out from the conversation. People become invisible.- hui participant

Other barriers identified included:

- Size and location. Regions can be very big, and members may feel disconnected from each other.
- Technology. Some people cannot access devices, data, or internet coverage.
- Contract processes. Contracts are often small or short-term and have limitations. Procurement processes are competitive not collaborative.
- Political and policy changes, and turnover of staff within external agencies can interfere with progress.
- Not keeping purpose and function relevant to members.

Nothing about us, without us – group feedback sheet

Communication

Attribute 13 requires DPOs to have a variety of ways to ensure that members are informed of key decisions at both a local and national level. Balance Aotearoa acknowledged that one of the areas they could potentially improve on was communication with membership.

> *Okay, so we know that we need to do better in terms of communication with membership. That's a big one and needs to be two-way. That's a capacity issue. We need assistance in terms of funding to be a DPO for a start, but we also need to sort out the most effective ways of communicating with our membership and having that information come back from the grassroots about what's going on.*
>
> – Balance Aotearoa Board member

Effective ways to have input and stay informed

A range of methods were seen as useful – meetings, phone calls (0800 numbers), texts, hard copy documents, letters, newsletters, surveys, social media, emails, websites and radio. Meetings could be in-person or virtual, formal or drop-in. It is important to offer a range of methods, because different people have different communication preferences.

The importance of face-to-face communication was emphasised:

> *We concentrated on what really works well and we came up with in-person and upfront and one-on-one, because it builds connection and relationship. From the attributes, we were really around collaboration and partnership and the way that the attributes can create a space.*
> – group feedback sheet

What works well to meet the DPO attributes?

Participants felt that two-way communication is important:

> *A lot of organisations are quite good at putting things out there, publishing a newsletter, and newsletters take so much but other methods…[enable] people to get back in touch. Are they enabling enough time for people who want to get in touch to connect and provide genuine feedback, or is it going to be a rushed process, which isn't going to uphold and enhance people's ability and right to participate?*
> – group feedback sheet

A DPO needs to listen and provide a space to share:

> *It’s really listening, listening to what people need, and right alongside that, giving people the time and space to share, creating that environment where people have the ability to share.*

Barriers to communication

Barriers discussed were:

- Organisational capacity – the time and resources needed to communicate and use information effectively.
- The “digital divide” – access barriers including lack of provision for sensory and cognitive impairments, infrastructure problems, cost barriers, not having the knowledge and skills to use digital media or preferring not to.
- Not using plain language.

Opportunities to advocate for systemic change are often structured in complicated ways, and need to be made accessible for everybody.

> *We talked a bit about the importance of not being made to feel dumb, and how having in-person or video explanations where a real person can break down a complicated advocacy, systemic advocacy opportunity, and say, ‘This is the background to, for example, the Mental Health Act, and these are some of the conversations that have been happening. Now, we're suggesting these amendments. Here’s what it will mean to people.’ Once you can get your head around things in simple terms, it makes you a lot more confident to be able to say, ‘Yeah, I have something to say that connects with that.’* – hui participant

Closing

Attendees came together to reflect on the two-day hui, on what they had learnt, and on the connections they had made. Many attendees reflected that the environment felt safe and welcoming:

> *I hope that the rest of us have felt that same sense of safety and it sums up everything, that sense of safety, of belonging, of being welcome, of being part of having meaning, of having purpose. All those things I could possibly ask for have been achieved through the sense of aroha that's here.*

It was noted that such opportunities for people with lived experience to meet and connect are very rare:

> *It's quite emotional to be all together in one place for our own interests, not brought together to have input into someone else's project, but to do something for us and for the furtherance of our movement and to recognise everyone here as social movement activists. We get called other things. We get called lots of things. Some of them were on that slide on the first day, like crazy and nuts and mad and whatnot, but we also get called the peer workforce and we get called volunteers. We get called leaders, but the work is so important, and it is so under-recognised. There is nowhere in the system that really seems to uphold and resource us to do this.*

One objective of the hui was to contribute towards building a stronger, larger network of people. The need for building larger and more diverse networks was endorsed by attendees:

> *The only way to change things is to get diversity of opinions, views, experiences and stuff like that. I saw that this was an opportunity to get that diversity, and I haven't been let down.*

Some expressed that more diversity and representation from marginalised communities was still needed:

> *You need to do that relationship building. It can't just be an invite, so you need to build those relationships. That takes a lot of mahi and a lot of time and genuine power balance. That needs to happen. It's a long-term plan, not a short-term plan.*

In closing, Balance expressed thanks to Tāngata Whenua:

> *Your support and your whānau support to bring this hui to Whanganui has made it special, made it perfect for us.*

One participant reflected on the relationship between the two days of the hui, and the challenges going forward:

Yesterday, we engaged with an open mind in conversation around the convention. There was recognition of the fact that many people are hesitant to embrace the label of disability, but Balance Aotearoa is a Disabled People’s Organisation.

The challenge to everyone here, people who do experience psychosocial impairment, that's mental health issues, conditions, however you want to phrase it, do not reject that term disabled or disability. All it does is it reinforces stigma, discrimination, and otherness. That is the exact opposite of what we are striving for.

We are one of many Disabled People’s Organisations. There is a whole community of staunch advocates out there that want to stand side by side with you.

– Balance Aotearoa Board member

Appendix A: Disabled People’s Organisation (DPO) Role and Attributes

Written by the DPO Coalition

Background

The United Nations Convention on the Rights of Persons with Disabilities (Convention) describes key roles for Disabled People’s Organisations (DPOs). Articles 4.3 and 33 oblige states to closely consult with and actively involve people with disabilities through their representative organisations and to fully participate in the process of promoting, protecting and monitoring the Convention.

In any country that has ratified it, the Convention creates a form of partnership between that country’s government and people with disabilities. A partnership that upholds the mantra “Nothing about Us without Us” by ensuring people with disabilities will be closely involved in decisions that affect us and impact on our lives. Article 4.3 of the Convention recognises the role of organisations that represent people with disabilities as having the authority to dialogue with the Government on behalf of people with disabilities on the issues that concern us.

Defining “What is a Disabled People’s Organisation”

The term Disabled People’s Organisation (or DPO) has developed to encompass a variety of organisations made up of, or primarily governed by, people with disabilities. There are some DPOs that have both a representation and a service delivery function. As there is no universally accepted definition of what a disabled people’s organisation is, there are a variety of organisations that might consider they are a DPO.

The Convention does not define organisations that represent us. It does accord special recognition however, to organisations that do represent us by creating an obligation on governments to engage with us through our representative organisations on issues that impact on our lives.

DPOs are working collectively and we have developed a proposal on how we can engage with government. We have outlined our vision, mission, values, and principles for implementation. We are committed to working with Government, non-governmental organisations and other partners within the disability sector to make the right real for people with disabilities in Aotearoa New Zealand.

We value our allies who walk alongside us and stand up for the principles that engagement with DPOs, based on real information and evidence drawn from our lived experience, will bring real economic benefit in society and the economy, including the elimination of poverty in our people.

Description of Te Tiriti o Waitangi

Te Tiriti o Waitangi (The Treaty of Waitangi) signed on 6 February 1840 is the founding document of Aotearoa, New Zealand and is not only a blue print for how Māori and Pākehā can live together, but it contains a set of rights guaranteed to Māori with regard to self determination and sovereignty and also with regard to equality in society (Article Three).
Given the different ways in which Te Tiriti has been read, interpreted and understood by Māori and Pākehā, the government and courts developed a set of Treaty of Waitangi principles. These principles have become the primary way in which the government and its agencies understand and express commitment to the Treaty of Waitangi. The four primary principles include: (1) protection and the Crown's duty to protect Māori lands, waters, possessions and self determination; (2) partnership and the idea that the Treaty established a partnership between Māori and the Crown and the duty of the Crown to act in good faith; (3) participation in which Māori are guaranteed all the rights and privileges of citizenship; and (4) consultation in which the Crown has a duty to consult with Māori.

The 'principles approach' to the Te Titiri o Waitangi has arisen out of western legal deliberation. Notwithstanding this criticism, Māori continue to use the articles of Te Tiriti o Waitangi, as well as the principles, to advance their claims for redress, equality and self-determination. *(Higgins, Phillips, Cowan, Wakefield and Tikao 2010 - Growing up kāpo Māori: Whānau, identity, cultural well-being and health / E tipu kāpo Māori nei: Whānaungatanga, Māramatanga, Māoritanga, Hauoratanga, 2010).*

DPO Attributes

New Zealand DPOs have produced a set of attributes to help define what a DPO is, in Aotearoa New Zealand. These attributes are:

	DPO Attributes	**Yes/No**
1.	The organisation has a legal existence i.e. must demonstrate it exists as a group of individuals with certain rules that bind them to a common purpose or goal (refer appendix for additional information).	
2.	The organisation has a national structure and focus. If the organisation has a regional focus, it demonstrates that there is no national organisation that speaks on behalf of its members.	
3.	The organisation upholds and promotes the philosophy that people with disabilities have the right to participate collectively in decisions that impact on our lives (Nothing about Us without Us).	

4.	The organisation's primary goal, objectives and operations reflect and support the primary purpose of the Convention (refer appendix for additional information).	
5.	The organisation functions effectively and demonstrates it is putting into practice its constitutional requirements (refer appendix for additional information).	
6.	The organisation may focus on a single disability or it may be a multi-disability organisation. It is open to all disabled people who meet its membership criteria.	
7.	The organisation must be governed by a significant majority of disabled people who reflect its community of interest and meet its membership criteria.	
8.	Only disabled people who meet the organisation's membership criteria may elect and vote for its governing body.	
9.	A significant majority of the organisation's members are disabled and reflect its community of interest.	
10.	The organisation demonstrates that it has a mandate or authority to speak on behalf of its members and this remains paramount over any other obligations including direct service provision (refer to appendix for additional information).	
11.	The organisation responds to and is driven by the collective voice of its disabled members who reflect its community of interest (refer to appendix for additional information).	
12.	The organisation demonstrates that it has strong links to its members throughout the country, or throughout the region for a regional organisation (refer to appendix for additional information).	
13.	The organisation has a variety of ways to ensure its members are informed of key decisions at both a local and national level (refer to appendix for additional information).	

Conclusion

Each member organisation should meet the requirements set out in the schedule of attributes. Essential to being a DPO is that the organisation is the authoritative voice of the disabled community or community of interest the organisation constitutionally represents. A number of factors can be taken into account such as the number of members the organisation has compared with the size of its community of interest, any characteristics of its community of interest that would impact on the number of members or their ability to organise, how well spread the organisation is geographically through the country or region, etc.

It is anticipated the DPO Network will make every effort to ensure it has member organisations that cover the full spectrum of the disabled community. The DPO

Network will try to avoid any situation developing in which it appears that a particular group becomes over-represented due to too many separate and disparate organisations each claiming to speak on behalf of that group.

Appendix B: Group discussion tables about organisational structure

This appendix includes notes made by groups during their discussions about organisational structures.

We have included some comments that we don't clearly understand so that we can seek further information about them.

Networks and relationships

- *Wide networks and representation*
- *Different needs will be identified across the country*
- *Similar to iwi/hapū relationships*
- *Contact with national members at grassroots networks*
- *Regional knowledge translates into better understanding and like-mindedness*
- *Learn a lot about what is good or bad around the country*
- *Use existing networks*
- *Collaboration*
- *Purpose in the primary drive of how things are done. E.g. Sharma. One person has the Government ear and then there are multiple groups around the country that contribute to the discussion.*

National body

- *National group would very well – in Board, Māori representation*

Tikanga-based

- *Tikanga-based addresses issues with representation DHB funding.*

External relationships

- *Single body to be a point of contact for Ministry of Health which generates trust*

Membership and participation

- *Diversity of members*
- *Fresh perspectives*
- *Member-driven, supported by decision-making body*
- *Non-exclusive – bring other people and experiences in*
- *Allow members to participate – lots of options to participate in different ways: Facebook, email, monthly meetings*
- *Democratic process*
- *Ability to choose who to invite, when and how. E.g. Whānau.*

- *Mana Oreti – at least 50% Tāngata Whenua*
- *Include DHB representation*

Activities / way of working

- *Emergency meetings are a great idea to be responsive*
- *Like-minded conversations*
- *Social experiences*
- *Funding to allow people with lived experience to come together, talking, developing relationships and unity.*

Accountability and governance

- *Accountability to membership*
- *Members vote for board members*
- *Biennial elections of board or executive*
- *The attributes give accountability*
- *Accountability via membership of the KPI network*

Management and leadership

- *Aspects of mixed approaches – revolving, dynamic and purposeful*
- *Strong leadership – stir the pot, change positions, revolving door of leaders*
- *Management – need succession and training*
- *Skills: finance, policy, property, consumer reps and community reps*

Mission

- *Shared common good*
- *Safeguards against "mission creep"/takeovers*

Communication

- *Communications: Diverse community, diverse roles, conduit information network, reciprocity, national representation, informal accessibility.*
- *Two-way communication systems*
- *Communication from governance to grassroots*

Legal form option 1

- *Structure of incorporated society*

Other

- *Not alone*
- *Expectations of malevolence – very important.*
- *Having this hui*
- *Like-minded conversations*
- *Balance Aotearoa seem to meet most of the attributes*
- *Tuakana/Teina: Find Teina services more than the Tuakana.*

Then the groups were asked to consider “what works well to meet the DPO attributes”

Legal form option 2

- *Charitable trust*

Collective voice

- *Driven by collective voice = accountability*
- *Lived experience mandate / mandate to represent*

Communication

- *Newsletter and communication*

Membership / engagement

- *Diversity of views*
- *Giving/getting regional voices/inputs. National advocacy issues with a regional take.*
- *Need to be connected to people who are accessing the services.*
- *Meaningful engagement*
- *Māori and whānau inclusive*
- *Totally membership driven*

Accountability and governance

- *Performance markers come from people accessing services/people with disabilities*
- *Depending on the constitution, could be a majority or minority “disabled” on board*
- *Accountability via a membership DPI Lived Experience network (Eg, 9D of the 2009 Disability Action Plan). Smaller groups work better.*

Other

- *2-National structure and focus – distributed.*
- *Does not preclude national status*
- *Good, solid structure*
- *Access to government officials*
- *Scalability*

Next, the groups considered “what are potential barriers or challenges”

Size

- *Regions can be very big and make membership disconnected*

Funding

- *Cost to bring people together*
- *Lack of funding.*

- *Challenge of procurement and competitive nature of funding, relationship management - relies on collaborative approach but contracted for competition.*
- *Scope of contract – limited in terms of resourcing/funding*
- *Not funded to gather/share information*
- *Funded for small pieces of work.*
- *Meeting fees*
- *Lack of funding brings creativity*
- *Inequities in funding for lived experience/peer voice and it shouldn't be pre-emptive.*

Technology

- *Need for technology where not always available*

Privilege

- *Only people with resources get into positions of influence*
- *Privilege*

Capacity

- *Trying to do work on top of own work.*
- *Financial constraints for meeting – Not funded for much of work.*
- *Lack of staff*
- *Skills invested in 1-2 people.*

Membership and representation

- *National entities could dominate in the regions*
- *Predominant culture/s voice the loudest.*
- *Individual regions too loose and different expectations*
- *Under-represented regionally – especially in the South Island. Large regions with few people to represent – limited connection at ground level.*
- *Person-centred networks*
- *Decision-making and equity*
- *Diversity of thought and representation – a membership who is largely 'white' or 'conservative' or 'straight' etc. might elect others like them consistently to roles in the executive team further marginalising the marginalised. Large membership across the nation could create barriers to hearing from members.*
- *Size and number of the groups to be consulted.*
- *Membership needs to make more of a contribution.*
- *We need to put trust in people to speak on our behalf and that gives privilege which is sometimes misused.*
- *People in rural communities are often excluded because of isolation.*

Relationships

- *Difficulty of gaining awareness within DHBs and council.*
- *Not strong relationships.*

Communication

- *Transparency / information sharing / getting information out to members*
- *Communication is key – Inwards/Outwards.*
- *Needing more constant contacts.*

Accountability and governance

- *Performance markers*
- *Risk of hijacking by interest groups*
- *Board vs Members.*

Purpose and mandate

- *Having the right purpose and function.*
- *Ad Hoc strategic planning.*
- *“Nothing about us without us”*
- *Need to have a mandate.*

Change

- *Succession planning becoming a challenge here.*
- *If moving roles risk that people lack skills to carry roles.*
- *Lose momentum if too much change – need continuity, new ways of thinking/ideas and youth*
- *Constant changes within the health system (Broadly) and contextual changes.*

Other

- *Single spokesperson for region and not including district-regions not holding national focus.*
- *Top driven could be “toxic” extreme ends*
- *If National body is colonised it loses its efficacy/integrity.*
- *Understanding structures, language and associated language.*
- *Are the government reports really by members?*
- *4-3 about surely.*
- *Collective/DPO – Obstruction/Dilution.*
- *Less Hui more Doee*
- *Exploration – Analysis – Action.*
- *Working with what we need because it is different from what we are required to do.*

Appendix C:
Group discussions about how to have input into a DPO, and how to stay informed.

This appendix includes notes made by groups during their discussions about how to have input into a DPO, and how to stay informed.

We have included some comments that we don't clearly understand so that we can seek further information about them.

The first question that the groups considered was what works well? Some items were mentioned more than once.

Meetings

- *Regular meetings*
- *Drop in meetings*
- *Meetings held in places that people know and trust (libraries)*
- *Individual or group options*
- *In person – investing time and thought into connection*
- *Via video link, zoom*
- *National lived experience hui*
- *Mini-meetings*

Support & access

- *A person explaining and simplifying a complex advocacy opportunity*
- *Teach people to use devices*
- *Not being made to feel dumb*
- *Plain language*

Written (often hardcopy) communication

- *Newspapers*
- *Newsletters*
- *Paper letters*

Phone-based

- *Text*
- *Phone calls / 0800 numbers*

Online

- *Email / Email with links to reports*
- *Social media, Facebook, Linkedin*
- *Websites / digital blogs*
- *Microsoft teams*
- *Web forums*
- *Hangouts*

Promotion

- *TV/radio advertising/promotion*

Surveys

- *Surveys / Marama*

Other

- *Smoke signals*
- *Doctor referrals*

Next, groups were asked what works well to meet the DPO attributes?

Two-way communication

- *Communication channels need to enable two-way communication. E.g. Peer network forum, Conversation Café.*
- *Need to enable enough time for genuine feedback.*

Listening to what people need

- *When people listen to what a person needs.*
- *Giving people time to share their needs and space.*
- *Gentle, regular reminders about barriers.*

Data collection

- *Data collection – Thematic analysis, DPO Coalition/Ministry networking from governance to outreach.*

Meetings

- *AGMs*
- *Zoom meetings.*

Other

- *Outreach.*
- *Newsletters.*
- *Safe environments.*
- *Collaboration.*
- *Partnership.*
- *'Space'*

Then, groups were asked to consider what are potential barriers or challenges?

Social media

- *Using social media when members/people hate social media!!*
- *Different social media reach different generations.*

Capacity

- *People to initiate the work.*
- *Staff resourcing.*
- *Capacity to do the work.*

Funding / resources

- *Access to resources.*
- *A need to resource peoples want in staying informed, barrier there's not enough resource to enable and empower people to stay connected.*
- *Financial resourcing and capacity.*

Communication

- *Alternative options of input and staying informed.*
- *Different people prefer different models of communication.*
- *Intellectual challenges/challenges of illness – Communication differences.*
- *Getting info out from the Peer Network forum.*

Digital divide

- *Bridging the digital divide.*
- *Not having the funds to pay for the means of communication.*
- *Technological access – Cellphone/PC/Tablet.*

Location

- *Locality.*
- *Geographical distance, isolation, coverage.*

Other

- *Connectivity.*
- *Navigation of Hub options.*
- *Willingness to engage.*
- *Lack of trust.*
- *Locus of control/power.*