



Kia whai tikanga te Kawenata ***Making the Convention Real***

Disability Matters Conference
26 – 29 November 2017

Report: overview of presentations
26 October 2018

University of Otago
Dunedin, New Zealand

The key theme from the conference is intersectionality between rights. During the conference, the following ideas kept coming up:

To fully access my potential, I need all my human rights working together to make my voice heard, give me choice and control, give me access to justice, give me inclusive education and the ability to educate others. I need to be healthy and to have access to healthcare systems that respect my rights and way of communicating, and when I have these things I will be participating fully in the community – culturally, economically, politically, legally, socially – as a rights-holding member of society.

Foreword

In November 2017 we invited people to meet us in Ōtepoti Dunedin, Aotearoa New Zealand. Together we learnt from those who have gone before us and those involved in disability matters.

We welcomed all who were on their journey towards making the United Nations Convention on the Rights of Persons with Disabilities (CRPD) matter: people with stories of their experiences, their family/whānau, advocates and support people; educators, practitioners, service providers, legal, business and community representatives; policy makers and government employees; researchers and students of any age.

We welcomed all who had an interest in, and commitment to, disability and social justice. The priority of this conference was to provide a forum for discussion of disability matters by a much wider range of participants than those typically involved in academic/research conferences.

Notes were taken throughout the conference so that we had a record of the important Convention-related issues affecting people's lives. Our idea was that by doing this the record could be used to help understand and challenge the way the Convention is brought to life in Aotearoa New Zealand.

The Convention needs to work in a way that respects the diversity of our country. Together we look to the Convention for tools that will help us navigate and enhance our lives. Collectively, we can make a difference for future generations.

The Committee expresses its thanks to those who attended the conference and those who took notes in the sessions. Particular thanks to Tom Barraclough for his work compiling this report. Finally, we would like to thank the New Zealand Law Foundation for their generous support of the conference and for providing a grant for the production of this conference summary.

Dr Gill Rutherford, (Chair)

Professor Leigh Hale

Dr Brigit Mirfin-Veitch

Ms Melissa Lethaby

Dr Denise Powell

Ms Barbara Fogarty-Perry

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Executive Summary

In November 2017, there was a conference in Dunedin, New Zealand. We talked about the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The conference had a theme. The theme was "Making the Convention Real - Kia Whai tikanga te Kawenata".

There were lots of people at the conference. The people at the conference had different experiences. People at the conference were people with disabilities, researchers, academics, support people, families and advocates.

We wanted this conference to be different and we challenged ourselves to write a report afterwards. The New Zealand Law Foundation has supported us to do this. During the conference, volunteers went to the presentations and made notes. We have put all those notes together. We read the notes and tried to understand parts of the Convention that were not real in people's lives.

This report is a summary. It does not replace the voices of people with disabilities. It does not represent the experiences of everybody at the conference. We are clear that when people want to understand the experiences of people with disabilities, they need to talk to people with disabilities.

The conference showed us that there are some very important issues that need to be examined by the United Nations Committee on the Rights of Persons with Disabilities.

The Convention requires nation-wide positive actions to support people with disabilities to access their rights. The Treaty of Waitangi requires the same. Agencies need funding to facilitate this access and to help people to exercise their rights.

High profile areas:

1. We need supported decision-making. It's time to change. This will be big and will require training of lots of people.
2. We need to change the Mental Health Act. There is not enough attention to keeping track of people with compulsory treatment orders. Our current systems do not result in us checking how people are doing often enough.
3. New Zealand needs to do better at consultation and hearing the voices of people with disabilities. Consultation has to happen all the time. Consultation has not been good enough in areas of accessibility, health, and education. Disabled Persons Organisations (DPOs) and the Independent Monitoring Coalition are not well-funded enough to do their jobs.
4. New Zealand needs to do better with the right to accessibility. This includes physical accessibility and access to interpreters, particularly in

healthcare settings. There have been missed opportunities in Christchurch while it is being rebuilt.

5. The right to health is not being realised for people with disabilities, particularly Māori with disabilities and women with disabilities. We need better training for medical professionals about the Convention. There is still inequality between different health systems in New Zealand. There needs to be better access to education, rehabilitation and training.
6. Support workers and family members need more support. The Government needs to recognise how important families can be as advocates for their children. Advocacy is important with all rights under the Convention, especially education and health.
7. New Zealand needs to do better for Māori under the CRPD. Policy has to reflect Māori ways of being, including the way Māori families live.
8. People with disabilities often do not have access to justice. Access to justice means getting everything you need to enforce your rights. There is not enough training about the rights of people with disabilities in the justice system. There needs to be wider access to lawyers and advocates who understand the Convention.
9. Many disabled children are not getting their right to education. All teacher education needs to have a focus on inclusion. Many teachers need to critically examine their values and beliefs re: 'special'/inclusive education, as well as have access to enough resources to be able to implement inclusive approaches that are responsive to all students. We need an enforceable right to inclusive education.
10. New Zealand has a big issue with housing and accessible housing. This undermines many other rights like the right to participation in the community, the right to choice and control, and the right to employment.
11. The New Zealand government needs to support better collection of data and research. DPOs need to be funded to keep data on how their members are doing. People are falling through the cracks. If we don't know they exist or that they are having problems then we cannot get access to resources to help them realise their rights.
12. People with high needs and complex needs feel totally alienated from the system. Their family members are finding it very difficult and they need more support. People with high needs don't have access to their rights under the Convention.

New Zealanders' rights under the Convention are all interconnected. For this reason, this report should be read as a whole. Different rights are woven throughout the report. New Zealand still needs to focus on some of the basic rights under the Convention like choice and control, accessibility, health, access to justice, culture, family and whānau, education and participation. These rights are essential for other rights to be realised.

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About this document

What is this document?

We hope this document can be a line in the sand for future advocacy and research.

During the conference, we asked volunteers to summarise key themes and conclusions that presenters spoke about. This document is intended to summarise their notes. We used a standard-form template with open and closed questions and we have included this in an appendix to the report.

At the opening of the conference, we told people and presenters that there would be volunteers doing their best to summarise the presentations and any key themes that came out of them. We also wrote this on the conference website.

Recorders were also asked to reflect audience contributions and discussions that occurred around the presentation itself. They were told that their job was to communicate conference participants' views as much as possible rather than their own impressions. Recorders did explicitly make comments about their own reflections on subject matter. We thought this was a good thing because it distanced their own perspective from the perspective being put forward at the conference. You can see an example of the template the recorders used in the appendix at the end of this report.

How is this document arranged?

We have tried to make this document reflect the Convention: everyone who presented has a right to be heard and they are important. This document should not be seen as creating a hierarchy between presenters. It is about communicating in the most effective way possible to amplify the voice of the community.

The chapters in the document each deal with a particular stream at the conference. Each stream included discussion of particular rights. But one of the most important points to come from the conference was that rights under the Convention are connected to each other. To fully access my potential, I need all my human rights working together to make my voice heard, give me choice and control, give me access to justice, give me inclusive education and the ability to educate others. I need to be healthy and to have access to healthcare systems that respect my rights and way of communicating, and when I have these things I will be participating fully in the community - culturally, economically, politically, legally, socially – as a rights-holding member of society.

Who does this document represent?

We did our best to capture the core subjects of the conference in a way that heard the voices of the people who shared their experiences. We also presented an oral summary of our conclusions at the closing of the conference.

The document is a summary. We are aware that it will not capture all the important details discussed in the conference sessions by the presenters and audience participants. We cannot speak for them: we can only do our best to record what we understood. We have had to make decisions about what we could communicate in this report and what material would be left to the community who attended the conference to take forward into their CRPD advocacy.

But we especially wanted to capture things that people said were urgent. We wanted to hear how people were making the Convention real in their lives to inspire others and give them a way to advocate for their own rights and the rights of others.

We hope that this document will inspire and reassure you that voices in the disability community are being heard. There were so many presentations that demonstrated ways to amplify the voices of disabled people so that their rights could be respected.

We apologise in advance for any misunderstanding or inaccurate representation. This document is meant to be a point from which the wider community can move forward and advocate on its own behalf about the New Zealand government's compliance with the CRPD. We encourage readers to reach out to presenters directly to hear their experiences and refer you to the conference book for those details.

Reporting context: how to advocate

Keynote: Professor Ron McCallum, special rapporteur for New Zealand

Professor McCallum spoke from his experience as a special rapporteur - the UN Committee's representative for the dialogue with New Zealand in 2014. His presentation talked about the most effective way of communicating breaches of the Convention to the UN Committee through the shadow report process. He said:

1. State the problem as clearly and simply as you can using plain language.
2. Show how it is affecting people's lived experiences.

3. If possible, refer to data/empirical basis (but don't recreate this empirical basis in the report itself).
4. Give a solution about how you want it to be fixed.
5. Work together with other Disabled Persons Organisations (DPOs).
6. Keep it as brief as possible.

He encouraged us to look at the way that Australia had reported to the Committee (including on the National Disability Insurance Scheme (NDIS)) and the questions that the Committee had asked Australia in response. The questions from the Committee to Australia are the best guide to what the Committee is likely to ask New Zealand. The list of questions put to Australia are "right on the button" and are a good example. Australia responded in July 2017.

Tips on shadow reporting

Shadow reports are a key way to make the Convention real by facilitating input by persons with disabilities into country reporting processes. They are a confusing process and it's important to be strategic about getting what you want. Professor McCallum noted:

1. The need for brevity and concision in reporting.
2. That Committee members are not paid!
3. Be clear about what you want the discussion between the Committee and New Zealand to be about.
4. From the Committee's perspective, New Zealand isn't a problem
5. Prioritise increased use of indicators, including using the Sustainable Development Goals.
6. The Committee's processes are evolving and dialogues are becoming more interesting. The Committee has adopted a new simplified reporting process. The Committee will give its list of issues. They were released in March. The New Zealand Government will have six or seven months to reply. Shadow reports are done on the list of issues.

Professor McCallum had some other reflections on the process. He asked, why does every member of the Committee have to have a disability? Why don't we broaden the Committee and bring in other expertise? He said we have never had a parent of a child with a disability on the committee for example. He also didn't want the Committee to be the only voice on disability. He wanted there to be people with disabilities on all UN Committees to educate the UN on disability rights.

He said the Committee does interesting work but the hard work in response has to come from the Government.

Professor Mark Henaghan, Dean of Law at Otago Law Faculty: tips from watching Ngāi Tahu

Opening remarks at the conference were made by Professor Mark Henaghan. He talked about how to get Choice and Control by referring to seven "Rules of Influence" that he had seen Ngāi Tahu use in achieving their settlement under the Treaty of Waitangi with the Crown.

1. Be one of "us", not one of "them". We're all New Zealanders and we all have to move forward together.
2. Be persistent. He noted the conference had grown since last time.
3. Be consistent. Stay on message. The UNCRPD provides the key message.
4. Be unanimous. Everyone's got to be on board. That's why we have conferences.
5. Be flexible. Say the right thing at the right time. Adjust the message to the circumstances. Communicate in different ways with different people. Tune into their way of thinking so they can understand what you're saying.
6. Make the subjective objective. Objective evidence is the most powerful weapon. "Here's the facts". David Lepofsky gave a talk at Otago showing a video of a building that was meant to be accessible, but had no people with disabilities included in designing it.
7. Don't expect immediate influence. Celebrate every small victory. The world will not change overnight. People want to do the right thing. It just takes time.

Keynote: Robert Martin (United Nations Committee on the Rights of Persons with Disabilities) and Paul Gibson (former New Zealand Disability Rights Commissioner)

Robert Martin and Paul Gibson highlighted that well-meaning law changes are one thing, but unless they go along with attitude changes they'll be paid lip service and repealed after the next change of government. Redressing past wrongs is uncomfortable for those who benefit from their predecessors' wrongdoings. They won't do it willingly without being convinced.

Robert and Paul also reminded us that many people with intellectual disabilities are still invisible and still locked away in institutions in New Zealand and other countries.

They identified some key articles to focus on:

1. Article 8 is about having good information.
2. The heart and soul of the Convention is Article 12, supported decision-making.

3. Another good one is Article 19, living in the community and choosing who I want to live with. So often, even today, people with the highest needs don't get to choose whom they live with, and to me it should be a given that they do have a choice.
4. Health, Article 25, we know people with learning disabilities die earlier than other people of their country.
5. Article 30 is about cultural recreation and sporting.

From Robert and Paul's perspective, big issues in the disability system currently are:

1. Inclusive education.
2. Transformation of the support system was a big issue and New Zealand needs to catch up with the conversations Australia has been having.
3. Work around New Zealand Sign Language: celebrating the concept of Disability Pride, which was growing across the community, led by the Deaf community.
4. Psychosocial disabilities: we are not a great role model in many of these areas. We have one of the world's highest suicide rates.
5. Bioethical issues are the most complex such as non-consensual sterilization and the Ashleigh treatment. End-of-life issues will be in the news before too long. There are countries where 100% of Down Syndrome pregnancies are terminated. Robert and Paul shared a story about a young woman with Down Syndrome saying that "special schools", which many people thought were a great idea, was actually apartheid. And the government official who was taking notes struggled to spell "apartheid" and she spelt it confidently for him.

A key issue is going to be the inquiry into historic abuse. That needs to include what happened in psychiatric facilities and institutions around New Zealand over the years. It should also include compensation.

Paula Tesoriero: New Zealand Disability Rights Commissioner

How Paula intends to work as Disability Rights Commissioner

Paula Tesoriero talked about identity not despite, but because of disability. She planned to focus on attitudinal shifts. She noted the power of social media and the fact that change doesn't have to take generations any more. She emphasised the opportunities to work with new Ministers, and the strong emphasis on co-design processes through which people with disabilities could have input.

Paula said she wants to be collaborative. She will raise red flags, but only on serious issues. She emphasised the need to be strategic. She wanted to see the community unify around key things.

She stated that she wants to encourage strong and supportive criticism of her in her role.

Priorities as Commissioner

Paula stated her top priorities as Commissioner are education and employment.

1. Education. 42% of disabled young people are not in employment, education, or training. Our education system must be more inclusive. She wants a systemic comprehensive look - not at what's wrong, but at what needs to be done. She said we cannot afford another generation where nearly half of the young people are not in education, training, or employment.
2. Employment. 25% of disabled people participate in the labour force, compared to 75% of non-disabled people. That gap is too big.

Paula said there are some other foundational things we need to shift.

3. She said attitudes are the bedrock that a lot of other issues can arise from as symptoms. Unless we change the hearts and minds of New Zealanders, we won't see a shift around disability. She believes we're at a time where we can run a social campaign for change, with tools we've never had before.
4. She wanted to support a strong disability sector. She had thought hard about what her role is in this: what is her leadership function. She concluded that part of her success in her role depends on the sector being strong, credible, representative and robust. She encouraged the sector to challenge ourselves. Are we as strong and organized as we need to be? She said she was not hearing loudly enough the voices of young disabled New Zealanders, of Māori and Pasifika. She said she'd gone out and tried to hear these voices. But she asked whether we were being as representative as we need to be. Will we make sure that we're not talking within ourselves, that we are talking up and out?
5. Her final priority relates to data. She said there are large gaps - what can't be counted can lead to unintended consequences. So she's building a programme of work in conjunction with a range of other organizations around those priorities.

Choice and control

Attitudes, human rights and Disability Pride

People with disabilities have their identities shaped and controlled by others. Disability pride is an opportunity to have groups of disabled people self-identify and talk about our own identities as we see them.

Research conducted after Disability Pride week showed people felt positive about the way they could communicate their identity. It was a good opportunity to have a conversation within the disability community too about what it means to identify as a person with a disability. This is a good way to generate unity within the disability community given there can be matters of disagreement or competition when it comes to access to funding and control.

Disability identity is a fluid concept and it can change, move and evolve throughout a person's life. It is important people are supported to develop their own identity in a way that is consistent with their experience.

In a similar way, definitions and the way that the Convention is understood in context are being constantly reconsidered and disabled people have to have a say in these discussions. Being an organised group can help with this as well as finding ways to resolve disagreements within the group effectively.

Disability Pride Week let people with disabilities communicate disability identity and experience through public events, public art, and discussions about disability experience in specific ways - for example what it is like to live in Wellington as a disabled citizen.

Public events attract attention to the Convention and a human rights approach. They are important for normalising and celebrating important things like New Zealand Sign Language (NZSL) and encouraging people to take an interest in those things. They are also important for drawing attention to groups within the disability community who are not being heard: for example one audience participant drew attention to the need to include people who use tactile sign language, which blind people can use.

Presenters also illustrated the important reforms that could be achieved across a range of human rights areas through working together as a community. Deaf Action talked about their experience in working towards wider use of visual fire alarms based on members' scary experiences in being the only person left in the building when everybody else had evacuated. They have also organised to work towards District Health Boards (DHB) having 24-7 access to NZSL interpreters so that they can retain choice and control over treatment in emergency healthcare situations.

We will always need to protest and advocate, but we need to celebrate our identity too. It is vital that adequate resources are put aside for this important purpose.

The "My Rights" programme came about through another programme in mainstream intermediate school classes (around ages 12 and 13), because of a need to do something for young disabled people. The speaker had observed a lot of young people's struggle with identity and confidence, and also a number of things that challenged identity in their own teenage years. The conversation went from trying to convince others about the rights of "disabled people", to talking about "our rights". The facilitators were all disabled themselves. Because participants and facilitators are talking about "us", and not a group of people you probably don't identify with, My Rights created a space for young people to come together, learn about rights, and connect with each other. A young person found that hearing the stories of others helped to strengthen their own identity. One participant socialised with her peers quite well, but froze in a group situation. She was asked if she wanted to say something to the facilitator, who offered to relay it to the group. In most situations, she wouldn't get the opportunity to talk if she wanted to and the programme enabled this. Some whānau members only know their Deaf culture, and are isolated from Māori culture, and this is a barrier to participation and access to rights. Conversations flowing from the programme about disability rights might not be easy for parents, because their kids chose to change schools, or asked about housing, because they had learnt about their rights. It's not easy to discover such things if you didn't realise your rights before, but this is totally about choice and control and putting it in the hands of disabled people rather than others around them.

Keeping on talking about what the right to choice and control means

Having a strong and diverse disability community that can unify on important issues is important for continuing the discussion about what the right to choice and control means to different people. Presenters from the Deaf and Māori communities illustrated how communicating and exercising the right to choice and control meant taking into account a person's place in a wider community as well as an individual's will and preference. NZSL is an important tool for a wide range of people who communicate in ways other than spoken language.

Presenters emphasised that we have to constantly consider how we are talking about rights, how we classify them or give them importance, how we understand terms like choice, independence and agency. There is a risk, for example, that human rights access becomes determined by market structures that do not facilitate full accessibility for disabled people. This was a big concern when it came to access to housing. It also had significant effects for Māori living in urban areas where access to support services was difficult.

There was also a risk that Western Eurocentric concepts of "human rights" as rights against the Government dominates in a way that ignores the essential interdependence of humans in a community. There is a risk that human rights could be "read down", for example, by providing "choice" without taking responsibility for positive outcomes. There was a strong emphasis on the way

that individualistic conceptions of rights can exclude non-Western cultures like Te Ao Māori that place a high value on interconnection, community and interdependence.

Rights are interdependent and choice and control has flow-on effects

Choice and control affects access to a wide range of other human rights. Presenters emphasised that access to rights is often interdependent: without choice and control my right to housing is limited; without access to housing, my right to participation in the community is limited, which affects my ability to access my culture, to be educated and make my own decisions. Similarly, choice and control relies on being given access to means of communicating my decisions, including through te reo or NZSL.

Presenters focused on the ability to access housing in a choice and control context. This illustrated the limitations of choice and control when access to other human rights was limited. A right to housing and a safe living environment is not much good if there are no houses that meet my needs or my family's needs. There will be increased competition for accessible housing as the population ages. Housing affordability and availability are big issues but poor quality housing also puts a strain on people's physical and mental wellbeing. If you have to move frequently that affects access to other facilities and services, including ability to connect socially and participate in the community. An absence of appropriate housing makes it harder for young people to leave home and be independent.

There is a wider issue than just accessibility to a person's own home: access to other people's houses can also be impossible, which perpetuates exclusion from the community.

Lived experience of substituted decision-making

Presenters spoke about their personal experience being subject to substituted decision-making models and how that made them feel: people in residential care felt trapped.

One presenter spoke about his experience of being in residential care subject to a substituted decision-making model. It made him feel like an ordinary life was a privilege he had to earn. He had always wanted to live in his own home and didn't understand why it was so hard to let him be brave and leave the residence. He wondered who had authority to tell him who he is and felt he had to keep his real hopes secret. Because he was constantly monitored, he felt powerless. He was never actively involved in decisions being made about him. His own expectations of himself were limited by the way his living arrangements made him see himself. People only ever talked about risks, not possibilities.

He now lives in a home he chose himself. He feels free. His flat is near his family and his new group of friends. He has had to learn to do a lot of new things because previously people did these things for him. He found that talking to other people as "sounding boards" was very helpful. This let him become more confident in articulating what he wanted and how he was thinking.

Things that made a difference in his life were:

1. See and acting in a disability-rights way based on self-advocacy and rights-based education.
2. Being free to move to build networks of people and places of belonging.
3. Understanding "inclusion" to mean listening properly to people's ideas.
4. Encouraging and valuing people's creativity including giving him a space to say things that were important to him.
5. Meeting people who believed he could choose his own path.

Issues to overcome when moving from substituted decision-making to supported decision-making

It is important to move away from supported decision making to an approach based on a person's will and preference. Before article 12 of the Convention – and under New Zealand's substituted decision-making regimes – mental capacity was seen as binary: either you had it or not. If not, substituted decision-making was employed. The Convention challenges this traditional way of looking at capacity. It says that everyone is equal before the law.

Presentations illustrated how article 12 and supported decision-making models were being applied in Ireland, Cyprus, Australia, New Zealand and America.

Equal recognition has been denied to many people with disabilities. They are subjected to guardianship and mental health legislation (substituted decision-making) and they are unable to make important decisions about themselves. They can't participate fully and enjoy the rights stated in the Convention.

While not ideal, Ireland was seen as a positive model that was putting section 12 of the Convention into practice. While the legislation there has shortcomings, it is a useful precedent for New Zealand to adopt. The Irish legislation took a strong coalition of groups to get it passed. Old models focused on protection and new models need to look at protection of rights of people with disabilities.

We heard about the issues caused by translating words and concepts between cultures and languages. The Convention represents a new way of thinking about disability that is even harder to communicate across cultural and linguistic barriers. Article 12 can still be applied and interpreted narrowly. It shouldn't be.

We heard about some of the difficulties faced in other countries putting article 12 into practice including:

1. Access to self-directed funding was affected by personal characteristics, including where people live (geographic location), current living arrangements (e.g., with parent or relative), their age, the nature of their disability, and their ability to communicate verbally.
2. For some people, the shift from substituted to supported models was scary because it involved much more responsibility.
3. Difficulty recruiting a support person.
4. Finding a support person who could be trusted and was flexible and responsive to the person's needs. People with disabilities wanted to feel heard on their decisions.
5. Training on financial literacy and on what a support person should be doing needs to be provided to both the support person and the person being supported.
6. Some of the support people required an attitude change to meet the requirements of article 12.
7. There was anxiety around conflicts of interest between support people and the person being supported, particularly if the support person was a family member.
8. There were questions around risk and decision-making and how this should be accounted for.
9. There was a need for the support person to act as an advocate at times when dealing with others such as trustees who wanted to make decisions about the person's life and finances.

There needs to be a shift in how psychiatrists consider mental health legislation and a patient's ability to make decisions. They need to be less paternalistic. They don't listen to what we have to say and don't really let us become part of the dialogue.

Mental health legislation is not consistent with the Convention/human rights and stigmas (social, self and institutional stigma).

High priority issues

Housing

A significant part of choice and control is choosing who you live with and where you live. Housing affordability and accessibility for people with disabilities has flow on effects for access to other rights, including employment and participation in the community. High cost of housing and inability to participate in employment leads to poverty which leads to wider effects on people with disabilities and their families.

We need better housing data. It lacks demographic specificity. Disability should be a lens applied to all housing data within a holistic housing strategy

for New Zealand that goes beyond just the house that a disabled person lives in - an ageing population will increase demand for accessible housing.

There has to be real care taken that communal housing options do not undermine a person's choice and control.

Legislative amendment is required to make sure service animals are not excluded from rental housing.

Access to the right to choice and control is affected by the nature of a person's impairment and we need better impairment-specific qualitative and quantitative data on the experiences of people with intellectual disabilities.

Repeal of Mental Health Act and substituted decision-making

We must abolish mental health legislation and replace with capacity legislation on a rights-based supported decision-making model.

We need to talk to people in residential care and subject to substituted decision-making and ask them how they feel about the situation they are in.

Children under the Child Youth and Family Act don't have access to legal counsel, a social worker or independent advocacy. This undermines their choice and control.

There is no publicly funded independent advocacy service for people with intellectual impairment in New Zealand.

Before any legal capacity test is implemented, we must provide support to individuals to make a decision about whether they want their capacity to be tested.

Appropriate and effective safeguards are required to protect people against conflict of interest and abuse in supported and substituted decision-making models. The individual's will and preference needs to be ascertained. If it is consistent with their will and preference, then their capacity should be tested. Both people with disabilities and their support people need access to training on a rights-based choice and control framework and on financial literacy.

Greater participation of family, carers and talking to clinicians within a choice and control model.

Support for NZSL and for disability community to self-identify

NZSL needs to be celebrated and normalised in a similar way to te reo Māori because it helps many people with communication difficulties. Speech is one of the three main impairments experienced by children with disabilities.

It is important that people with disabilities continue to have a say as a community in what it means to identify as a person with a disability and how the Convention is being applied. There is a risk that rights-based structures or market-based solutions do not facilitate real access and overlook the interdependence inherent in the community.

ACCESS TO JUSTICE

Any legislation is ineffective unless it is also enforceable.

The access to justice presentations focused on legal mechanisms for giving effect to other rights, such as choice and control. They focused on the Disability Strategy, the monitoring process, the role and experiences of DPOs, and the shadow reporting process to the Committee. There was also a strong theme around the training being provided and available to participants in the justice process.

What does "access to justice" mean?

Different people have different understandings of what access to justice means. That can be a problem because it can mean criticisms and solutions do not line up. The right to access to justice is about more than just equality before the law. It's about facilitating your right to access justice.

Access to justice relates to justice in the Courts as well as justice outside the courts. Many legal institutions make decisions about people's rights that do not wind up in the Courts. It includes Parliament, consultation processes, law-making processes and complaints about breaches of your rights that don't wind up in Court, for example to the Ombudsman or the Privacy Commissioner. You need to have access to the things you need to enforce your legal rights: that can mean funding for lawyers, access to lawyers who understand the Convention, access to experts and respect for your will and preference in engaging with those processes.

Access to justice has bigger impacts on those that are already more vulnerable and marginalised facing intersecting forms of disadvantage. Access to justice is fundamental for people to exercise and enforce their other legal rights and rights under the Convention. In particular, there is a real problem with access to justice and the enforcement of article 12 issues of choice and control.

Article 13 is broader than just traditional notions of access. It means getting access to fair processes, the resourcing to participate in those processes, and a fair outcome. It includes procedural issues, accommodations, and steps to ensure active participation in the process. It also specifically requires effective training of individuals working within the justice system. DPOs should be given a prominent role in this training and monitoring process.

People with disabilities have to be part of the conversation to decide what access to justice means because they have to have a say on how the law is interpreted and applied.

Implementing the Convention through the Disability Strategy

The conference heard about the history and process involved in the creation of the Disability Strategy, outcomes framework and action plan. The Strategy is intended to reflect articles 3-7 of the CRPD by developing principles and approaches that feed into the Office for Disability Issues (ODI) Strategy. Eight "outcome domains" were drawn from the most important areas arising from consultation with disabled people. There are accessible copies of the Strategy available and it is considered world-leading in terms of co-design and co-governance.

A significant limitation of the Disability Strategy in the past was that there was no accountability measures for non-compliance with it by the Government. There were also no indicators or outcome measures to hold the government accountable for progress.

Consultation and co-design around the Disability Strategy

A fundamental requirement of the Convention is that people affected by policies help to design them. There are thirteen attributes of a disabled persons' organisation that were developed by DPOs to assess whether an organisation can represent a particular body of people. DPOs represent their members as well as working collectively for disabled people. The Special Rapporteur commended this approach in the past.

DPOs formed a coalition that is intended to work with an independent monitoring mechanism comprised of government agencies like the Ombudsman and the Office of Disability Issues. They also have a privileged role in reporting to the Committee on the Rights of Persons with Disabilities.

The ODI has tried to go wider than just the DPO coalition and convened a reference group to go wider. It has been criticised in the past for excluding some DPOs from consultation. Some groups were entirely omitted from the Disability Strategy.

The ODI is effectively about eight people responsible for reaching across all of government. This limits their ability to fulfil their purpose.

The working relationship between ODI and DPOs is not perfect. There are some risks of working with government as well as opportunities. There are also risks of how DPOs and the ODI are perceived by the community. This also affects ability to work together and the process to be followed.

Funding for DPOS and outcomes monitoring is poor in relation to the Disability Strategy

Despite this working relationship, DPOs are severely limited in their ability to exercise their functions by a lack of funding and resourcing. Resourcing for

DPOs was described as being poor. As well, there is a huge volume of work for what are quite small organisations.

There are also significant risks to DPOs if they aren't funded to properly monitor the Government's adherence to the Strategy, the Convention and the outcomes produced. It is vital that DPOs have enough funding to represent the disabled community, otherwise they will be perceived as having been captured by their relationship with government. This in turn will undermine consultation and co-funding, as well as the legitimacy of the Strategy. Funding is particularly vital for monitoring whether the Government has complied with the Committee's concluding observation from the previous session.

There isn't enough funding directed to one of the core goals of the Convention and DPO arrangement, which is to see disabled researchers doing disability research with disabled people to generate an evidence base for reform. This is particularly significant given one of the key functions of DPOs is to conduct research to monitor the Government's compliance with the Convention and its implementation of the Strategy. This also undermines DPOs ability to monitor the outcomes of the Strategy which is fundamental to its success.

This lack of resourcing has contributed to some groups of people with disabilities not being represented, notably Pasifika people with disabilities.

Concern about Cost Benefit Analysis and Social Investment

One presentation focused on concerns about "social investment" approaches followed by the Government based on predicted life course and maximum financial return for resource expenditure. These are based on cost benefit analyses that are inconsistent with the rights of people with disabilities and the need to help the most vulnerable people. If you allocate funding solely based on what works, you can end up disadvantaging people for things that are out of their control. There is a lot of prejudice, discrimination, bias around who can work and who cannot. If you have a greater need for support, you should get more support, rather than targeting support for people who are likely to get a better outcome for an agreed period of time. Say you have two groups, and you have one where you have a good cost-benefit ratio, and for the other you have a negative cost-benefit ratio. If you go only with what works, you would only fund one group. But this feels like you are punishing people for something that is not their fault (that you don't know how to support them as well as the other group). Is support about making the most difference, or about helping the most disadvantaged? Cost-benefit analysis is too narrow and clashes with the Convention.

The Shadow Reporting process

Acclaim Otago, a DPO for people with disability caused by injury, shared their experience of making a shadow report to the UN Committee. In 2011, their concerns were ignored in the ODI's initial report. They were concerned about

a lack of attention to the CRPD in the Accident Compensation Corporation (ACC) system. As a DPO, they had the following advice for getting the most out of the shadow report process:

1. The Committee can only process a small amount of information. Make your shadow report as simple, short and specific as possible.
2. Try to achieve one very specific question from the Committee on a particular issue as a result of your shadow report.
3. Survey Monkey can be a good tool for capturing people's voices and illustrating people's experiences
4. Harness the support of a wide range of other stakeholder organisations in your report to demonstrate widespread experience of the issue

Acclaim got a shadow report award from an NGO (The New Zealand Law Foundation). While this was vital, it was only enough to cover minimum costs and there should be more government support for this process.

Change requires using a wide range of tools. Don't limit yourself to legal tools: use politics and the media too. Human rights can be a very powerful tool for embarrassing the Government. The Government is held to a very high standard by the UN Committee.

Lived experience people with high needs being deprived of access to justice

We heard presentations from family members about the lived experience of advocating for their children. These were very important and illustrated how the rights of the Convention are interdependent and intersecting and cut across education, health, the right to live in the community, support for whānau, choice and control, communication, housing, transport and mobility and access to justice. Negative experiences that people had with medical professionals had stayed with them their whole lives. It is important to note that parents are often interpreters for their kids that play an important role in access rights and justice. It was very important to keep asking how high level changes were affecting the lives of individuals and how individual people with disabilities would feel about the decisions being made about them if they could be explained to them in ways that are accessible and meaningful to them. The most important thing is making sure that people's voices are heard and that we learn from their experiences so they do not have to happen again. Audience members at the conference said that these experiences were not unusual in New Zealand.

As an example, one presentation focused on the continued detention of Ashley Peacock. His experiences raised issues around choice and control, institutionalisation, access to justice, right to family and to live in the community, access to health, including articles 12, 13, 23, 25, 29 and 30. It required huge time and effort to get public attention to the injustice of his experience. Ashley was restrained, subject to seclusion and heavy medication, suffered violence and abuse including fracture injuries, was

denied access to facilities and urgent dental treatment, personal possessions and relationships. His situation was a result of misunderstanding of his disability and behaviour. Tools used included Facebook groups and grass-roots organising, use of social media, the Human Rights Commission being involved to help with expert evidence, using petitions, litigation under New Zealand's Bill of Rights Act 1990, a failed complaint through the Health and Disability Commissioner against the DHB's conduct. The CRPD "may as well not exist" and the High Court praised the medical professionals involved in Ashley's experiences. Ashley had only one witness whereas the Government had a huge number of expert witnesses. There was a huge flood of cases once Ashley's case was publicised. There is no real coordination or research into how many cases like Ashley's there are. There is a real problem with access to the optional protocol because of the financial burden of going through so many legal processes.

People's experience of the Court process

Presenters discussed their research about people with disabilities' experience of the Court process. People with intellectual or learning disabilities responding to the researchers' survey:

1. Wanted to feel like others in the process knew about them and heard their story.
2. Wanted to be at the centre of all legal decision-making and representation.
3. Needed a plain language format.
4. Wanted to learn from people who had similar experiences.
5. Need more accessible ways to get legal aid and better access.
6. Needed to interact with people who understood learning disabilities at the time they were arrested.
7. Had other accessibility issues.

Lawyers who responded to the survey:

1. Were lawyers who already wanted to talk about access to justice for people with learning disabilities, so might not represent the rest of the legal profession.
2. Wanted access and support from disability specialists who could help people.
3. Wanted to know early on about a person's disability and what was required to provide them with support.
4. Needed better access to disability related content to help them advocate effectively.
5. Wanted better education for judges and police.
6. Wanted better access to restorative justice processes and legal aid.
7. Wanted more systematic responses to people's experience of access to justice.

Judges who responded to the survey:

1. Wanted early identification of a person's learning disability and their needs.
2. Wanted to understand the person's experience in the past and currently.
3. Were concerned about systemic issues that affected people's experience of access to justice and led to their experience in the system.
4. Were interested in reviewing courtroom attire and dress codes and architecture to the extent this would facilitate access to justice.

It was interesting that various people surveyed with different roles had similar strategies and recommendations for providing access to justice. Judges still need to have specific training in the Convention on the Rights of Persons with Disabilities. For the last three years there has been some training through the Institute of Judicial Studies and a sexual violence court pilot that has included training about responsive practice with people with disabilities. An online resource of best practice guidelines for lawyers is under development.

Difficulty of using legal processes to enforce the Convention

There were a number of presentations aimed at understanding people's experiences of justice processes and breaches of the Convention. There were also presentations about specific changes to justice processes that had been made through research and advocacy. People need knowledge in order to be effective and self-reliant. There is a tendency to assume that someone with an intellectual disability is incapable of self-expression, but with the right accommodations and support, they can express their needs quite well.

The conference heard a presentation about Kia Noho Rangatira Ai Tātou. This programme is a series of workshops delivered by disabled people designed to increase knowledge of the Convention among people who do not have previous experience or knowledge of it. 18 workshops had been run at the time of the conference. Day 1 focuses on the principles underlying the Convention and breaches experienced or observed by participants. Day 2 focuses on creating action plans for people with disabilities and their supporters to address breaches of the Convention in their lives. Surveys showed that people left these workshops feeling much more confident about their knowledge of the CRPD. Workshops were conducted with people with disabilities and people who support them. The workshops resulted in reports of a wide range of very serious breaches. Breaches were especially bad for people with learning disabilities. Issues raised at the workshops by participants included:

1. Inequity between health and disability systems and the ACC system.
2. There were many examples of breaches such as physical and chemical restraint, which are degrading practices associated with institutions in the past.

3. There were issues with homelessness as well as the right to live independently in the community; questioned whether people are going back to living in institutions (cluster of 11 people in the same site is not quite a home).
4. Some schools are also practicing seclusion (which feels similar to solitary confinement).
5. The right to have sexual relationships including same sex relationships.
6. The barriers faced by people with mental health and learning disabilities versus other impairment groups.
7. People focused on awareness training - that lack of awareness by state agencies.
8. A lot of breaches around accessibility - transportation, public spaces, information, advocacy services.
9. Substituted decision making common practice supported decision making often challenged by families, health practitioners, legal/financial authorities.
10. Noted that breaches of articles 15 and 16 (relating to safety) do occur in New Zealand - there were many examples of breaches that people were aware of e.g., seclusion and restraint, chemical restraint, physical abuse by staff, bullying by staff.
11. Article 16 - family violence, sexual abuse, financial exploitation by families.
12. Living independently in the community was a huge topic of debate: lack of resources, vans, staff to assist no choice re: housing and so on.
13. Education: full inclusion was seen as a myth, denied access to local schools, unequal access to quality and inclusive education, time out rooms and seclusion as punishment, 'difficult' behaviour means disciplinary process, lack of support for tertiary education.
14. Work and employment: low employment rate, stigma, discrimination and inaccessibility, lack of reasonable accommodation, lack of disabled chief executives and senior level managers, lack of professional development, minimum wages exemptions.

There was a shared perception that there is a need for education on the CRPD to be given to a wide range of groups, including: disability provider organisations, families and whānau, funders and planners, Ministry contract holders, Ministry of Social Development (MSD) policy-makers & staff, employers (public & private sectors), health practitioners, police judicial staff, lawyers, judges, Boards of Trustees, and media.

Accessibility, communication and access to justice

Representatives of People First gave a presentation about Easy Read and their translation service (called "Make It Easy"). They have produced some of the first Easy Read employment agreements and done 71 translations including legal documents to help people engage a lawyer. Easy Read can be used to make information easy for people with learning disabilities to understand. It is also good for those with English as a second language. Easy Read has one idea a sentence, hardly any punctuation, lots of white space, pictures for just about every sentence. In Easy Read they explain hard ideas.

Easy Read is an accessible format like Braille or signing but less people have heard about Easy Read or understand what it is - People First are making sure that everybody knows what Easy Read is. Easy Read is being used as a way to walk the talk of the Convention. Easy Read is a 'reasonable accommodation', which is a term used in the Convention - so that disabled people can have the same freedoms as non-disabled people. Knowledge is power - if you cannot read and understand information, then it's hard to stand up for yourself. Easy Read is very important as a tool under article 12 for choice and control, and article 25 for accessing health and health care rights. There is a need for government departments to make better use of Easy Read formats to help people access services and understand their rights under the Convention on the Rights of People with Disabilities. People First is working with Blind Citizens NZ to develop accessible information, websites and services.

The participation of children

The process of interviewing children with disabilities is difficult because it is very important to help a child give the most accurate, complete and reliable version of their story. It is very important that their stories aren't ignored just because the interview process doesn't meet their needs. Children with disabilities can be disadvantaged if interviewers are following interview models that don't give guidance on how to make reasonable accommodations. Presenters discussed how these reasonable accommodations had been made after their research and led to practical training for interviewers. Reasonable accommodations included asking the child some questions to make sure the process works for them and use of a flow chart that shows the whole question process to make them feel more comfortable. The presenters' research had been made available to police at all levels.

People with disabilities conducting research

One presenter talked about the difficulties she had faced in getting University research ethics committees to respect the choice and control rights of people with learning disabilities. The Committee believed that people could not keep information confidential and couldn't be researchers. They thought the co-researchers were the research subjects rather than the researchers. There was a need for better education of participants in ethics committees, and better representation of people with disabilities on those committees.

Rights of refugees with disabilities

Presenters discussed the experiences of refugees with disabilities. New Zealand is party to both the 1951 Convention relating to the status of Refugees and its 1967 Protocol. The New Zealand Government's quota allows 75 places for refugees with disabilities but these are not always filled or accepted. War produces impairments for people as well as making the experiences of people with disabilities who are already marginalised much

worse. Refugees are selected based on their perceived value to society and this standard is applied in a discriminatory way against people with disabilities. There is a lack of recognition of how people with disabilities are affected by war and conflict. This absence of research into the experience of people with disabilities in peace and conflict studies is an example of discrimination and direct, cultural and structural violence facing the disability community. There is a need to counter this with better research methodologies that are inclusive and put the onus on the government to examine what steps it is taking to prevent discrimination. It is important that disabled people are not just treated as vulnerable subjects but also treated as active participants through such methodologies.

Co-designing accessibility legislation

New Zealand needs to move towards mandatory, enforceable accessibility legislation and Access Alliance is working towards an evidence based proposal. The legislation needs to be developed with the disability community and the Government to apply to public and private sector. Accessibility must be about accessing communities, communication and information. They have worked towards an evidence base to persuade the government to adopt accessibility legislation, including economic research quantifying benefits to Government and examining approaches in Canada, UK, Australia, Israel and Singapore. The Access Alliance also worked on securing commitments from political parties prior to the election and had good success with this approach. The Access Alliance came together around 13 principles that the legislation would be built on but want to engage further with the community. They are focused on engagement with DPOs and unity towards legislation by 2019.

High priority issues

The Government is not providing access to justice in New Zealand in the way it is meant to be done under the Convention. There is not enough access to supports for people with disabilities to enforce their legal rights.

The systems for providing healthcare, social support, financial support and rehabilitation in New Zealand discriminate based on the cause of disability which is inconsistent with the Convention and creates legal disputes against Government agencies. This is part of a wider fragmentation of social services and funding streams that undermines access to rights and services. Access to funding, and difficulty of meeting criteria - "arbitrary inconsistent criteria" – and other systemic barriers

Judges and others in the justice system need specific training in the CRPD and in particular what article 13 means because it is not understood properly.

Communication in justice processes and consultation

There is a shortage of counsellors and psychologists who know how to communicate with adults and children with intellectual disabilities.

Consultation is still not adequate for legal reform in relation to disability rights and people's experiences of the justice system.

Mental Health Act and access to justice

Continued institutionalisation in New Zealand occurs under the Mental Health (Compulsory Assessment and Treatment) Act including the use of restraint and seclusion. There is a catch-all diagnosis of 'mental disorder'. People are locked up without being convicted of an offence. There needs to be better access to justice for people detained under the Mental Health Act.

There is lack of transparency around how many people are detained under the MHA and the arrangements for their care.

Access to justice and right to education

There is an increasing misuse of s 14 Education Act 1989 to exclude children on grounds of gross misconduct when it's more appropriate to look at it as a lack of inclusive education issue. There are process failures, absences of natural justice, and a lack of investigation. Section 13 points out that removal is a last resort. Section 8 of the Education Act must be strengthened. There is a need for an advocacy service and an independent tribunal in relation to education. There should not be a burden on individuals to take test cases. These are often settled to avoid legal precedents.

WHĀNAU / FAMILY

This section relates to the rights to whānau and family. A significant focus at the conference was the way that implementation of the CRPD can often prioritise Eurocentric concepts that ignore Māori ways of being. There was a strong overlap between presentations about family and other areas such as health and education. There was a strong emphasis on support for family as carers. The summaries in this part of the report therefore focus on the ways that whānau is fundamental for identity and the assertion of human rights.

The chapters on Inclusive Education and Health and Wellbeing also discuss the role of families in upholding those rights.

Keynote: Gary Williams, Ngāti Porou, past CEO of DPA, Aotearoa Disability Sector Leader

People with disabilities are subject to intersecting forms of disadvantage. We need to consider how the CRPD interacts with other UN treaties too, for example the Convention on the Rights of Indigenous Peoples. What about people's right to access their culture and language? There is an inconsistency between traditional family caregiving arrangements and the model adopted in family carers legislation.

Family carers should include partners – they're the one who's going to attend to you at 2am when you feel unwell or need to be turned over. They decided that disabled people who were going to be covered by this legislation needed to be the employer.

Gary doesn't want the legislation itself repealed, because he can see advantages for disabled people to get a few more dollars into their households under current arrangements. Gary is asking the new government to repeal the vindictive and cynical parts of this legislation.

Gary thinks that Māori could see the Convention as a tāonga, but only if Māori are really certain about what the words of the Convention might mean to Māori. The UN and the Convention are sterile and full of words that don't mean what you think they mean. We need to be in partnership with all kinds of people. You can't leave us behind any more. We need to be there up front and doing our stuff.

Thinking about Enabling Good Lives: it's great to be at the table: congratulations to DPOs and Ngāti Kāpo, but how do we know what people in Gary's hometown think? How do we ensure access for people not at the table?

The inquiry into historic care and abuse shouldn't be limited to just an apology, it should grant compensation too. We need to acknowledge the lost lives and lost opportunities that resulted from abuse.

We need amendment of the family carers legislation. Carers shouldn't be paid at the minimum wage. We need to retain judicial oversight of the legislation.

We need to incorporate the collective reality and mātauranga of disabled Māori "as read" in the Convention and policy.

The role of whānau in rights for Māori

The conference heard about Karanga Maha, which is a vehicle for people to share what they have and speak and advocate for themselves. It's a space to share the things that no others will listen to. It is led by Rangatira. Elements of the pōwhiri process are important to engage Māori, and making the Convention real is first about engagement. Participants are able to share NZ Sign Language, learn more about te reo, and share things together. Whatever is said, they follow it up. Teaching people about who they are as Māori has enabled young people to become who they are today. The presenters saw people with amazing talents. Karanga Maha shows that the whānau identify as Māori first, but they find strength from coming together in a place of their choosing. Then they become good advocates and get other whānau to come along. After the wānanga and hui, those who participate organically create another community, another whānau. Identity for all people is a journey. They will have more than one identity. It's important that whānau can speak with each other about the Convention and what it will take to make it real because sometimes it's more about food on the table than rights.

Karanga Maha was seen as positive because it was whānau focused, so it feels accessible. A lot of disabled Māori are put off by the word 'disability' because they don't relate to it. There was a need to decolonise and re-indigenise. If you're going to engage with the Māori community you have to be in it for the long haul and engage in grass roots activism.

One person in the audience felt that it was difficult to go outside the whānau and interact with people outside the whānau because it was outside his comfort zone. One of the presenters replied that once Māori disabled people are all together they draw strength from one another and that "identity for us all is a journey".

Family / whānau as carers

Many recommended that this conference is used to go to the current government and for them to review under urgency the Amendment to the 2013 Public Health and Disability Act. There were calls to reconsider this matter to ensure that all family members who are carers are paid on the same basis as other carers. Under the Treaty of Waitangi, the Government is required to account for Māori ways of living and being and refusing to acknowledge the role of family members in care was unacceptable to speakers at the conference.

The conference noted the UN Committee's recommendation that the State Party reconsider the family carers issue to ensure that all family members who are carers are paid on the same basis as other carers (2014, Concluding Observations, p. 5). A lot of parents don't have the knowledge, skills and energy to find information to access proper funding and other support and are consistently shut down when doing so. This is a particular issue in regard to education for their children when issues arise with access to inclusive education. Presenters noted that paragraphs 17 – 40 of the decision from the *Atkinson v Ministry of Health* judicial decision were removed because they described types of care needed by the plaintiffs or the adult children which were deemed too sensitive for the public to see. There has to be a health and safety plan and no complaints can be made relating to human rights for family who are carers and may be paid carers. This is having a big effect on carers. New Zealand research from 2009 has shown the serious consequences of government policy on carers: 30-39% had the highest level of depression. 30-59% had the highest levels of stress. Less than 1% of caregivers of people under the age of 65 were happy with the support they were getting.

Impact of housing on whānau and care

Accessible housing was a significant issue addressed at the conference and was also connected to whānau and families. While Ministry of Health and the Ministry of Social Development have some good inclusive policies, parents don't necessarily know about them. Presenters talked about Disability Connect which works in the area of disability information and advice. It's about navigating the complicated disability sector New Zealand has.

People with disabilities cannot live in the community without huge amounts of unpaid support. Presenters used local knowledge, targeted questionnaires and public meetings and they found that older parents were often lost outside the system. There was a need for system transformation, and they found that including the Ministry of Health in public meetings that identified multiple issues was good. Parents had an opportunity to discuss how they had gaps in basic knowledge of housing.

Generally, rent is too high for people on a WINZ benefit. Families can't find carers in rural areas and they go through sleepless nights. They ask themselves whether steps toward independent living will help people in the family be independent and who will be there for the person when the parents can't be? People felt there was a lack of concern from the government. There were concerns around service staff being underpaid and that this undermined the care being provided to people with disabilities.

Policies do not meet the needs of people with complex disabilities

Policies not developed to meet specific needs of those with complex disabilities. Barriers are lack of knowledge and understanding of their existence, vulnerability and their needs. People found it was hard to talk to

someone (in Needs Assessment and Service Coordination (NASC), for example) and feel they must constantly prove why they may need additional help. Many needs are then often ignored after this initial difficulty anyway. Home support works around a flawed system for high and complex needs. There are not enough support workers, and not enough emergency provision for situations where a main carer is incapacitated. Many have funding but finding someone willing to work the hours needed and to do a good job is hard. Respite care is not of a high standard. Neck braces are commonly put on upside down and there is lack of knowledge about disabilities by nurses and doctors. There are very few vocational services. This is very difficult because parents often adopt a siege mentality and this undermines participation in culture and the community. They feel constantly attacked, oppressed or isolated in the face of negative intentions of the rest of the world, groups, individuals, bureaucracies, and so on. As an example, one support group sent round their usual yearly survey. They have a membership of 160 yet only 19 surveys returned: they say this low return rate illustrates the point. When things rated good or very good there were no additional comments; however, when rated poor or very poor there were always additional comments as to why they were rated that way. 7 respondents rated NASC as good/very good whereas 12 rated it poor/very poor.

High priority issues

The needs of people with high and complex needs are not being met by current systems.

Parents are not being paid appropriately for the care they provide for their children. They also lack knowledge and feel they are not given enough help and information to understand such issues as being paid.

Where can information about inclusive policies be found for family members? Where are the houses for those wanting to live independently? Who has primary responsibility for connecting families with opportunities and support as their disabled young person gets older? Who is providing the housing? Are disabled people expected to compete with others in the market rental scenario?

INCLUSIVE EDUCATION

The conference heard some key messages from keynote speakers on article 24.

The negotiations that took place in developing the right to education under the Convention deliberately set out requirements for a single general education system. The Convention does not permit a segregated parallel system. This conception of article 24 has not been realised in New Zealand.

Inclusive education is not the repositioning of special education into regular schools. We need to avoid administrative categories that can have a lasting effect. We need to be careful that we don't create an environment where the education industry puts in place an educational triage system where students are labelled as a high risk or a potential asset and triaged accordingly.

Inclusive education is not just about people with disabilities but about educating all of us into an inclusive society.

Suggestions for realising the right to education were: (1) training teachers in the Convention on the Rights of People with Disabilities and (2) use of domestic legal mechanisms to enforce domestic and international rights.

Domestic enforcement mechanisms are not effective in New Zealand and impose too much of a burden to access them. There were calls for development of national-level enforcement mechanisms, and a regional human rights forum similar to the European Framework.

The New Zealand Disability Strategy (2016-2026) says that inclusive education will be a core competency for all teachers and educators (at page 24 or p. 24?).

The Human Rights Act and the Human Rights Review Tribunal are not providing effective access to justice to enforce our rights to inclusive education. The IHC case started in 2008 and now a decade has passed. Those students in year 3 when it started have already finished school. Regardless of the reasons for the delays, the current infrastructure for enforcing rights does not work.

A key priority in New Zealand across a number of presenters was the need to develop formal rights that can be applied in practice using enforcement mechanisms. This was especially the case with tertiary education.

Accessibility also had to become a key concept in education practice in a wider sense. For example, accessibility should be modelled in teacher education, syllabus development, teaching in ways that reflect accessibility, accessible learning techniques, use of Easy Read, note-takers, access to NZSL, and audio description of visual materials.

It is fundamental that disabled people are part of shaping what this accessibility looks like: expertise and co-design processes need to put disabled people at the centre.

Disability rights need to be situated within a wider social justice framework. There were also presentations illustrating intersections and parallels between ableism and racism and there are opportunities to use research theories and methodologies across these areas.

A further comment noted the need to acknowledge and reflect the input of disabled people when it does occur. For example, people's intellectual property and input must be acknowledged and appropriately compensated. Similarly, people with disabilities should be considered from the perspective of other minority groups: whose stories are we taught when we are taught?

Keynote: Prepared speech by Professor Rosemary Kayess delivered by Dr Brigit Mirfin-Veitch, with a reply by Professor Kelley Johnson

Professor Kayess prepared a speech for us on article 24 of the Convention but unfortunately she could not attend for health reasons. Her prepared remarks were delivered by Dr Brigit Mirfin-Veitch.

Professor Kayess noted how article 24 of the Convention was drafted through the participation of people with disabilities who had very different experiences of mainstream and segregated schools. It was only when people agreed that they could force the State Parties to adopt the wording that they chose.

Inclusive education is about getting rid of separation and segregation. Disability is just one more way to look at the human condition. People with disabilities are seen as exceptions to "normal" people, just like racism and sexism sees people of other cultures and genders as "not normal". People were worried that inclusive education systems would try and remove what made them different and unique. It was about removing the detriment people faced in the system but not the things that made the person different and diverse.

Without access to adequate education, persons with disabilities have diminished prospects of gaining employment and taking part in economic, politics and policy discussions. Education plays an important role in social development and interaction.

Teachers have to be trained in the Convention, including in augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities under article 24(4). They need to be aware of the Convention and can be a powerful force for change. We also need teachers who have lived experience of disability. One suggestion to enable teachers to make changes was that they be involved on Boards of Trustees at schools.

Professor Kelly Johnson's response to Professor Kayess

Professor Kelley Johnson responded to Professor Kayess' paper. She told the story of an autistic boy who couldn't bear the sound of the school bell. The school let him leave class early and go to a safe place before the bell would ring. That helped a bit, but he was still scared of not being able to get to his safe place in time. His thinking was dominated by the need to get to that safe place in time to avoid the sensory trigger of the bell. She suggested that a better solution for that boy might have been to get rid of the school bell. The school found this unthinkable. The fact that this was unthinkable for the school goes to show how difficult it can be to change parts of our society and find an approach that suits everybody.

Someone in the audience noted how hard it had been just to get changes about discrimination against people with disabilities and the right to reasonable accommodation into the Human Rights Act. She paid tribute to the people who had been through the education system and found it so difficult. She wanted recognition of how difficult that had been for them and how, even when they educated themselves, they found it difficult to find work because of discrimination against people with disabilities. She wanted discussion to focus on education that went beyond school, into tertiary education and then onwards into employment.

Professor Johnson noted how Governments were requiring schools to focus more and more on consistency and measuring performance. Schools were being measured against each other on things like reading and writing and maths. Teachers are being given less ability to make their classes flexible to take account of different people's needs. This is limiting teachers' ability to take account of people's needs and achieve inclusive education.

Keynote: Professor Roger Slee, University of South Australia

The language of the Convention is resplendent with words like respect, dignity, autonomy, freedom to make choices, independence, non-discrimination, full and effective participation and inclusion in society, respect for difference, acceptance for peers with disability as part of diversity, humanity, quality of opportunity, respect for evolving practices that include children with disabilities and respect for the rights of children with disabilities to preserve their identities. The articles have to be read in full because there are overlapping messages from each of the articles: they interconnect and shape what article 24 is about.

Exclusion resides deep in the bones of education. Inclusion or inclusive education really gives us the opportunity to ask the most fundamental question about the purpose of education, and that is what kind of world do you want to live in? Who is in? Who is out? Why, or how come? Who decides, and what is the basis of those decisions? And then, going back to Marx, the

purpose of philosophy is not just to understand the world or interpret it, the purpose is to change it.

Inclusive education is not about assimilation or normalisation. It is about representation at the table. A democratic education is an education where everyone is in. When Professor Slee thinks about that, he doesn't think about everybody being in on Wednesday morning, for one hour, half an hour. When he thinks of inclusive education, he thinks of education for all: it is a subset of that greater purpose of educating the citizenry for a democratic society.

In neoliberal times, where the ethos of individual competition is the bedrock of social organisation, there are collateral casualties. People become surplus, redundant. We live in a condition Professor Slee called ambient fear. He said that every society creates its own set of strangers in its own particular way.

Education systems have focused on increasing competition and public displays of competition between students and schools. This has reduced students to being the bearers of results. There is a website where schools present their profile there. Part of their profile is their academic credibility as based on student performance. Some children present schools with risk and other students have the potential to invite various assets. In response, schools have set up an educational triage system where they are working out who should be taken and who should not.

Schools have always been rather reluctant with some students. There has always been the production of success and failure. Failure wasn't a problem because there was somewhere else for kids to go. The farm, a factory, a shop, domestic labour: now there is nowhere to go. How do we manage this?

International certification has a reductive pressure on schools. It has gotten to the crazy level where earlier and earlier we are subjecting our children to being ready for school. We are taking childhood from our kids and Professor Slee is not happy about that. He expressed concern about the use of DSM diagnoses and a "special education industry" that creates bell-curve thinking, which tells us who in the population is worth investing in, what are the chances with the other, and how might we manage them in their displacement.

Professor Slee referred to the way that perspective is created through a vanishing point in art: objects shrink as they recede into the distance and this can be modelled using mathematics. He talked about the excitement artists must have felt having the ability to conjure up a measurable, precise illusion of the world. But these pictures just create an illusion. It is very difficult to see past the illusion. He said that the organisation of the education campus has drawn a line between the so-called regular school and the special school that has forged its own rules of perspective. Those rules of perspective have trained our eye to see education in a particular manner. The school became an expression of humanity and a demarcation of the limits of humanity. It became a representation of a descending human value. It created a boundary, which categorized some people as being "surplus population".

Special education serving the so-called special educational needs of children perceived as being “not normal” was established in bricks and mortar and has endured through the organisation of institutional discourse around education. This has to change.

Inclusive education is not the repositioning of special education in regular schools. It is actually saying that both the regular and special school have this co-dependent relationship that is not healthy. We know the regular school is not a great school for those whose tenure there is in question. There is work to be done in making schools better places per se: this does not mean incorporating special education into “regular” education, but greater work to make all education truly inclusive.

Families and inclusive education

The conference heard presentations about the lived experience of families seeking to enforce the right to education. There was often a disconnect between professionals (who see parents as uncooperative and unprofessional) and parents (who see professionals as unnecessarily restricting choices available). Families had the following wisdom and tips to share:

1. Participating in as many school and community events as possible can help to develop relationships with the community.
2. One child was excluded from an event supported by Halberg Trust. Her mother was able to call Halberg Trust to come into the school and support her ability to be included.
3. Family members joined PTA groups, which presented an opportunity to have conversations with school administrators and the principal that was positive. Communicating by email often had negative results for relationships. Joining groups allowed for covert advocacy at PTA meetings and this worked well. It also led to proactive efforts by the school to take an inclusive approach in later events.

One presentation described the creation of the NZSL Sector Advisory Group. This is a collaboration between Deaf Aotearoa and the Ministry of Education towards implementing article 24, and particularly article 24(3)(b). It is a partnership that works together with families. The group represents Deaf people, Māori Deaf people, parents, Deaf education centres, schools, early childhood services, other agencies and service providers. The group developed a plan that led to the government allocating additional funding and the "First Signs" programme. There was a 2013 Human Rights Commission report that contributed to the Ministry of Education being very supportive. The HRC report found that Deaf children who have sign language as their primary mode of communicating in regular schools have little or no access to NZSL or positive Deaf role models. Children needed fluent staff, more resources, better data collection and analysis of what was happening and what needed to happen and promotion of early childhood centres, to enable acquisition of

sign language. Deaf children were not getting the opportunity to be fluent in their language, culture and identity.

The First Signs project has a strategic focus set by the Deaf community. Families go through new-born hearing screenings. If a child is deaf, within 48 hours, every family receives a pamphlet from First Signs, so that parents know that this support exists if they want it. If support is requested, facilitators from First Signs come into the home and help families learn to sign. The programme is family-centred and has huge demand. Currently there are about 500 families registered and the programme is facing funding issues as the number of families increase. They are currently exploring technological solutions to reach more people. Someone from the audience asked what would happen to families in the programme when they reach the school environment. Presenters noted that there is a huge shortage of staff that speak sign language in schools and this is an urgent priority area. There are two centres of Deaf education, but the system is not providing for people who need NZSL. There is an issue about the available workforce of Deaf professionals but this will take time and attention to resolve.

One presentation discussed how to create a sense of belonging for whānau in early childhood education. UNCRPD article 24 doesn't identify the role of families. People at the conference wanted to discuss this, given the central role of families in early childhood. Families are part of their children's education. There was enthusiasm for creating spaces that are both child-centred and family-focused and both of these are required. The presentation discussed the Te Whariki Early Childhood curriculum report in 2017 that guides people's work in early childhood. One of the principles in the report is family and community. There is also a focus on belonging for both children and families. The question then becomes, what does this mean for families of disabled children? Researchers investigated what was meant by active participation. A distinction was drawn between simple enrolment and attendance, that falls short of inclusion, and more meaningful participation with the ability to realise their citizenship and human rights. Researchers conducted an ethnographic case study involving 3 teachers and 30 children at kindergarten level. They found it was important to create a community and to empower kids in a way that respected their choice and gave them a sense of security. It was important to listen to and honour the child and the family and respect the knowledge that families bring. Children need consistency. Families feel they are not being heard and do not matter. There is no collective sense of responsibility and decision-making and families feel teachers are enforcing their own definition of wellbeing over families. There was a need for a place that is warm and welcoming for families that makes them feel valued.

In his keynote, Ron McCallum noted that the Committee had not yet had a member who was a family member of a person with a disability and suggested this could be a future development for the Committee's practice and procedure.

Parents play a key role in negotiating between institutions and disabled children. They are key players in creating change. Presenters wanted to see a shift away from perceiving parents as problems who ask institutions for too much, cannot accept why services are the way they are, or raise concerns. They wanted a shift toward seeing parents as solutions because they come with experience, resilience and applied experience. Where parents and the disabled community are involved, success occurs. Relationships are key in creating this connection. Presenters emphasised the way that parents model what works: parents model how to treat kids with disability in inclusive ways that recognizes their agency. Teachers need to model inclusive teaching and include disabled students in developing new strategies. Misinformation and a lack of skills to interpret information (e.g., how to understand non-verbal communication, how to understand policies, how to understand the meaning of data collection) are obstacles in implementing the Convention fully. By making information accessible and offering skills to break down complex information, presenters believed we will remove the resistance of dominant groups in society to engaging with disability, and better understand the importance of inclusivity.

The conference heard about the positive effects of establishing forums in Tasmania for students with dyslexia who felt their right to education was being undermined. The forums were intended to allow parents to act as a voice for children, raise awareness in the community and provide practical and positive support. When offered workshops, lectures and summer schools, teachers reacted very positively and have since implemented the lessons learnt. The number of support groups has grown in Tasmania and advocacy has improved. The group started community outreach via radio, free magazines, and TV. They made inclusive education a community issue rather than just a school issue. In one school, 13 out of 14 teachers thought dyslexia did not really exist: their views had changed by the end of the programme. The forums linked up with other groups in New Zealand too in order to increase their ability to advocate. There are now four parent support groups in Tasmania and they are self-supporting. They invite a speaker to address them each month. Following their efforts, the Department of Education in Tasmania has funded 28 teachers in 2017 to do a module on dyslexia and they have brought experts from the UK and Australia to participate in conferences.

Enforcement mechanisms: access to justice and education

One organisation presented on the way it had used a wide range of legal processes to enforce the article 24 right to inclusive education, including judicial review, the Human Rights Commission, mediation, the Human Rights Review Tribunal, the Human Rights Act, the Education Act, and common law actions in negligence. They had noticed the Court was more receptive to these kinds of legal actions, including by bringing private institutions under public oversight regimes. Sometimes the threat of legal action under s 16 of the Education Act and article 24 of the Convention was enough to come to a

mediated solution, when combined with Human Rights Commissioner complaints and filing proceedings in the Human Rights Review Tribunal. They also drew on research literature in their court actions. They felt that development in the law was being undermined by decisions to settle cases but it was important for individual access to justice. The obligations under article 24 were not being met and there was not enough funding to schools to meet it. It was being undermined by a hierarchy of funding systems, different funding streams, and the use of population based formulas with decile rankings. The criteria for access to Ongoing Resourcing Scheme (ORS) funding was arbitrary and unsuitable. There was a repeated problem with schools using disciplinary mechanisms to address behavioural issues related to disability. It was taking too long to use legal mechanisms to enforce domestic and international instruments and the development of the law was being undermined by last-minute settlements to avoid precedents.

Some presenters urged caution about the language of "rights". Rights can sometimes imply hierarchies, or imply an ability to exclude others' rights to support. There was also caution around terminology of "need".

Accessibility of methods, modelling accessibility

Inclusion should not be confused with assimilation. Inclusivity is part of a broader revision of orthodox systems that can draw on, for example, queer theory.

Similarly, presenters were concerned about tendencies to see education in commercial terms as a private rather than a public good. Language around competition, performativity and the market should not determine who is worthy of rights and what kind of education is deserved. Education needs to be about social justice and inclusion, rather than about return on investment.

The conference heard about research into building a supportive teaching practice model for students with learning disability and Down syndrome. A literature review identified that there is a gap for these students. The research focused on full participation in light of article 24 of the CRPD and the United Nations Convention on the Rights of the Child (UNCRC). Children as a vulnerable group can be alienated and decisions made against their interests. The study involved 42 primary students with learning disability or Down syndrome and 190 adult participants: teachers, teacher aides, parents, Special Educational Needs Co-ordinators (SENCO) in Bay of Plenty, Christchurch and Wellington. The participating schools did professional development seminars looking at disability theory, specific learning profiles of students in the classroom, evidence based assessment, inclusive practice, Universal Design for Learning (UDL), literacy, numeracy, communication, social skills and behaviour, and a packet of resources. The researchers used questionnaires and teacher reports to gather data. They aimed to give teachers skills to help children have the ability to make their own choices, but also operated based on a full-class approach rather than removing children or singling them out. There was a specific focus on being socially inclusive according to article 24. Researchers aimed to adopt approaches that would

build a student's self-esteem, confidence and friendships. The student is not a guest but part of the school and classroom like all other students. The study had some interesting findings. Currently, the provision of inclusive education varies between schools based on location. Teachers did not know where to go for help and did not feel confident teaching students with disabilities. Research found that, after the programme, teachers felt more confident and were better equipped to bring services together and access resources to help support children. The researchers shared some recommendations.

1. Consider the school's commitment to children with disability – do they take their obligations seriously? Researchers referred to a social contract.
2. Develop an inclusive assessment framework that goes beyond academic skills to include social skills and participation.
3. Cease using the contemporary term "below level one learner".
4. Situate children as the key participant with a voice and valuable experience in childhood settings.
5. Children with disabilities require an equal place free of exclusion.

One presenter spoke about developing an "Access" syllabus: it is based on modelling accessibility in both content and practice. It is available to be used by other teachers and scholars. It was created in light of the Convention based on identified points where education is often inaccessible, for example: lectures are available in writing, Easy Read, NZSL, or on a screen, and slides are read out for students with visual impairments. Outcomes and feedback from the use of this syllabus was positive for students with disabilities but also for those where English is a second language, or others who struggle with class content. When used in teacher education, it begins with an access statement that defines accessibility as a learning outcome. Teachers are assessed on their knowledge of the Convention as well as applied accessibility in their presentations and work. Critical thinking is applied to deconstruct and interpret messages about disability and visibility of the disability community. In this way, teaching about accessibility and the Convention is modelled through accessible approaches and techniques. Accessibility is not "additive" but essential, and it is therefore essential to devote resources to it in the same way that resources are devoted to adequate light and air conditioning.

Presenters discussed a course on inclusive design. It was taught to students of design studies as well as non-design students. An evaluation framework was developed that incorporates inclusive design principles and the Convention. The process of designing the evaluation framework included input from people with visual impairments and other disabled people. It was emphasised that inclusive design benefits people outside the disabled community as well. The framework allows students to go back and assess their work against the specific requirements of the Convention. The framework can be used by design students, teachers, businesses, and others. This is an important quality given that assessments can often focus primarily on cost and price. The framework was important for increasing consciousness in businesses around accessibility issues and people in the disability community.

They also found a discrepancy between those who normally assess student work in design studies and those in the disabled community when it comes to assessing the quality of work - for example, teachers might classify work as being too simple where people in the disability community see it as excellent because of its accessibility for people with visual impairments. The framework closed this gap to an extent. It was emphasised that people with disabilities participated on the basis of goodwill and volunteering and this should be replaced by an approach that recognises the labour of those involved so that they can devote more time and energy to working with students.

Inclusivity can also be modelled through wider social commitments and programmes, including the "Network for Inclusive Cities" described in one presentation. This network is made of Mayors from 35 cities committed to fulfilling the rights of persons with disabilities. The network of city governments organise public events. Inclusivity in this network includes education policies.

The conference heard about the urgent need to include people with disabilities in physical education programmes. One researcher found that none of the children in her research sample had been included in secondary school physical education. Children are frequently excluded from camps because of health and safety. Children with disabilities are required to prove their ability and are often excluded. PE is thought of as being for children who "can" based on neoliberal ideas around competition and ableism. The Halberg Trust programme was noted as being one that worked specifically around children with disabilities and inclusive physical education. Educators need to be flexible and Convention-thinking needs to be at the forefront of their minds.

Teacher education

The Convention must be a core part of teacher education. In teacher education courses however, there is limited time to explore the Convention. In some courses, the student body is also relatively homogenous – for example, student teachers are typically 'able-bodied', middle class, pākehā. This means that some students may have little awareness of human rights concepts and little experience of discrimination. Student teachers also come to teacher education programmes with their own preconceptions of who is valued in the classroom from their own education experiences. If they have observed some students being given less value, being excluded or segregated, this will impact on how they conduct themselves as future teachers.

Presenters discussed the impact of cuts to resourcing for humanities courses on their ability to adequately educate student teachers in human rights and the Convention. Research shows that if teachers don't feel confident teaching some students, they may simply withdraw from teaching them at all. Further, there was discussion around situations where teachers feel compromised in their ability to teach those students and consequently leave the profession. There is a need to assess the impact of education and humanities funding

cuts on the way this undermines teacher education in disability rights and inclusive education.

Parallels were drawn to disability from teacher education about racism, in the sense that some white teachers may experience feelings of reluctance, fear and denial when faced with having to adjust their teaching to accommodate experiences they have not personally encountered because of their own identity and background. Overcoming these barriers requires extended amounts of time for discussion and reflection that can be undermined by cuts in teacher education and funding issues. Pedagogies that teach about other oppressions can contribute to understanding disability rights. Critical pedagogy that focuses on race, gender and class can now be used to incorporate transgender rights, disability rights and the rights of other marginalised groups of people.

People in the school community (including professionals) often assume that non-verbal children are not competent or don't understand what is going on around them. This can lead them to ignore children or treat them inappropriately for their age. It was important to move past focussing on deficits and what kids can't do to focussing on what they can do. People in the school community will approach situations with their own preconceived ideas - there were repeated issues with teachers not making the effort to give children choice and control and instead assuming that they know what is best. Children with communication problems are frequently excluded from decision-making. When children feel like they have agency and have been heard, they are more content, and have greater educational and behavioural success. Staff also feel more satisfied with their decisions.

Data, research and education

One presentation described a collaborative research project that drew on the experiences of students with dyslexia. They ran four focus groups of 10-12 students across a year on the basis of a collaborative knowledge-gathering exercise where students shared what worked for them. The focus groups were run in a natural setting and at a time and place that allowed it to be a student-run process. That information was then shared with a Polytechnic, who could enable staff to build capacity to respond. As a result, the Polytech could take proactive steps to provide facilities across the board (e.g., note-takers and peer mentors) that reduced the need for students to self-advocate all the time. They could also look at exam regulations that were making things more difficult for students and could incorporate more rest-breaks, for example. As they became aware of issues they could also take steps to prevent them impacting on students: for example the institution obtained a grant to facilitate assessment processes to identify students with dyslexia and could negotiate reduced prices for such assessments.

In Australia, the Nationally Consistent Collection of Data (NCCD) on School Students with Disability exists as a source of data. There are important gaps in this data: schools can still opt out of being counted in this data and parents can refuse to have their children included. Lack of information about the

NCCD to parents and the disabled community (not knowing about it or knowing what it does) results in parents not being included. This gap results in inconsistent funding, as schools will receive less funding than they need simply because they are not included in the data.

High priority issues

Resources for schools: educating teachers, access to devices and above all centring families and disabled people in the developing frameworks for schools

Resources are needed for inclusive education: it cannot be funded on goodwill alone (volunteers taking notes, not having sign language and so on).

Education cuts disproportionately affect minority students. Cuts in funding for humanities courses affect teacher education.

It is important to prioritise non-verbal communicators: 'communication privilege' leads to communication-impaired people being less included in the decision-making process.

Access starts before people are in the classroom and not once they are facing a barrier. A proactive approach to access and rights is required rather than reactive approaches. Institutions and teachers should have to show how they are accessible rather than students having to point out that they are not (reversing burden of proof).

Teacher education is key in changing the education experience of disabled students, it is key in creating access to jobs, representation, and so on. Inclusive education cannot be reduced to something that is only taught for a few hours within other sessions but must be part of general teacher education.

Assistive Devices need to reflect accessible processes and consultation processes.

Inclusive design, just like inclusive education, should not be an additional extra but should be part of the general program instead.

The inclusion of students in physical education curriculums in NZ schools is very poor.

There is an urgent need for a way to enforce the right to inclusive education. Enforcement mechanisms need to take a choice and control approach. The existing mechanisms under the Human Rights Act and the Human Rights Review Tribunal are not enough: they need development. The IHC case started in 2008 and that is too long to wait.

HEALTH AND WELLBEING

Keynote: Dr Sarah Gordon, Research Fellow, Department of Psychological Medicine, University of Otago - Wellington

The conference heard a powerful address from Dr Sarah Gordon. Some key points about advocacy, health, training and education were collected by our volunteers.

Neither the word "advocacy" nor "advocate" appears in the CRPD, but advocacy is key to making the Convention real. This includes both systemic and individual advocacy. The job of advocacy is not about protecting people. It is not about doing anything for someone. Instead, it is about supporting a person to exercise their rights. That is particularly important in situations where someone is at their most vulnerable. Advocacy needs to extend to all areas of our lives and be focused on the rights that apply across all of those areas. Systemic advocacy is about being prepared to stand up to human rights abuses and say "No, that is not OK." Where professionals are advocating for someone's rights, their job is not only to support a person to self-manage their impairment: their job is also to help that person exercise their human rights in response to their experience of disability. There needs to be a focus on the immediate present as well as the future.

However, we have a problem in New Zealand. There is a lack of systemic training and awareness-raising for mental health personnel on human rights. Dr Gordon announced that medical training from 2019 will specifically include human rights modules.

However, there is another problem. Dr Gordon had spent the last seven years encouraging medical students to critically evaluate their experiences of being placed with mental health services as part of their training. Dr Gordon gets feedback like "I felt uncomfortable with the way they were talking about clients in the staffroom." Dr Gordon then asks if they've shared that feedback with anyone else. Not one student has said yes. Students feel they're at the bottom of the pecking order. Dr Gordon points out to the students that this is still one step up from service users. In her opinion, medicine and the associated professions are among the most hierarchical and bullying professions.

Dr Gordon described how her education was important for her wellbeing given the impacts of her impairment. She said it had given her options and opportunities that were not available to her peers who had not been able to access education. She contrasted her own experience with a study of progress on social inclusion for people with mental impairment. Participants were asked about places where they feel socially included. Education was notable by its absence. Not one participant cited an educational setting as a place where they feel socially included. She also emphasized the contrast

between her own experience and supported employment. While supported employment is common in the mental health sector, it can often be limiting in terms of options and opportunities.

Dr Gordon said article 24(5) of the CRPD is key. There are four main tasks that are crucial to recovering and living without mental distress. They are framing, self-management, positive identity, and valued social roles and relationships. In Dr Gordon's opinion, education is unique in being able to provide for each of these important things.

Framing means making sense of the experience as part of the person, not the whole person. Self-management means the impact of services or interventions depends on the choices made by the person using them. Positive identity relates to the way that stigma and discrimination almost universally have a negative impact on the identity of people with experience of disability. Dr Gordon had struggled with positive identity throughout her academic career. The completion of her PhD and confirmation of the title Doctor has been the most significant. She said it was embarrassing, but one of the mantras that replays in her head when she is struggling is "Please join me in welcoming Dr Sarah Gordon."

In NZ we seem to think of human rights as annoying things which prevent countries from getting on with what they want to do. We might be socially minded, but we're not human-rights minded.

In terms of the Mental Health Act, New Zealand is infamous for having one of the highest rates of compulsory treatment in the world. We have 103 people per 100,000 under compulsory treatment. Since 2005 this has increased proportional to population growth. It's hypothesized that 75% of people subject to compulsory treatment orders have treatment decision-making capacity. You might ask how this is possible given the philosophy of the last decade. New Zealand's Act is over 20 years old. It allows for indefinite orders - if you have three successive six-month orders, your treatment status becomes indefinite with no requirement for any official review. The criterion under the Act is mental disorder: it is not capacity-based. Qualifying mental disorder can be of an intermittent nature. New Zealand had a Mental Health Commission for a while, but it didn't monitor use of the Act and it was disestablished anyway (at the time of the conference). There's an annual report on the numbers subject to the Act, but it does not report on the use of force or the number of people under indefinite detention orders. That means that in New Zealand we have an unknown number of people with treatment decision-making capacity without mental disorder who are subject to compulsory treatment and could have been subject to compulsory treatment for over 20 years. No-one seems to care.

Doctors from other countries are often shocked in NZ that seclusion is used and how often it is used. But in becoming a participant of the system, they too come to use seclusion. So New Zealand's system and the extensive use of measures contrary to the CRPD are a barrier. The CRPD has told NZ to take immediate steps to revise the relevant laws and replace substituted decision-

making with supported decision-making, and New Zealand has responded by saying they'll look into it. To Dr Gordon's knowledge, no country has made the necessary changes.

Dr Gordon had some excellent examples of how the Convention could be made real including:

1. Educating student assistance professionals in Mental Health service users' experiences. Undergraduate and postgraduate medical training to specifically include human rights modules – CRPD.
2. Research led by people with disabilities about experiences of people with disabilities.
3. The way that leadership figures within education institutions (for example, the Dean in her situation) could be advocates. The Dean had offered her whatever she needed – that was reasonable accommodation, but it was never known by that name.
4. Experiential knowledge needed to be prioritised.
5. She described the United Kingdom's development of "recovery colleges" - which are run like any other college, but education is seen as a route to recovery rather than being a form of therapy.

Training for health professionals and new models

Health services generally need to be more respectful and understanding around disability and disability rights. Health staff often don't have specific training in the rights of people with disabilities. The health system should consider the role of peer education and support for health professionals and for people with disabilities in the healthcare system. An audience member who did a study in Australia said peer education made a significant positive difference to health care there.

One presentation described the experiences of a hospital that worked to break down medical model expectations to adopt a more inclusive model. They changed from wards to community homes and units, raised staffing hours and made sure people receive the medical help they need while giving them a quality of life and life experiences. For that institution, it's not just about providing care now, it's also about providing a life. This means going beyond your job description. They spend a lot of time trying to get people into the community, while also starting to get the community to go to them for those finding it difficult to travel. Job position descriptions need to be broader and more flexible to ensure that patients are given a life as well as medical care. Asking staff to go beyond their medical duties is hard. The medical model of care is still given too much focus. The presentation outlined a good example of how to transform medical areas such as hospitals into communities of care. All of these changes have been made within the usually available funding, no extra funding was necessary, proving that changes can be made successfully with few funding implications. Challenges discussed included that the hospital was still audited as a hospital on a medical model: auditing processes still matched people to contracts, rather than matching contracts to people.

Data gaps in health and wellbeing

There are a lot of data gaps in the healthcare data system that are undermining the ability to resource and provide access to services for people with disabilities. In particular, the voices and experiences of women with disabilities is missing.

Foetal Alcohol Spectrum Disorder (FASD) is not seen as a disability so there is no funding available. People with FASD do not 'tick' the correct boxes for qualifying as having a disability under a medical model. There is a data gap in NZ about FASD – 3-5% of the general population are estimated to have it but this is based on international data. Māori are over-represented in FASD populations and system bias is inevitable. There is stigma and intolerance and high numbers of children with FASD are in care. The following aspects of care and rights for people with FASD and their families were identified:

1. Healthcare and help.
2. Full participation, particularly in education.
3. Lack of knowledge and capability in the professional workforce to diagnose, understand and support people and families with fasd.
4. Lack of accommodations to impairments in cognitive and social/behavioural domains.
5. Lack of buddies and mentors, which are hard to come by and pay, and can be financially burdening.
6. Lack of diagnostic capacity in most places.
7. Lack of public, professional and community awareness.

Violence

There was prominent discussion about violence experienced by people with disabilities. Violence was experienced in an immediate physical sense as well as in a wider structural sense.

Women with disabilities experience many different forms of violence on a daily basis. Violence can be disability-specific, physical, psychological, sexual, economic and based on neglect. The Convention specifically recognises the increased risk for women with disabilities to experience violence, injury, abuse, neglect and negligent treatment, maltreatment and exploitation. Denying a person with disabilities their rights to choice and control is properly understood as violence. Violence should be understood as any act directed against another person that hurts, scares or offends them. People do not leave abusive relationships because of guilt, shame, loneliness, fear, economic reasons, the needs of children and mutual friends in the community, and hope that things will improve. There are additional barriers like self-blame, lack of alternatives, normalisation of violence and dependency. Forced dependency is a kind of violence too. Surveys show that more than half of women with disabilities have experienced physical abuse. This is contributed

to by poor living conditions, increased dependency, and the fact that people with disabilities are often invisible to the community because they are not included.

The conference heard about prevention programmes in Australia and Sweden. Accessibility and the right to effective communication is a key part of violence prevention. Presenters described Pict-O-Stat, a web-based accessible survey that asks questions about experiences of violence that can be answered by individuals independently. It is important to actually ask about violence as few people will spontaneously talk about their experiences with violent behaviour. Presenters described the Talk About Violence communication tool. This tool uses pictures to ask a person about whether they have experienced violence. It is accessible and opens an opportunity to talk about violence given people often do not dare to ask people about their experiences. It is important to let people know that it is their right to live free of violence and they should not feel guilty for talking about it. It is important to clearly define violence and violent behaviours and give people an accessible way to talk about it.

Te Ohaakii a Hine National Network for Ending Sexual Violence Together (Tauwi caucus) described its research into the Good Practice Guidelines for Mainstream Crisis Support Services Responding to Sexual Violence. The guidelines set out principles for sexual violence services. They apply to every service you come into contact with, for example police, courts, forensic medical staff, psychologists in the aftermath of abuse or assault, either historic or recent. There are some key things that sexual violence services should have to promote good practice. Some services have been operating for more than 30 years and it is important that they have grassroots beginnings. It is important to adopt evidence-based practice and interventions and this is important to funders. Finally, crisis services will be accessed by victims of historic abuse reporting for the first time, as well as recent victims of sexual assault. The guidelines were updated to bring in insight from communities of interest but they did not change too much other than to include sustainability, the need for multiple supports within services, and collaborative principles for working nationally and locally. The guidelines set out a vision for service delivery that is inclusive, includes 24/7 accessibility through phone and internet, acts as an information and resource bank for acute practical need, contains social work support and is integrated across services. After receiving extra funding, an advisory group was set up to focus on different streams for people with disabilities, male survivors and Māori. They conducted focus groups, interviews and questionnaires about what good practice would look like. There is a draft consultation report and other reports online. The critical thing for victims is knowing they can contact services and get help and knowing that policies and practices won't inhibit access to support. Services should understand the strategic, philosophical, and legal contexts of providing accessible support for disabled people. In particular, communication with disabled people should meet their different access needs. There is a need to evolve legislative settings and government policies to align with the UNCRPD. There is a need to encourage and facilitate ongoing research into disability and violence.

Access to interpreters

The conference heard about a Deaf advisory group that was set up to advise a District Health Board (DHB) on making sure that every healthcare place has an NZSL interpreter available. While NZSL is an official language in New Zealand, this has not flowed through into access to interpreters in healthcare settings. This has undermined Deaf people's access to adequate healthcare. There have been some very serious examples of negative health outcomes traceable to ineffective communication by healthcare professionals about the risks of medication. One example was a woman who had a stroke because the GP did not advise her of the risks of the medication she was taking, and there was no interpreter at either the GP or the pharmacy, not even at the Accident and Emergency clinic. The group's research found that most health providers do not have a full-time interpreter and just say they will use an interpreter when they need one. There was a general lack of data kept about people's access to interpreters and how many health care providers actually had an interpreter. By contrast, most health providers' staff did not know how to book an interpreter. They were also worried about the cost of hiring an interpreter. Instead, staff relied on family members, or even tried to use children as interpreters, which is not acceptable. They found that Deaf people did not understand much of the health information they received and were generally poorly treated by health staff. They identified lots of experiences of disrespect and poor attitudes by health staff towards Deaf people. Many patients who are Deaf still receive appointment letters telling them they have to telephone a doctor's clinic to confirm the appointment. They also have difficulties being called through to the doctor's rooms from a waiting room because their name is called out verbally and there is no interpreter. It was important to remember that you need a good match between an interpreter and the Deaf person so that there is a good language match, otherwise this would undermine access to health. Wellington has a 5-year action plan to address issues that the Deaf community have identified from this research.

Access to healthcare for women with disabilities

When the Convention was drafted, people with disabilities had to fight to have article 25 included. Making article 25 real is a different matter. The conference heard about research done in Auckland through 6 focus groups, including 13 Māori participants, and participants had physical, sensory and cognitive disabilities (many had more than one disability). People with disabilities are not getting equitable and proper access to sexual health and reproductive health services. In particular, cervical screening is not free, meaning it is not accessible for many who are experiencing poverty and intersecting forms of disadvantage. Researchers found that all participants experienced difficulties accessing cervical and breast screening. In particular there was a lack of Deaf awareness among staff. Information and advertisements did not take into account Deaf women's needs making it incredibly difficult to book an appointment by phone only. Rather than booking interpreters, some healthcare professionals would rely on the person's children to be interpreter,

which is not appropriate. We know that women with disabilities are at a much higher risk of sexual abuse and so screening services can often be re-traumatising. There was a strong need for better data on how many women with disabilities are accessing screening services and health services more generally. People had issues with appointment times that were too short, access to interpreters, and wider accessibility issues including parking and access to venues. Stairs and toilets were not disability friendly and the screening tables were often not suitable for women with disabilities. They lack dignity and respect. Healthcare providers were not taking responsibility for reasonable accommodation and expecting women to do this for themselves, for example advising women to just ask someone to read them one of the inaccessible advertisements. Continuity of care was compromised by appointment making services that were not accessible.

The conference heard about issues faced by women with disabilities undergoing health screening. Many venues for the screening were not accessible. People also found difficulties in being allowed to take a support person with them. While screening is available for women with disabilities, quality and standards differ and many providers are not willing to make the effort to ensure services are disability-friendly. A 2011 study by the Ministry of Health attempted to capture the experiences of women with learning disabilities. In relation to mammography, 39.9% women with learning disabilities getting screened was less than the 48.7% of women without learning disabilities getting screened. In relation to cervical screening, 33.6% of women with learning disabilities received screening compared with 70.6% of women without learning disabilities. The researchers interviewed 14 women aged 26-66. There was an urgent need to improve the data about and access by women with learning disabilities to screening services. Women's access was being undermined by the way health professionals communicated with them. They were not receiving the information they needed in an accessible way. Health services needed to be more respectful and understanding and there had to be training for staff in the Convention. It was also important that women are given a choice as to which health professional carries out the screening and that they know them well: gender can be important to this especially where women may have been victims of sexual abuse. Most important to women was knowing the professional and receiving respect. Health professionals needed to demonstrate listening, respect and empathy. Women would feel more comfortable and get better access if photos or videos could be used to illustrate what to expect during screenings and peer education and support would make a big difference.

There was an identified need to change the resources and stories around losing a baby for women. The stories and resources currently don't cater to women with disabilities. They also assume that the loss of a baby with a disability is somehow more acceptable. It is very ableist. There is a real lack of data on the experiences and rates of women with disabilities suffering miscarriage or sudden infant-death.

There is a specific and urgent need to make healthcare screening services genuinely accessible to people with disabilities. Specific recommendations

include a need for longer appointment times, interpreters, and information and advertisements that are accessible, to be able to make appointments other ways, and train staff to be Deaf-aware. There is not enough disabled parking. Stairs and toilets are not disability friendly. Screening tables are not suitable for many women with disabilities and service provision often deprives them of dignity and respect. Many women need to be able to get into a different position than that required by screeners. Webpages and ads not accessible for blind women and appointments sent by mail are not accessible.

Women with disability who are pregnant urgently need better medical care that is tailored to their needs and is respectful. There is a specific need to make resources, support and care for women with disabilities who lose their babies more appropriate and accessible.

Pasifika people's health

There was a presentation by people about the need for Pasifika support groups and mental health. Presenters shared their personal experience of losing family members, including to suicide, and going through very difficult times. Other family members suffered head injuries due to assault that had severe mental health consequences. Pasifika disability often encompasses disability, mental health, and addictions, and it's quite hard for people when the sector divides disability on one side from mental health and addictions on the other side. Addictions are not just drugs and alcohol. It's also nutrition. If you look at the high rates of diabetes in Pasifika people, for around 70% of Pasifika people going to a GP, it's not just the physical presenting condition, it's anxiety and depression too. The presenters found it difficult to know how far they could share their personal experiences in situations where they also represent organisations. They said they talk about creating honourable spaces. What that means is having a space that allows people the dignity and respect to portray their story the way they really want to. Pasifika people are talked about in government as a high-needs group, but they don't have a voice at the table. They are part of the wider disabled community. Some of the people the presenters met knew nothing about the Convention. So many organizations still see disability in the medical model and there is a need to keep pushing for the CRPD paradigm shift.

Access for Māori

Māori need urgent access to proper, culturally appropriate support services. They are not accessing adequate healthcare because appropriate and accessible services and resources are simply not there. Māori are already marginalised and much more so as Māori with disability. Māori need to have their own voice and be much more visible. Māori with disability should be at the UN, present, in-person, having a voice. There is a need to focus on inter-dependence not independence to meet the needs of whānau. There is also a lack of tri-lingual interpreters.

Haua Māori access to health and wellbeing services in Murihiku (Southland) is very poor. There is an issue with access to funding for transport in rural areas. Collection of statistics and data about haua Māori access to health services in Southland is poor. There is a failure of mainstream services to recognise the importance of specific cultural traditions. There is a need to think more widely about disability, not just physical access, and include cultural as well as physical access.

Presenters reflected positively on the fact that DPA had increased its diversity. Some presenters believed the Convention articles were not adequate for indigenous persons with disability - 33% of Māori have disabilities but mainstream population the rate is 24%. 49% of Māori up to age 25 have disabilities, 50% of them are intellectual and 39% have physical disabilities. Only 16% of Māori have access to any supports or services. Government policy to refuse to pay whānau to care for children with disability is a violation of the Treaty of Waitangi.

The conference heard about research into health providers' awareness of the needs of haua Māori. The aim was to confront practitioners with the invisibility of haua Māori to their practice and illustrate what that means for their practice. The research was conducted through questions and surveys put to and answered by health providers. They reported the physical accessibility of their service as being good but their cultural accessibility as being poor. There was low employment of Māori staff and low percentage of Māori clients seen. Ethnicity data was generally not collected by asking the person but just by assumption. Disability accessibility was overlooked and just taken as being physical accessibility. There was a failure to appreciate that just "treating everybody equally" was not what was required because there was a need to provide greater services to enhance access for disadvantaged groups. Practitioners made assumptions that local Māori were not involved in their culture. Research shows that Māori have low access to health services compared with the population generally and practitioner responses were very unaware of systemic discrimination. They concluded there were very problematic attitudes in Southland to Māori people. Discrimination may not be active but passive discrimination is still leading to poor outcomes and access.

Duchenne Muscular Dystrophy

People with Duchenne Muscular Dystrophy (DMD) described their experiences with access to healthcare. Disability support services is ring-fenced money that only supports participation in the community. Support workers are not funded to help with hospital care and are not allowed in hospitals. Hospital care is inadequate: staff are untrained in the CRPD and the needs of people with DMD. Often people with DMD feel coerced into breaking the rules by taking a support worker without telling anyone. There are 20 different DHBs and all of them have different policies on this. People with disabilities experience better care from their usual care workers and continuity of care is important. The presenter outlined their research findings that people who experience DMD often find themselves outside of the state's capacity to care. Participants in the research regularly discussed their

anxieties when support workers were not allowed to come with them and how they are then also restricted on other care services due to funding. The introduction of flexibility in this system would better give access to health in compliance with article 25.

The conference heard a presentation about the lived experience of someone with DMD based on a blog kept to better share that person's experience. It helps people understand the real experiences of participation as noted in Article 30(1), (2), and (5). Continuing reference to and implementation of Article 30 is one strategy for creating positive inclusive and hopeful environment in NZ. The writer wanted to convey "what it is like" to live with DMD, not "what it is": he aimed to share his experiences on a daily basis with physical and mental pain and his spirituality. There was a real need to make sure people with DMD (and other disabilities) are able to access cultural and sporting life and opportunities as equally as others. Participation needs to become a more equal opportunity for all, with needs met appropriately. Examples of places this needs to be improved are movie theatres, community centres, domestic tourism spaces such as motels, public monuments and so on.

Wellbeing and participation

A music engagement programme in Southland reported positive results from taking an inclusive approach. The programme emphasizes engagement with music-making rather than skill-development. It has a non-exclusive philosophy that is not performance based. It defines expertise as being the way in which one uses the skill and intent in the community rather than on performance. The programme is based on the music outreach principle based on therapeutic use of music. Typical outreach is prepared with a group of students with the aim being to take their group into another group or community and actively make music together (for example a rest-home). The programme collects a lot of qualitative data. The aim is to engage everybody in some way and embed choice for each person to understand what they want and what they are communicating. They incorporate a range of visual aids that can help students who are non-verbal to communicate. The programme has gained a lot of support from the Invercargill community and some good success. For example, Ruru School students went to a rest home and the groups made music together. The programme mostly starts with singing because it is the easiest music engagement given limited resources. They have found that singing is good for behaviour management because it helps students monitor their own behaviour and change it. Singing a song can also make jobs like washing or cleaning easier. The programme is beginning to engage Southern Institute of Technology tertiary students too. The programme provides an opportunity for participants to demonstrate skills they may not have otherwise discovered to their communities and families. The programme's organisers want to continue to enhance the programme's outreach and compare it with other programmes. They would like to increase engagement with other community groups and schools.

The conference heard about the experiences of children in a therapeutic horse-riding programme. There is a problem generally with children with disabilities getting access to participation in meaningful wellbeing activities. With limited options and funding, children become more passive and solitary as they do primarily home-based activities. Researchers aimed to understand the "therapeutic landscape". By that, they mean the context of an activity that is associated with healing. There is a focus on relational dimensions and the experiences people undergo and the meaning they attach to those experiences. The aim is to create contexts that contribute to meaningful health outcomes rather than just focusing on individual health services for access to health. Research was conducted to understand how the context in a therapeutic riding programme allows participation in meaningful health and rehabilitation so that the context can be enhanced for greater outcomes that can be measured. They conducted focus groups, semi-structured groups, made observations, and took photographs of children then asked the children to reflect or respond to those photographs. There were 38 participants including riders, caregivers and teachers. Riders included people with ASD, cerebral palsy, intellectual disability, and bone disorder. Children wanted to participate in a meaningful way in a physically based but socially engaging activity to hopefully lead to growth in physical and social skills. The results of the research were very good. It provided a way to understand how involvement in therapeutic riding influenced changes in wellbeing. Children "gained tools" they could use, which included finding a niche in an environment they felt was their own, that was novel, fun, challenging, risky within a safe environment, individualised and normalising - children felt normal irrespective of their function and felt included. They got meaning from these activities that increased their confidence and self-esteem. From this context, children learnt to move, connect, succeed and adapt. They took a changed impression of themselves into other contexts of their lives in the community and at school. There was a complex relationship between the person and social factors. They built a relationship with their horse, caregivers, and teachers. Attitudes from staff focused on their capabilities rather than disease and dysfunction – it was a strength-based approach.

One presentation focused on how fashion could contribute to health and wellbeing. Fashion could be used to make clothing more inclusive and ethical by adopting a design framework based on human-centred design that focuses on users' specific requirements, functionality, preferences and needs. Human-centred design takes into account individual physical abilities, body shapes and sensory needs. Functional clothing has six main purposes: protection against things (e.g., heat, cold, UV exposure, germs, injury); medical uses such as scar management, bio-sensing, monitoring heart rate and body temperature; sports including enhanced performance and fatigue management; vanity to enhance appearance; cross-functional to protect and support life; and "special needs" clothing that enables people to participate. The design process focuses on gathering users' needs and preferences, evaluating them, generating design ideas, and then creating the design. The presentation noted some examples of human-centred fashion, including the Teatum Jones collection, Runway of Dreams, ABL Denim, Chairmelotte, Lucy Jones FFORA, Takafumia Tsuruta: Tenbo, and Open Style Lab. These case

studies revolved around celebration of diversity, inclusive approaches to modelling, adaptive clothing to meet individual needs including wheelchair users and those with sensory processing issues, accessible fastenings (e.g., zips rather than buttons), use of Braille on clothing, and many of these initiatives had been started or produced in collaboration with people with disabilities and their support-people. Many of these garments are not very affordable but hopefully that will change over time as access increases.

High priority issues

There needs to be improvement to the way health professionals communicate, particularly with women with disabilities - they are not getting the information they need in a way they can understand. This is affecting their access to healthcare services.

There are continued issues around Māori access to healthcare and this is compounded by discrimination against people with disabilities.

All points in the healthcare system need access to interpreters, including GPs, hospitals and pharmacies. They also need better data about access to interpreters and whether their services are engaging with people with disabilities.

Persons with disabilities are still not getting access to adequate, respectful, client-centred healthcare. Resourcing and access to healthcare is still not accessible, appropriate, or respectful for persons with disability. Disrespectful and discriminatory treatment by medical practitioners is common.

There is a lack of systematic training and awareness-raising for mental health personnel on human rights. There is an impact from the hierarchical ordering of medical professions on the ability to implement attitudinal change through educating junior practitioners.

There is an attitude to human rights in NZ that they are an annoying thing that gets in the way of "getting on with things".

There is an unacceptable use of seclusion in New Zealand in mental health facilities.

The Mental Health Act and substituted decision-making regimes are inconsistent with CRPD and must be abolished.

Compulsory treatment orders under the Mental Health Act and the way they undercut treatment decision-making capacity and supported decision-making. Community treatment orders start a slippery slope that means the order becomes indefinite after three successive six-month orders. There is no independent monitoring mechanism for mental health or mental health commission.

Mental capacity is not the same as legal capacity. Perceived or actual deficits in mental capacity must not be used to undermine legal capacity. It assumes you can divine the workings of the human mind from the outside. Further, mental capacity is not an objective phenomenon, it is contingent on social and political contexts.

People with Duchenne Muscular Dystrophy have needs that do not align with the rest of the population so they fall outside of the economic rationale for funding from the economic system. Their hospital care is inadequate. Staff are untrained in their needs. When they need to bring a support worker into treatment facilities, they are forced to break the rules because the system does not allow this. This leads to fears about losing funding. Some flexibility needs to be introduced into this rigid system.

FASD is not acknowledged or viewed as being a disability, thus no funding, service or education is available. "We give support for Dyslexia, for example, so why not FASD?"

Training, employment, standard of living and social protection, participation in public and cultural life, recreation, leisure and sport

People's right to participation in the community is not being realised. The conference heard many presentations about people's lived experiences of being excluded or failing to receive the support necessary to participate in wider public life and the community. Often this was because of difficulties in accessing support workers, support worker training, and/or flexibility to bring support workers with them into the community or treatment contexts.

Employment

Employment is a key focus for Paula Tesoriero, Disability Rights Commissioner in New Zealand.

Employment is important for people, and gives them a sense of autonomy, self-esteem, income and ability not to depend on public welfare. Employment is mentioned in article 27 of the Convention. If people with disabilities have the possibility to return to work, then this gives higher life satisfaction compared with people who are unemployed. However it is important to maintain choice and control for people with disabilities based upon their own experience and knowledge of their needs. It is wrong to force people into menial jobs or jobs that do not suit their needs purely because of a focus on employment. Volunteering and other forms of participation in the community - when consistent with the person being properly remunerated for valuable work - can also be important.

There was a clear need for employment services providers to have better training and funding to take a CRPD approach. There was also emphasis on the need for long-term support into employment with workplaces that are properly trained in the CRPD and the person's needs.

Presentations focused on the intersection of a range of rights in either promoting or undermining the right to employment, rehabilitation and training. Research, transport, and accessibility played significant roles in undermining access to employment. Mobility aids are often used as a proxy for disability in research statistics. All presenters emphasised the incompleteness of their own expertise when it came to discussing disability experience.

Research was shared based on interviews about people with acquired brain injury who returned to work. Support and adaptive rehabilitation was essential to facilitate return to work for this group. There were three themes identified as a result of the research. Commitment: a person feels they are important and given a sense of security during the rehabilitation process. Adaptation:

employers can be extremely helpful and want things to go well - they're open to change not just during rehabilitation but also in later working life. Cooperation: workmates need information and they need assistance in knowing how to follow up - this helps include others in the rehabilitation process. More research was needed to generalise these findings as it was based on a small interview study.

One presentation discussed an Equilibrium Systems Model of Employment (ESME) model. This proposes that systems must provide equilibrium, where there is reciprocal benefit with the client at the centre. It was important not to see employment as "just a job" and it provided significant benefits for a person's wellbeing and participation in the community. Under Australia's National Disability Insurance Scheme (NDIS), there is a projection that employment services will reach \$3 billion per year in funding, which is a fundamental shift in employment services in Australia. There was a description of American programmes of customised employment as progressions from old "sheltered workshop" models that were unacceptable. In Australia, what came out of disability service centres were a set of standards that ensured compliance for funding. Disability employment services largely ignore families, because the family is not the client. Consultants who were interviewed highlighted a lack of disability knowledge. Many consultants are required (and require people with disabilities) to put in a diary what they are going to do two weeks in advance, by the hour (which does not indicate trust) and employment plans were required to change very thirty days, which was unnecessary and failed to recognise the experience of long-term disability. Some consultants said they had lots of training, and others that they had none. But there was no indication of evidence-based application of processes. Google was the preferred source for learning which is unreliable. Consultants said that employers had discriminatory hiring practices. What is missing from disability employment centres are the clients' voices. Clients talked about how they had to prove continually that their lifelong disability had not changed. Consultants found that compliance-driven system indicate a lack of trust.

One presentation focused on the limitations of outcome-based approaches to employment for disabled people based on research that had been conducted. Employing disabled people has been promoted as reducing welfare dependence. An outcomes-based framework is most interested in sustainable employment, for more than 15 hours per week: this is also the threshold at which people's benefits disappear. The presenter argued that employment frameworks like this steered people toward underemployment. There were three outcomes of an "outcome based" system. First, it is more likely that services will exclude people that it sees as less employable, for fear of not getting funding. Second, they reframe disability as a potential taxpayer burden rather than capital of human diversity. Third, it exposes those triaged away from employment to a life trajectory of hyper-marginality. For most people it was a dehumanising experience to be steered away from employment that they found unsustainable. One respondent with a lifetime of craftwork, who was future-proofing by learning Braille, says that she thought she had lived a wasted life. Another felt that support was organised around seeing placement

as the outcome (11 hours cleaning toilets, rather than working as an architect). 62% of respondents contributed through voluntary employment. Most enjoyed voluntary work, because of being a social equal and being there for others. There is a real risk that, if steered towards voluntary work, odds of being unemployed were 11 times higher, which presented a cul-de-sac that they found difficult to get out of. Someone might be told that they have no skills, but they have a plethora of skills that they use in their home. Material poverty limits people's ability to make life choices, and people spent days confined to spaces like their homes. Respondents were eight times more likely to want more contact with community organisations. Those who were employed rated community life significantly higher than others. If you have the sense that your social capital is not going to be recognised, this will deter you from engaging. The NZ Outcomes Based Framework Model streams disabled people into 3 mutually exclusive streams: finding a job, job training, participation and inclusion. The presenter described data showing that respondents said they would like to be in paid employment, but there were important specifics to this. Only around 13.6% said they wanted full time employment. Around 18.5% said they wanted 20-25 hours of work. Around 19.5% didn't want any paid employment (the largest percentage).

Participation in democratic processes and stigma

One person shared his experience of standing for local government as a candidate. He said supporting disabled people into public office should be the priority regardless of what party they stand for. He found there were barriers to standing as a candidate. He said there was a financial cost to become a candidate and other barriers such as needing two people to endorse you. Highlights for him included building relationships with other candidates and the opportunity to raise accessibility issues in his city. Significant challenges arose in terms of accessing buildings, getting microphones, and the attitudes of some of the other candidates, who criticised his right to participate on the basis that people would not understand what the disabled person was saying in debates.

One person spoke about their experiences in political advocacy groups. This links in with Article 29 of the Convention and "full and effective participation" is the key. The person was involved in the divestment from fossil fuels movement and they reminded themselves and people at the conference that other people will appreciate knowing what will make their lives easier. If the person knew they were going to be at a conference, and find themselves getting lost because the slides depend a lot on images, rather than quietly asking the person next to them, they will put up their hand and ask the presenter. Once they mentioned the need for reasonable accommodation, the whole room became aware of what was missing, and the next presenter is often very helpful. It can be awkward to put people on the spot but it does have a remarkable effect sometimes. Sometimes persisting with things like asking people to describe posters they've put photos of up on Facebook can start a culture which keeps the behaviour on going without further input.

One presentation discussed research into media attitudes towards disability four years after the publication of the 'Disability Rights in Aotearoa New Zealand 2013: Media. A Report on the Human Rights of Disabled People in Aotearoa New Zealand'. They looked at publications including Newsroom and The Spinoff and the Otago Daily Times. They looked at the type of story, the type of impairment covered, the area under the UNCRPD covered, disability voice, framing, and the language used. They found: lack of disability voice in media stories; lack of disability awareness/responsiveness amongst journalists; lack of focus on issues facing Māori, Pacific and ethnic disabled people. They noted that a disability voice was being heard more often on new social media outlets, compared to mainstream media outlets such as those examined in the research. There was a lack of comparable coverage on disability issues in the mainstream media in the run up to the New Zealand General Election.

The conference heard about the My Voice Matters project, which is a collaboration with CCS disability action, Disability Connect, Vaka Tautua and other groups. The project arose from dissatisfaction with other forums' compliance with article 29 and the quality of debate on disability rights. In particular, facilities and materials for voting should be accessible, easy to use, and easy to understand. They wanted to draw politicians' attention to a broad range of issues for people with disabilities and allies (families and providers). They have tried various approaches since 2013, including use of twitter handles and hashtags on Facebook and Twitter #myvoicematters and @MyVoiceNz. They surveyed parents and families about what issues they wanted to raise with politicians. They shared a summary of the results with political parties and arranged a candidate forum that was accessible as possible. Six politicians attended and two of them identified as disabled. They had a social media panel that would allow people to attend via social media. They wanted to give people the opportunity to practice so they would know what happens in the voting process. They also created postcards that would enable people to write the name of the MP on it and post it to parliament. They had a scorecard that disability action had sent to political parties. Most parties promised to improve their website accessibility after election, but this was too late. They also wanted to draw attention to the following things that are intended to make voting more accessible:

1. Telephone dictation voting, promoted through the Blind Foundation.
2. When it comes to casting a vote, telling an anonymous person is better than taking a family member or a friend into the voting booth with you.
3. Issues with updating enrolment details, and making sure that they are aware of accessibility of voting places (many would have mobility parking and so on). Voting places are graded accessible, accessible for assistance, or not accessible, but this information often comes out far too late for people, and format is not easy to read.
4. People weren't aware that they could have takeaway votes. During advanced voting or on election day, you can give verbal permission for someone to go into the voting place and collect the blank forms for you.

5. People are excluded from enrolment if they are in a psychiatric hospital for more than three years and have been charged with a crime. But everyone else is required to be enrolled to vote (except for prisoners).
6. There is a Registration of a Mentally Incapable Elector, so that the family members could enrol for you.

Physical accessibility

Many presentations focused on people with disabilities sharing accessibility problems from their own experience. There was a need for accessibility and the voice of people with disability to become a core part of the way we plan transport systems.

One presentation focused on the need to capture data and experiences of people with disabilities and their experience of the transport system in order to advocate for change. This required innovative approaches to data collection that were based on respectful and collaborative relationships. We can advocate at an anecdotal level, but we need the system to be collecting data and evidence. The presenters had started with a pedestrian counting tool, at least counting people with visible mobility aids. In Hamilton they made an intersection more accessible and based on their data collection there was a 70% increase in use by people with mobility aids. They used images to demonstrate their argument that the transport system "fails to enable movement". The audience was asked questions that illustrated the depth of accessibility problems in the public transport system for participation in public life: who's not taking trips? How many have not taken a trip because the footpath's dreadful, the taxi hasn't turned up, the bus has just driven right past you? Who bears the cost of those trips not being taken? If people live their lives differently because of impairment, those people are bearing the cost of that system failure. At the moment the transport system has no way of measuring how many people it's failing. That's not fair. Footpaths are crucial and the presenters believe that the current transport system doesn't capture any data about movements of disabled people within the transport system. This makes it difficult to make good investments to enable the movement of everyone. Disabled people have a lot of knowledge and expertise on how the transport system does and doesn't work. The transport system has a huge amount of data on people who drive cars - where they're going, how fast they're going, how many trips per year, and so on. But there's no data on disabled people's use of the system. An audience member pointed out that mobility impairments were one thing, but it was important to consider the needs of people with learning disabilities - for example people who can't read road signs. Others on benefits cannot afford bus fares. The presenters emphasized that what was needed was a tool to highlight to the transport planners that they had no idea how to plan for people with disabilities. At the moment they use either electronic devices or visual spotters, and they wanted something obvious. They emphasized that this was a starting point and they would move to wider consideration of impairments in the future, particularly those with learning disabilities or neurodiversity. They invited anybody with that expertise to work with them.

The conference heard about how the Convention had been used as an outcome for health policy formulation. The CRPD was not thought to be well understood in health in a wider sense, other than in the disability sphere. The presenter noted that sometimes lack of understanding of the Convention led to push-back and it was important to incorporate the substance of the Convention covertly to the same effect where you can. One presentation described a "health in all policies approach (HIAP)" drawn from public health literature. The CRPD was incorporated into a HIAP approach to secure positive outcomes from synergies between the CRPD and other health models that examine the impact of the environment in disability experience, consistent with the social model. These frameworks could then be used for advocacy and decision-making. A particular example was the use of District Plans to change the entry heights for carparks to make them more suitable for wheelchair users and mobility vans. The emphasis was on using existing tools in health policy to implement a Convention-based approach. The use of planning law to remove barriers to access to health and wellbeing was seen as a good way of implementing a Convention-consistent approach in a situation where the Convention was not well understood by health or planning practitioners.

The Conference heard about a research project funded by the Health Research Council, about expanding young people's possibilities for participation. The study involved 40 disabled children and young people from 12-25 years with vision, hearing, and mobility impairments. It did not include people with intellectual impairments. Assessment measures tried to look at what things people liked to do. They began by using a mix of qualitative and quantitative methods, with a combination of GPS units, accelerometers, trip diaries, at-home and at-school interviews, parent interviews, and neighbourhood interviews. GPS units were worn around the waist, but could be connected to a wheelchair or worn elsewhere. They also attached an accelerometer that measures physical activity. A travel diary asked the participants to write about where they would go, how they got there. It turned out to be very useful, because they revealed a lot that they would not have done just by talking. The study included around 60 questions, and provided a lot of information. People would then start to talk about why they liked something on the list, or why they were stopped from trying it. They started off wanting to use the same sorts of methods that have been used with other non-disabled participants, so that they could compare and contrast some findings, but quickly moved away from this, because it was not appropriate. They found some interesting results from using "go-along interviews" in order to look at what places are accessible, where people like to go, and some of the problems for people with mobility issues. Their research meant they could get the impressions of the person, but also document some issues and point them out to local councils. Participants chose a place and time that they wanted to go. In earlier research, they had chatted as they walked, and taken photos, but this would not work well with some disabled participants. Those with visual impairments needed to look or feel where they were going. With Deaf people using a sign language interpreter, they could not walk around and watch the interpreter at the same time. So they would stop periodically for

a chat. One of the participants said that go-along interviews were good to showcase skills and strategies for getting around when blind.

The conference heard a presentation on research under a recent Masters Degree involving 15 participants in the South Island aimed at promoting the voice of scooter users. Participants were aged 62-96 and the research was meant to fill a data gap in this area. While there were recommendations for regulations about the use of scooters, these recommendations were flawed. Currently there is no assessment of scooter use unless they are accessed through public funding. The risks of scooter use must be calculated holistically and ethically. There is a lack of risk assessment in current literature - scooter users should be aware of personal and public risks of using a scooter. NZTA has released recommendations on motorised chairs and so on but this does not include mandatory recommendations. Screening driving based on age is ageist - this can be seen when examining data from other countries who do not assess risk on age but actual risk factors. It shows that risk and accidents are the same for 75+ age group regardless of focusing on age or risk factors. Looking at risk in this way and not through age could be used for scooter use as well. Some areas have made accessibility onto footpaths better such as lower ramp angles, tacks near crossing and so on. Scooters are a good alternative to discounted taxis which were still leaving people financially burdened and close to poverty in some cases. There was a need for mandatory regulations about how to use them properly, maximum speeds, and how to use them on footpaths. There is a risk from improperly maintained footpaths. Any regulations may be controversial and input of people with disabilities will be required.

One presentation discussed forthcoming research about people with disabilities' experience of the tourism sector in New Zealand. This was limited to mobility impairments at this stage, because mobility impairments account for 58% of all disabilities in NZ. Travellers with disabilities face both physical and social constraints. Participants with disabilities in any tourism activity face certain constraints and negotiate to overcome those constraints. The objective of the study is to identify negotiation strategies to enable better access and participation.

One presentation focused on accessibility of recreation and sport. It described a project looking to identify 15 different opportunities within each region of the country - 5 waterways, 5 walkways, 5 cycleways. They've broken the project down into three phases, and a different organisation leads each phase. The Halberg Trust is bringing everyone together. Phase 2 is going to be led by the Department of Conservation. On DOC's website, there are only 15 walks that they call accessible. There are more than that. There's another organisation called Be.Accessible. They work within the urban space, so they're profiling parks, museums, and cafes. All the information they're capturing from this tool will sit on the Be.Accessible website. That work will lead into activism at an appropriate point.

One presentation described research into accessibility planning for people with neurological disability. The research looked at public areas, sports and

recreational centres and their level of accessibility using a Social Ecological Framework. The study included 53 participants at 5 sites across NZ. Many participants spoke about barriers to physical activity/recreation for individuals with neurological disability. They spoke about how other people's attitudes were restrictive and unhelpful. The 53 participants were a variety of people. For example, people with disabilities, support workers, personnel from national sport trusts and so on. They found that accessibility planning for those with disabilities was seen as an "add on" - something which could be removed if funding became an issue. Until attitudes change about accessibility then it will continue to be restricted. Buildings tend to be built for a budget rather than being fit for purposes. The researchers were planning future trajectory research on mega-scale sports facilities and their research would be used to evaluate the effects of intervention.

One presentation discussed participation in the community for older people. Seniors believe living independent active lives is good for them. Presenters showed a pedestrian crossing in Lower Hutt to illustrate the design of the crossing. There was a large patch of different coloured concrete before the crossing on the road so that cars would notice the crossing and this concrete was also textured differently. An ability to cross the road safely for those 65+ years was required in order to access such things as buses, shops and so on. This became more important because driving becomes less common when people get older. There was a need for more data on costs and benefits for all forms of transport so taxpayers' money can be spent where it does the most good. Fitness and aged care centres believe you can't make money from walking. The challenge for the disability sector is the number of people with disability from 65 is increasing. Data showed a growing death toll among older pedestrians in 2006-2014: Increase in pedestrian deaths by almost 20% over this time for those 65+ years. Presenters referred to monitoring of publicly funded discharges for 2009/10 to 2013/14 related to pedestrians and cyclists injured in collisions with numerous vehicles or other causes. The most common collision for pedestrians was with cars or heavy vehicles. Presenters referred to a petition that had been launched to put to the New Zealand Parliament.

Hamilton: accessible city

One presenter shared their experience as a part-time disability advisor for Hamilton City Council. The council has become good at asking what the disability community thinks. That has made it more likely the council will find issues before they become a serious problem, and prevents the need for people with disabilities to constantly raise problems after the fact. The Council entered an agreement with NZ Post about the use of motorised postal delivery vehicles and how drivers of these vehicles are meant to use them. They were concerned about the impact this would have on people with disabilities using the footpath. They were the first council to do this. Hamilton City Council has made buses accessible for everyone including those with disabilities. They lower for wheelchair users, the pavement shave has been raised at major bus stops, and an app has been developed to show where the bus is, the time it will arrive, and its accessibility features. This app also has a voice over option

for those with visual impairments. The Council has had a disability action plan since 2013, and part of that was to employ a part time disability advisor, leading to the presenter's role. The Council has partnerships with disability groups, disabled people, the public and with elected members and council staff. The presenter believed that through engagement things can change. Engagement is about storytelling and addressing issues leading to shared social inclusion. It is about sharing aspirations and concerns. The Council created a map of the CBD that demonstrates accessibility features like toilets. Hamilton was held up as an example for other local centres to aspire to.

Christchurch

The conference heard about research conducted by people with disabilities on the experiences of people with disabilities following the Christchurch earthquake. They found there was a lost opportunity in Christchurch to draw from the expertise and experience of people with disabilities to redesign Christchurch in a socially transformative and accessible way. Instead, much of the work was outsourced to consultants who had no disability experience. There was a need to co-produce socially transformative outcomes which was missed. There was a failure to conceptualise disability according to the social model following disaster. Instead there was a focus on individual preparation and ability. Comparison was made with Brisbane's South Bank, which is highly accessible.

After the earthquake in Christchurch, people with disabilities had very negative experiences. In particular, there was a massive increase in energy required just to live in the city, especially for wheelchair users. Their experiences were ignored in favour of external consultants. Their resiliency was a resource that was overlooked and could have been drawn on. There were huge issues with accessible housing in Christchurch, particularly in the rental market. The earthquake magnified existing barriers and especially affected community inclusion. An audience member noted their experiences in being denied access to a second motorised wheelchair. In civil defence situations, if they have to leave their wheelchair behind in an area they cannot access again, they are completely devastated in terms of their mobility and accessibility until that wheelchair can be recovered.

Participation in faith and culture and community

One presentation discussed disabled people's right to access Christian faith. They shared how disabled people within the church are reclaiming the liberating part of the Bible and identified some books that challenged discrimination within the church, which had historically adopted a charitable model. She said there was a catch-cry within the church: "A church without disabled people is a disabled church." That means that the church is lacking without the experience of disabled people, and even more without people participating. The church is purported to be a place of hospitality, welcoming all people, but often this is limited by the lack of access and discriminatory

charitable attitudes. There still needs to be attempt within the church to include disabled people in active participation, and this can be done in a way to link with the Bible. There were some specific examples of how to make churches more accessible and inclusive, including: a person attending a funeral should not have to ring ahead to make sure that they are able to get into church, let alone be able to get to the toilet; good lighting and sound systems should be mandatory; and announcements should be both spoken and written. It should always be remembered that a charitable model cannot dominate an approach based on equal rights.

High priority issues

In the building code, the height for car parks is often too low for mobility vans. One solution is use of District plans, but this was still a high-profile issue impacting people with disabilities that should not require individual advocacy.

The disability system won't allow people to have two motorised wheelchairs, which could be devastating if you have to leave a wheelchair behind while evacuating a building.

More disability responsiveness training needed for non-disabled media stakeholders.

Media needs to include more about people with disabilities, and include them in the planning of stories to do with disability issues, to enable the projection of the disability voice.

There was a need to assess and award funding from a positive participatory environment approach rather than from a biomedical model (e.g., riding for disabled, music engagement).

There is no disability safety plan. More data needs to be provided and research done on how to increase pedestrian safety, particularly for those 65+ who are more likely to have at least one disability.

Conclusion

We hope that this document gives an overview of the important topics discussed at the conference. We encourage you to consult the conference book for further information. Any errors in representing the subject matter of the conference is the Committee's and we emphasise that this document is simply a channel to ensure that the voices of people with disabilities continue to be amplified and heard.

APPENDIX: CONFERENCE SUMMARY TEMPLATE

Time and date of session:

Reminder of principles:

- Remember to consider responses from various perspectives: your perspective, the audience's, the presenter's
- The intended use for this document is to summarise the sessions at the conclusion of the conference and then for use in reporting to the UN Committee
- Try to ensure you take account of minority voices within the session – your comments do not have to be representative of the group as a whole
- Once you're done, email with the subject line of the email being the number of the session from the programme (e.g., 3.2)
- Please email the summary to the given email address as soon as possible so that they can be summarised as they are completed for use at the conclusion of the conference

GENERAL QUESTIONS

- Q. Please describe any common themes in the session that kept coming up across one or more of the presentations.**
- Q. Are there any other comments or reflections you have on this session or the discussion within the session?**

PRESENTATION 1

Name of presenter(s):

Time of presentation:

Relevant CRPD article numbers:

- (1) Please describe any notable examples of “making the Convention real” from this presentation.**

- (2) Please describe any notable examples from this presentation of the Convention being overlooked or ignored, or where the CRPD could be used better.**

- (3) Any other comments or relevant information:**

- (4) In this presentation, what were the data gaps or research ideas discussed by the presenter(s) or by the audience?**

- (5) High priority issues: please describe any issues that are very urgent or should be a high priority to put to the UN Committee in the next report to the UN.**

Please write any other comments or reflections you have on this session at the start of this document.