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|  | Speak Up – Kōrerotia  Disability rights, the Ombudsman and IMM (Independent Monitoring Mechanism)  21 September 2022 |
| Female | Coming up next conversations on human rights with “Speak Up” – “Kōrerotia”, here on Plains FM. |
| Sally | E ngā mana,  E ngā reo,  E ngā hau e whā  Tēnā koutou katoa  Nau mai ki tēnei hōtaka: “Speak Up” – “Kōrerotia”.    Tune in as our guests “Speak Up”, sharing their unique and powerful experiences and opinions and may you also be inspired to “Speak Up” when the moment is right.  This is “Speak Up” – “Kōrerotia” with Sally Carlton. Today we’re talking about disability rights, specifically looking at the IMM, the Independent Monitoring Mechanism, that’s a joint effort by the Ombudsman, the Human Rights Commission and disability rights groups. We are going to be talking firstly with Peter Boshier, the Chief Ombudsman, before a second interview with disability rights advocates, Mary Schnackenberg and Nick Stoneman.  Kia ora, in the studio with me today we’ve got Peter Boshier, the Chief Ombudsman for New Zealand. It’s really cool and we’re really lucky to have you here with us in the studio, Peter, you’re just passing through for a couple of days in Christchurch and you have an incredibly busy and hectic schedule but I’m really thrilled that you’ve squished in a bit of time to come and have a chat today. |
| Peter | Well kei te mihi ki a koe, Sally, and ngā mihi ki a tātou katoa. |
| Sally | The first thing I’d like to do is think about is what is the Ombudsman. And although I’m sort of familiar with the work that you do, I’m not so familiar with the term and it might not be a term that many of us here in our day-to-day lives. So I had a bit of a Google last night and here are some of the synonyms: defender, guardian, champion, watchdog, knight in shining armour, patron. So those are some pretty powerful words, some pretty powerful synonyms, and that might be a nice kind of introduction to the kind of work that you guys do. |
| Peter | I’d quite like to be a knight in shining armour. |
| Sally | It sounds nice, doesn’t it? |
| Peter | It is. The Ombudsman is a Scandinavian term, it’s gender neutral although you might think ombudsman means a bloke but it doesn’t, it’s a gender neutral term and we were the first country in the world outside of Scandinavia to set up an ombudsman scheme in 1962. And the first ombudsman, probably our most famous, was Sir Guy Powles. So we celebrate 60 years this year and it’s a big time for us. It’s not an easy word, it doesn’t easily say what we do and so Māori have created and gifted us the name of ‘Kaitiaki mana tangata’ and that says more. It says kaitiaki (the overseer, the caregiver, the looker afterer) and then mana, we all know what mana is, and tangata (of the people). So kaitiaki mana tangata – we look after the mana of the people and preserve their dignity. Then of course there’s complete resolution of all the things that go with that, that I’m very happy to talk more about. |
| Sally | Great and we’re particularly focusing on disability rights today, so it would be great to hear specifically around the work that you do for people with disabilities. |
| Peter | New Zealand has a number of conventions and one of the ones that we spent a lot of time with is called the United Nations Convention on the Rights of People with Disabilities. There’s another one related to it which is related to crimes against torture and that particular one gives us work that’s possibly our most known and that is we inspect places of detention, such as prisons, such as mental health units. There are a lot of people with disabilities in those. More recently we’ve gone into dementia care where there’s detention, and then MIQ [Managed Isolation and Quarantine] facilities. The other convention, though, is the UN Convention on the Rights of People with Disabilities. And what this involves is three bodies - the disabled peoples organisations, the Human Rights Commission and the Ombudsman - and we are called the IMM, the Independent Monitoring Mechanism and our job is to see how New Zealand does in a) recognising the Treaty and making it perform, and secondly, looking to see whether across Aotearoa New Zealand, people with disabilities are getting equality and a fair go. And at the moment they are not. |
| Sally | So the role of the IMM is to think about the international conventions as well as Te Tiriti, that’s really cool that it’s got that international and domestic focus. |
| Peter | Yes very much so, and so what we do we look for instance… something I can just tell you a wee bit about. Right now two members of my staff are in Geneva and the United Nations does an overview of a country and how they are performing with the Convention and whether it’s said to be up to scratch. So two of my staff are undergoing an examination by the UN right now. In preparation for this, in February of this year, we ran what is called a Domestic Forum and we looked at six themes which the disabled community felt were really important for them at the moment: key obligations under Te Tiriti; poverty; equity and access during a humanitarian crisis particularly Covid; integrity of the person - that is things like domestic violence and how the disabled people are treated in the community; we looked at equality, non-discrimination and access to justice - a number of people with disabilities don’t feel they are treated well by the justice system; and finally, accessibility and independence. So those are the things that the IMM focused on at our forum earlier this year. |
| Sally | And so those were the themes that were brought to you by people with disabilities themselves, and then you brought those to the UN? |
| Peter | Put it this way, what we did is we ran this forum and we asked government agencies to front, to outline their response to these concerns and what they felt we were doing. We then produced a report on the outcome of the domestic forum, ‘Making disability rights work’. That’s the report that we have forwarded to the UN. Now, the UN actually is examining New Zealand, not us. So we have a minister there at the moment, we have a lot of state agents who are answerable, because we are a state party, that is New Zealand to the UN. What we are there to do as the IMM is to do a value check on how we think New Zealand is doing. |
| Sally | That’s great, so it’s both the IMM and the UN are both monitoring what is going on here. |
| Peter | Correct. |
| Sally | I’m glad that you mentioned the disability groups and also the Human Rights Commission, because one of my questions was how does the Ombudsman work alongside those other groups. So you obviously work together for the IMM but in other senses - so for example, I know the Human Rights Commission has done work looking at seclusion and restraint in facilities - so do you work together on those sorts of things as well? |
| Peter | That’s a very good question because we all have a measure of independence and particularly the Ombudsman has got to be careful because by statute we are an officer of parliament. I’m not permitted to be an advocate in that outreach terminology, whereas the Human Rights Commission is there in many respects to make sure that it advocates strongly for the protection of human rights. I’m there for two reasons: one is to answer complaints and to give people fairness and justice when they complain to me; and the other is to monitor the state and see how it is going on a whole broad range of things, not just disability rights but it might be the prison worker, it might be how school boards of trustees are working.  And so we do work together but we’ve each got a portion of our responsibility… There is collaboration to an extent but there’s also necessary independence of roles. |
| Sally | I can see how that is important. In terms of your work with disability rights, I know there is a disability rights panel: Te Rōpū Kaiārahi Hauātanga. |
| Peter | Yes. |
| Sally | It would be great to hear about how that group works in with the stuff that you do. |
| Peter | Right. Let me start explaining why we did this when we talk about Te Tiriti o Waitangi and te ao Māori. We realised that our office needed to upskill in te ao Māori and so some years ago, having consulted some others, I decided I’d create an advisory panel. We did and they are prominent Māori but also younger generation and we call it Puhara Mana Tangata and that really means… Puhara is a looking-out platform, an overseeing platform looking out over. Mana - we all know what that is, it’s the dignity. And then tangata: people. That has worked so well in giving me insights and in giving me the correct way to engage with Māori.  So I felt that when we came to disability rights, we ought to do the same. So you’re dead right, Te Rōpū Kaiārahi Hauātanga is the panel in which we have people who are disabled on it, who give me advice on engagement, on things that matter, on presentation of material I’ve got which might need to be changed, made more customised. We are early days, we’ve been underway with this panel about a year but it's showing all signs of being incredibly valuable.  I think if I can just say that it’s really important for someone like the Chief Ombudsman not to be paternalistic, not to think that I know what’s best for everyone else but to try and understand what they think is best for them. |
| Sally | Definitely, I can imagine as well it’s probably a tough time to get something like that up off the ground, when everyone is living in this time of Covid and doing things remotely in many ways, it’s not quite the same getting a group up and running. So yes, good on you, I think it sounds like a fantastic group. I was reading through the website about all the things that it is doing. |
| Peter | Just perhaps a word or two about the Ombudsman in New Zealand. We’ve got a big office; we’ve got a staff of over 200. Our staff are very specialised now and trained because I want them to know a lot about their areas that we are dealing with. The one good thing about us, because of our independence and because of the fact that we are answerable to parliament, we are very well resourced, we’re well funded. If anything, parliament wants us to work and wants us to be effective, unlike some other agencies where they’re looking all the time to cut back but that hasn’t happened with us. So probably there’s never been a time where our office has been more potent and more effective. |
| Sally | And so as well as disability issues, what other issues could people come and see you about? |
| Peter | Well the broad range of work that we do is simply enormous. There are a couple of major areas. So when the Ombudsman Act came in, in the very first place, the idea of that is maladministration and a complaint that says someone hasn’t had a fair go by a government agency. But look, this is incredibly broad. For instance, every week we will get a complaint from a parent of a child at school who feels that the board of trustees has made a decision which isn’t fair and we do a lot of decision making in relation to school boards of trustees.  During the Covid time, a lot of people objected to going to MIQ, they objected to having to pay for it, some couldn’t get back into the country and objected to the lack of a visa. So you’ll see that those times generate work, with Christchurch and the earthquakes that have occurred, a lot of work over people unhappy with the sort of payments out that they got. So that’s the Ombudsman jurisdiction.  Official information generates an enormous amount of work and we’ve seen it play out in politics just this last week where it was said that allegedly by a member of parliament, much in the media at the moment, that there was manipulation as to how members of parliament could avoid saying things which might be OIA-able and people are really sensitive about transparency and the need for the proper flow of information to occur. So that’s a large part of our work as well.  And then there’s other work I can talk about but it’s mostly monitoring and seeing how agencies are performing and whether we need to say to them you need to do your work a whole lot better. |
| Sally | Great thank you, that was a great summation. You talked about school boards and complaints coming from schools. I know there’s been a recent case that the Ombudsman has been involved in regarding funding and the fact that MSD… you can probably explain it better but as far as I could understand, MSD does an assessment of people with needs and assesses them as high needs or very high needs and then that determines how much funding that person gets moving forward. And it seemed to me fairly surprising, as somebody who isn’t familiar with this, that that assessment that is undertaken when someone is leaving school rests with them until they turn 65 - which seems an awful lot of decades in which people’s circumstances presumably can change. And this presumably exactly the case that was brought to you guys. So I’d be keen to hear about that case. |
| Peter | Yes well as far as complaints go, we tend to assure people when they make a complaint to us that it is done in confidence and the reason for that is that you would not want your personal affairs being broadcast. So we operate very, very carefully, every staff member I employ takes an oath of secrecy and the point about that is to instil confidence into everyone that what we do remains confidential.  However, when a case makes a point about something, we publish a case note and we put that on our website. We anonymise it so that if it is your family and your business, the neighbours in the street aren’t going to know that it is you. Now the reason I mention this is that we have done a lot of work on our website to make it accessible, especially to disabled community and I want people to be able to use it and feel it helps them.  There’s a thing under the Ministry of Education’s ongoing resourcing scheme where what they do is they use an assessment - I’ll call it an ORS assessment but that stands for ongoing resourcing scheme - and they make an assessment to determining funding for disabled people for community participation services, from the time they leave school until age 65.  If that assessment goes back many, many years, by the time years have gone by it may not be fair. And the complaint to us was that the assessment of the school was incorrect, that this person should now be assessed as having very high needs resulting in higher funding. It seemed to me to be very, very logical, the fact that the complaint was being made. MSD said to me that there was no specific legislation or regulatory framework for its community participation and services funding.  Well I work on a basis, Sally, of saying is something reasonable or unreasonable. So whereas courts will find someone guilty or not guilty or something proved or not proved, my terminology is, “Is what is occurring reasonable or unreasonable?” And it’s a really good test. I don’t just say it because I feel like it, I assess clinically why something is occurring and whether the reasoning process to get to a conclusion stacks up… And in this case, it didn’t.  So I formed the opinion that it was unreasonable for MSD to use ORS assessments to determine funding for community participation services for disabled people. And what MSD undertook to do was to apologise, to provide a flexible payment and engage with the complainant to explore other existing assessment options and mostly, mostly - and I say this with a great degree of confidence - when I do a report and I make a recommendation, it’s invariably accepted and implemented. So I may not have the coercive power of a court, but most agencies do what we recommend and ask them to do. |
| Sally | That’s great. And in that particular case, is that likely to lead to change at a greater scale? So for example this one complainant has had some positive movement there but has there been suggestion that MSD may look at implementing ongoing assessments, for example? Do you think this is likely to lead to anything beyond this one single case? |
| Peter | The answer is yes because if a certain fact situation results in something that is unreasonable, anything else that bears on similar facts is probably going to be unreasonable as well. So while every case of course has to be looked at individually in turn on its own facts and issues, if something pretty much leads from the front, we do what we call a ‘lead case’. For the disabled community, there are ways in which the state isn’t kind and doesn’t treat people with disabilities fairly.  Now an example was some children who have autism can have big moments when they act out and what was happening in a couple of schools, they were locking them in seclusion rooms. So a complaint was made both in Invercargill and in Wellington of respective children who were locked up in seclusion rooms for a period of time. And the complaint to us was this is unreasonable, there must be a better way of handling acting up behaviour than locking someone away. Within a very short time of us beginning this investigation, the Minister of Education banned the process. So not only do one or two cases sometimes give a lead for others, but they actually succeed in changing the law. |
| Sally | That’s great and it just goes to show doesn’t it, it takes a very brave person, I think, to make that complaint initially but if you can see that kind of change, goodness doesn’t it make it worth it? |
| Peter | Absolutely, I think you’re dead right. It takes a lot of courage to make a complaint, culturally a lot of people don’t want to do that, you don’t like to expose yourself, so to speak, that is to say your personal affairs. Sometimes some are not articulate, they find working their way through bureaucracy difficult. What I’m trying to do more and more is get my office into a way in which people feel that we’re not overdoing it but we are as friendly as we can be when we’re giving assistance.  Lead case… And this is by the way what we are doing in MIQ. We received hundreds of complaints about MIQ and we grouped them into four pillars, if you like, of the things that people complained about. To do 400 cases individually - hard, hard work. So we put them into four baskets and each one we have a lead case analysing the facts which are bearably close to all the others in a similar basket and the others will follow in due course.  So the answer to your question is where there is a case which we feel will lead general process, that’s what is likely to happen. |
| Sally | Are we able to hear those four categories of complaint from MIQ? |
| Peter | People are mostly concerned about these things. First of all, they said that the allocation system is said to be unlawful, they felt that the allocation system and the requirement breached the New Zealand Bill of Rights. Others said that the allocation system was unfit for purpose and this was much publicised at the time. People trying to get into an MIQ spot and getting utterly frustrated with the technology and finding that the places available closed and had to start all over again and didn’t feel that it was a fair system at all.  Then the allocation system was said to be unfair which is a little bit related, but you know how often you will go into a website - it might be for a concert, it could be for something large - and you will be… you’ll find your way logically moving your way through a queue. And it could be that you are someone who should receive priority, it could be that you are a qualified nurse or a qualified doctor or a qualified teacher who might be of real use to the public and yet there was no ability for anyone to be treated other than level. And the final thing is that the allocation system was said to be poorly managed and that was really about the voucher system, the fact that there was no discerning of what was a good case for either not going into an MIQ or going in very, very quickly. So those were the four areas where people felt there was unreasonableness and we’ll deal with all four of those. |
| Sally | Something that you mentioned there was around the publicity accompanying some of those. I wonder what is the role of the media in getting some movement behind some of these recommendations that you’re making? |
| Peter | Huge, absolutely huge. The media is often called the fourth estate and it has an absolutely pivotal role. I happen to believe that if I am a force for good and I am trying to achieve change, I must engage with the media to be able to enable that to be seen and heard and I do.  So for instance, years ago we were quite quiet about the work we did and you don’t succeed in getting traction if the public is not behind you. So I happen to believe that when I do a report, I table it in Parliament and I say that something is not right and media pick up on it and publish it, I’m much more likely to get traction for change. |
| Sally | Doesn’t surprise me at all. Okay just moving finally now onto the IMM report. Did any of you or your team find those key themes surprising? |
| Peter | No not really. Look, I was a judge for a long, long time and we struggled to create a justice system that coped with other than the norm. I had people appearing before me who were deaf and we didn’t have appropriate hearing facilities. Sometimes and I remember one case specifically where I was not told in a long list court date that someone was in a wheelchair and they were waiting right until the afternoon and I tell you, I felt… I felt so let down and so upset actually, is not too strong a word, that I’d been unable to deliver that person a hearing ahead of others because they needed it.  So accessibility for the disabled community is often physical accessibility but it goes much further than that, as you probably know. During Covid, a number of communications occurred that could not be accessed by the disabled community. Now there were good bits and we want to be balanced and fair about that: when the Prime Minister and Ashley Bloomfield did their stand ups, there was an interpreter.  There are some things we are doing really, really well but sometimes when people are accessing an MSD website to find out something, they find it really, really difficult. With poverty, the fact is that in statistics disabled people are overrepresented. Are we surprised? Well it disappoints me that that is so and everyone under the UN Convention on the Rights of People with Disabilities, everyone is entitled to be treated with equality and we’re not doing it.  I just want to talk about integrity of the person. Again, some research has been done on how people with disabilities fare when it comes to where they stay. That is to say the sort of environments that are available to those with disabilities and in some of the research they are routinely reported that they are more likely to suffer violence and they are more likely to suffer unreasonable coercive behaviour by caregivers. These are things I’d just like us to acknowledge and to move on so that gradually we are doing much, much better in our responses. |
| Sally | Thanks Peter for all that you have shared with us today. We are going to have our second part of the show with a panel of people with disabilities or experiences with disabilities, talking through some more about the IMM report and the findings from that report. But in the interim, we have a waiata, a song that you have selected for us. If you could just please tell us what it is and why you have chosen it? |
| Peter | I have a ukulele and the Ombudsman’s job is pretty busy - there are long days at times - and so there are two things I enjoy about the ukulele - and there’s a point of this story - I will play it in my room when I get home, we live in Thorndon and in the office we have a lot of music and I play the ukulele with others sort of better than me. But one of my favourite songs is a Jim Reeves song called ‘He’ll Have to Go’ and this is ancient. Well, over the past weekend, the Koroneihana which is the celebration of the coronation of Kingi Tūheitia Potatau Te Wherowhero VII of the kīngitanga and one of the waiata is a beautiful, beautiful song and I recognised instantly. It is to the tune of ‘He’ll Have to Go’ and it is beautiful music and beautiful words and that’s why I thought this one is so fresh, that when I listened to it being sung on Tūrwangawaewae Marae this past weekend, I was visibly moved and I hope everyone enjoys it as much as I did. |
| Sally | Thank you Peter, and thanks so much for taking the time to come and have a chat today. |
| Peter | Thank you very much Sally. |
|  | **MUSIC** |
| Sally | This is “Speak Up – Kōrerotia” with Sally Carlton. We are back again after having spoken with Chief Ombudsman Peter Boshier and now we have got two new guests who are going to talk us through their role in the disability rights space and we’re going to specifically focus on the IMM report that Peter was talking a little bit about as well. It would be really fantastic to hear from you both about who you are and what it is that you bring to today’s kōrero. Perhaps Mary, we’ll start with you. |
| Mary | Well thank you very much for having me on the show, it’s very interesting and I’m looking forward to this. I am a lifelong blind person. I have been involved in disability rights work particularly since I left my fulltime employment at the Royal New Zealand Foundation of the Blind which happened in 2008. So I served on the Convention Coalition which was the forerunner of the DPO Coalition and I was the chairman for a while. So I got to know the Human Rights Commission and the Office of the Ombudsman who are the other two partners with the disability… with the disabled people’s organisation coalition in the Independent Monitoring Mechanism.  So I have had quite a deal of experience in the human rights environment and I’m probably one of a few people in New Zealand who has taken a complaint to the Office of the Ombudsman, the Human Rights Commission and the Health and Disability Commissioner. So I know something about… from a practical point of view, about how taking complaints can be a real challenge. We have seen progress and there will continue to be progress in this area. |
| Sally | You bring a range of different perspectives then, Mary, your lived experience of somebody who is legally blind but also as you mentioned, those different complaints that you’ve taken to these various agencies and also of course your disability advocacy, that’s obviously a really critical hat you wear as well. |
| Mary | Yes it is. |
| Sally | And Nick? |
| Nick | My disability advocacy started probably in 2015/16. I’m a lifelong autistic so I was diagnosed in 1997 when it was a bad time to talk about being ASD. I’m at the very mild end of the spectrum so I’m considered what is Asperger rather than autistic although thanks very much to the DSM5, Asperger Syndrome doesn’t actually now exist in the DSM. It’s actually now known as autism and of course ADHD, ADD, is on the same piece of string.  So my experience, my lived experience around disability is that I have been doing this work probably since I completed Access Matters advocacy training in 2018 and I spent six months finding out what it is I wanted to do and in that time I discovered that there was a real need for an alternative style disability services navigation with government departments.  I’ve also spent time sitting on Ministry of Health disability support services consumer consortium, so that was 2017/18. From there I’ve just sort of been in this space, I’ve watched and like I am well aware of what the DPOs [Disabled Persons Organisations] are up to and how they function. Don’t have a lot of contact with the Office of Disability Issues but do have a bit of contact with the new ministry. |
| Sally | Great, so again a range of different experiences and kaupapa that you are bringing with you to this kōrero today. |
| Nick | Absolutely. |
| Sally | I’m really keen to hear from you Mary, in particular I know that you are one of the members of the Rōpū Kaiārahi Hauātanga, the Ombudsman’s Disability Rights Panel. We talked a bit about this with the Ombudsman and we got his perspective on the panel but it would be great to hear from you. What does it mean to you to be part of that group? |
| Mary | It’s a privilege, you get to share the learnings from all the other disabled members of the group, different representatives but also you get the opportunity to raise the issues that are coming from my experience. The Disability Advisory Panel doesn’t actually talk about the Independent Monitoring Mechanism specifically, but what we do talk about what we are experiencing and that helps Judge Peter Boshier feed into whatever the Office of the Ombudsman might be doing in the Independent Monitoring Mechanism space.  But perhaps more importantly it helps the Office of the Ombudsman think about its own work and so the Office of the Ombudsman is one of the entities that has investigative powers, for example in the health area, seclusion, anywhere where someone might be held in seclusion, the Office of the Ombudsman can go and check this out. So that might be prisons but there are also some institutions around New Zealand, mental health institutions and some other places, where people can be held in seclusion or at least locked in. The Office of the Ombudsman has the opportunity to look into those environments and comment on them and they have done.  They also comment on services to people with learning disabilities and so the special education has come to the Office of the Ombudsman’s notice. So there’s a considerable amount of work that the Office does do and is able to do. |
| Sally | Great thank you. It must be I imagine great to be able to bring your experiences and have a voice in that way. |
| Mary | It is. |
| Sally | Now the main part of our discussion today is about the IMM, the Independent Monitoring Mechanism. We have a wee bit from Peter just before about the six key themes that came out through the IMM report. Just to remind ourselves, they are: Obligations under Te Tiriti o Waitangi; poverty; equity and access during humanitarian crises and there was a particular focus within that on Covid-19; equality and non-discrimination; and access to justice; accessibility and independence. So those were the six and something for me that really came through was a lot of work in there throughout all of those different themes around the rights of Māori with disabilities. So I just thought what we might be able to do is work through those six themes and just provide your perspectives on what they are all about. Could we start with obligations under Te Tiriti? |
| Nick | A lot of the stuff that I kind of do in that space is really limited, I’ve only got a couple of families that actually have kind of that connection to Te Tiriti. |
| Mary | From my perspective, I’m involved in several consumer advisory groups where Māori and Pasifika are sharing their observations about the lack of equity for services and I can’t fix the past but I can try and support advocacy in the present and the future and that’s what I try to achieve. The statistics, life expectancy statistics, the education statistics, the access to health statistics, the access to employment - all of those figures, even if the data is not properly collected or completely collected - all of the figures that they have got are really very clearly showing that Māori and Pasifika are behind the eight ball in just about every aspect of New Zealand governmental services and society in general, which really needs serious attention.  But one of the things that I would encourage everyone to have a look at is the concluding observations from the UN Committee. There is about 13 pages of quite dispiriting material because everywhere you look, there are challenges that the New Zealand government and New Zealand society have to face. And the key thing that came out for me is that disability is absolutely a cross-cutting issue so government, the whole of government but not just that - government, local authorities and NGOs - have to work cooperatively to push forward advocacy in just about every area of services anyone could think of to provide a fairer society for all. |
| Sally | And I’m sure what you’ve just mentioned there, Mary, must tie into that second key theme which is poverty and the idea of poverty being such a crosscutting challenge, isn’t it, and all these things we’ve just talked about - access and equity, education, healthcare - poverty underpins all of that. |
| Mary | Yes it does and unless you have opportunity to get a good education - so that starts with good housing and public transport - unless you have opportunity to get to a good education, then the chances of getting good employment are negatively affected and so you’ll have a low income and so the poverty becomes intergenerational. |
| Nick | With the present system that is geared negatively to treat those who are in the poverty trap and can’t get out. Take for example, see with the Ministry of Social Development, if you are a single person on a main benefit, you are entitled to $200 every six months for food and then you are entitled on top of that to ask for additional assistance such as power, phone, gas. And when you reach 20 hardship grants, or you owe Ministry of Social Development say more than $22,000 in debt, the Ministry of Social Development have a policy where they will actually cut it off and they will not allow any additional assistance to be approved unless it is signed off by a manager.  How is that fair and just in today’s society when we should be acknowledging and valuing that assistance shouldn’t have to be restricted just because a certain point has been reached when an entitlement is due and needed and cost of living is just an absolute killer. |
| Sally | And what you are saying is that is contributing to this ongoing cycle? |
| Nick | Yes it is. |
| Sally | Okay how about equity and access and I’m particularly interested here in hearing about your experiences and the experiences of your communities during Covid and how that has really challenged the disability rights sector and possibly even set it back a wee bit as well. Or I guess there’s opportunities in there as well, aren’t there? |
| Mary | I think the most difficult of this is actually the digital divide in New Zealand. I think certainly for my part of the community, we’ve had quite a lot of material pushed out through braille and audio, it’s all online and there’s no way to market that material to the offliners. You would think there was and in years gone by, there probably used to be much stronger ability to market the availability of material than there is today and that doesn’t make sense and I don’t really want to go into that.  My company has produced a lot of braille material and I suppose we’ve produced only a few copies of two or three of the publications. We’ve produced braille files that are online that if people know about them, they can access those files - but the issue is how to market to people who are offline. And that’s not just about humanitarian crises, it’s about the whole raft of information that is available every day. Marketing the availability of information is remarkably difficult for people who are on the wrong side of the digital divide.  So that means that when Covid-19 comes along, if people don’t know who to phone, don’t have those phone numbers… and even today, it’s quite difficult to find somebody at the end of the phone. So I think that’s a real challenge for New Zealand society. It’s being on the wrong side of the digital divide for anything. |
| Sally | We had a show a couple of years ago and we had Sacha Green from Citizens Advice Bureau and others talking about this digital divide and exactly that, how people who aren’t connected into the internet are really struggling to get not just access to information but also for example, applying for jobs and all those things that come with your ability to connect into the online world. Anything else to add to that in terms of access? |
| Nick | Yes in terms of access, I found that discrimination around Covid-19 was really quite rampant towards the disability sector. Being in a situation where I’m not able to wear a mask on public transport for obvious reasons because it potentially brings on an anxiety attack and being challenged by bus drivers who don’t understand disability or don’t understand what it is like to be a member of the sector.  Lots of disabilities appear visible, others don’t, and I guess that’s kind of my point of difference is that because my disability isn’t visible, people don’t think I actually have one. And I found it really, really frustrating when I got a bus driver who basically refused to open the door to me because I wouldn’t wear a mask and I clearly had my exemption around my neck and it was quite well pointed out that I had it.  And at one point I sort of had to go to the bus company and say to them hey listen, please tell your drivers not to harass me because if they harass me I’ll just simply get very, very upset and it will potentially lead to a meltdown or a shutdown or something like that. How is a driver… How is a bus driver going to be trained to handle that if I have one in the middle of the bus? What are they going to do and how are they going to handle it?  The other experience for me with Covid-19 was being excluded from the local supermarket, that was in lockdown in August 2021. I went to the local supermarket down the road from home and we’d just gone into lockdown and they were operating the entrance down through the car park and up the ramp and into the store and I got to the head of the queue and the security guard said to me where is your mask and I’m like, “Um, I have an exemption around my neck, what is the problem here?” “Oh I’m sorry we can’t let you into the store” and I’m like, “What,? This is discrimination, you can’t do this to me”.  So I very politely turned around and walked away and never took it any further and yet I was able to go to the other local supermarket and had no issues, security guard just let straight through. That’s pure out and out discrimination. |
| Mary | Yes the situation around masks has been very difficult for blind people navigating out on the street. Hearing is absolutely crucial and even masks can affect your hearing, especially if it is windy and it’s affecting your hearing anyway. So my partner who is a guide dog user and is totally blind, finds it very difficult to wear a mask navigating up the road. He will put his mask on when he goes into a building, into a supermarket or wherever, but navigating even the streets can be a problem.  I don’t know how you manage to change the whole of society’s understanding in three minutes flat so this kind of discrimination doesn’t occur. It’s very, very hard and very unfair. |
| Sally | And this ties in, I’m sure, to one of the other points which is around access to justice and you’ve talked a lot about discrimination - and Covid-19, I suppose, is just an example or a context in which some of these issues that potentially in normal circumstances might be a bit more hidden, have brought it a bit more to the fore. It points to something deeper going on. |
| Mary | Yes the access to justice is a real issue, the UN Committee in Geneva has commented negatively about no progress with respect to supported decision making instead of substituted decision making. So that’s to do with people who have learning impairments, who need to be supported through the decision making process.  And I recall a really disturbing comment of Judge Peter Boshier, admittedly several years ago, but he did say to us how difficult it is to find people who are objective and very thoughtful and very caring, who can guide people with learning disabilities and people who just can’t speak for themselves, can’t talk for themselves to actually find people to be very objective and try and understand what would this person want if he or she could speak for himself or herself, what would they want. And it’s very hard to find people in society who just have that level of objectivity, it’s really easy for someone to perhaps say oh well I think such a such a thing should happen. Well really? What would the person say if they could? So there’s that whole issue of moving towards supported decision making and finding advocates who are caring and supportive. |
| Sally | And does that then tie into one of those other key themes, integrity of the person? Is that sort of what that is all about? |
| Mary | That’s one aspect of it and yes it does. |
| Sally | How about some of those other aspects? |
| Mary | Well it would be about decisions about where you want to live and how much support you actually need for that and what kind of support, what’s the best kind of support and just regular monitoring of the situation that people might find themselves in. |
| Nick | I’m in the situation where I have an hour’s home help a week that comes to me and just recently I’ve had really, really bad experiences with the provider. It’s not the support worker herself that’s the problem, it’s the management and it’s the way that it is structured. As a member of the disability sector, I should have had the right to be able to say, “Well I don’t want this”. Instead I’m getting people telling me what is going to happen and when it is going to happen.  Since however long it has been, the disability sector has never really - and I’m not being disrespectful - but the disability sector has never actually been properly empowered to speak. And when we get the situation where we get an agency telling the client what is going to happen, how is that fair and just to us? What if our lives are structured around the time that the support person comes in, they have to be there by a nominated time and we’re still… and half an hour before we’re getting phone calls to say or a message to say, I’m sorry the support worker is not coming today until 2.15pm. How is that fair on us? That impacts on our lives as well. |
| Mary | Yes I agree and I think the home support service right across New Zealand is undervalued, underpaid, undertrained and just under monitored. It’s absolutely miraculous that it works, in my observation, and it’s not… In my view, it’s not anything to do with the fault of the workers, the workers are trying to do their best in so far as they can. But it’s about recruitment, training, reward, payment.  One of the things that I’m very aware of is often the reward is just the gratitude of the people they are working with, it’s not sufficient at all to have the gratitude of the people they are working with. Are they doing the job that is needed? Are they doing the right job? And you’re not going to tell the person off who is supposed to be helping you and say well you’re getting this wrong and that wrong and something else wrong, because that’s going to damage the relationship and you want them to at least keep coming.  So it’s a very disempowering situation I think, right across New Zealand. |
| Sally | And that I think probably ties in nicely to that sixth key point around accessibility and independence and the idea that these support structures are there to enable some more independence but there are obviously challenges with this. |
| Mary | Yes the whole issue of accessibility is so broad. We’ve been building really poor housing basically since Europeans arrived in New Zealand and unfortunately accessible housing has just been associated with oh you need the odd ramp and you need a bit of this and you need a bit of that and if you need funding for it, you’re going to have to wait several months if not two or three years. Instead of saying if you design housing for lifetimes, there’s a very good chance that something like 90% of the people living in that house, properly designed is going to need the accessibility features that you are building into the house.  And unfortunately the New Zealand Building Act doesn’t have sufficient basic requirements to ensure that those accessibility features are built into your house and then there’s all the issue of navigating around our streets, footpaths, road crossings, getting on and off public transport, actually getting on and off the right public transport.  In Auckland, we can’t communicate with the driver to stop the bus other than by waving the bus down, so if you can’t recognise the noise you hear coming towards you as a blind person is actually a bus not a truck and if you can’t read the label on the front of the bus that says it’s route X, Y, Z going to somewhere, then you’re not going to be able to wave it down.  And then of course there are some people with physical disabilities who for various reasons are not able to wave the bus down even if they could recognise a) this is a bus and b) it’s the bus they want to ride on. And then if you’re lucky enough to get on the right bus, it’s only now that Auckland Transport is starting to roll out across the buses, audio announcements of next stops so that you are reminded where to get off. That rollout probably won’t be completed until the end of next year but we still have to wave down the jolly bus. When we eventually get that sorted, we will be able to use buses.  In the meantime yes, we can use Total Mobility but the taxi industry right across New Zealand has been damaged of course by Covid-19 so a lot of drivers have left the taxi industry. And depending on where you live and which taxi company you use and what time of the day you call them up, you can expect some considerable delay, even to catch a taxi. |
| Nick | I just want to pick up on your point, Mary, about public transport. Obviously Christchurch is a little bit different to how Auckland operates and yes I have used Auckland transport, yes it is difficult to use at the best of times. So the Christchurch system is just a little bit different. What we have here is we have a system where our local regional council seems to think it is totally acceptable to just hand somebody a bunch of cards with large route numbers painted on a yellow background with black writing and these cards act as a signal to a bus driver that somebody with a vision impairment or disability wants their bus at the bus stop.  So not only is it embarrassing to have to hold these cards up, you actually have to physically carry the whole pack with you in your bag and when you want a particular bus, you have got to get it out of your own backpack first, then you’ve got to get the card out of the actual packet that it is in and hold the card up for the driver to see it. This is part of our regional council’s solution. But the problem we also have here is that our bus companies aren’t aware of it so our drivers go what are you holding up, what are you signalling me for.  Or we get in the situation where we get a driver that pulls in and they won’t come up to the front of the curb, they won’t come up to the front of the hardstand and actually open the door, put the ramp out without being prompted. That’s some of the education work that we are doing here in Christchurch just to get our drivers to cooperate who probably do have the facilities and resources to be able to roll out next stop announcements but I honestly cannot see our regional council even wanting to consider that. They’re still having arguments from almost two years ago when they repainted everything into one livery and they’re going well we have to bring coloured strips back because people can’t see their bus. |
| Mary | Yes there isn’t a proper national standard to provide accessible public transport and the interesting thing is it is not just affecting low vision people, it’s affecting children who may not be tall enough to actually see the numbers way down the road, people using wheelchairs. I notice in the concluding observations there are frequent references to small stature people, so all sorts of people whose heads might not be high enough to get a really good view of the road. |
| Sally | That does sound like it would be a good step forward doesn’t it, some kind of national standard. |
| Nick | Yes absolutely. |
| Sally | Just to finish off, we’re going to think about the style of the IMM report. It’s produced in a way that is incredibly accessible. We’ve been talking a lot about accessibility and it’s accessible from a whole range of different ways. It’s accessible in that there are visuals included as well as text, the text is written in very short sentences, it uses very easy words, very short words, and there’s some warnings at the beginning, for example, this report is quite long so bear that in mind if you want to sit down. These sorts of things, making it incredibly accessible. I’d be really keen to hear about your views on this style and I know, Mary, you were involved in and translating it into braille. So it’d be particularly cool to have your opinion as well. |
| Mary | Fortunately, the Independent Monitoring Mechanism has been very good at getting their reports brailed. So those of us who are able to read braille, if we find out about the availability of the reports in braille, have direct access to the reports and I do agree with your commentary about the language, the accessibility. The Ombudsman and the Human Rights Commission, both writers have held the pen primarily but they’ve also worked of course with the disabled peoples organisations coalition. So it is a group of report writers but one of them has to hold the pen and currently it’s the Office of the Ombudsman and yes, I agree, they do a good job. |
| Sally | I particularly like lots of the key terms had definitions accompanying them. Very simple, very clearly set out definitions, just making it really easy for people to engage with it, I thought. |
| Mary | Yes and that includes words in te reo where people like me are being helped to understand them. |
| Sally | And that’s getting back to that first point isn’t it, obligations under Te Tiriti. |
| Mary | Yes. |
| Sally | Right well as we wind up our kōrero for today, have you got anything else you would like to add around the IMM, the particular report or disability rights in general? |
| Mary | I’d just draw people’s attention again to the concluding observations that have come from the UN Committee. I have been very comforted by the way in which the Committee has picked up all the issues that have been raised with them and drawn New Zealand government’s attention to the Committee’s advice. Not just to New Zealand in 2014 but their various different publications. So there really isn’t any excuse, there is very clear guidelines for where we need to improve as a country. |
| Sally | It’s now up to us to try and implement them, isn’t it? |
| Mary | Absolutely. |
| Nick | Probably the only thing that I would add to this is as a member of the disability sector, I’m really concerned about the stats that presently exist for those on long-term income support payments, that’s welfare. With a whopping 55% of us in the disability sector who are at risk of being on long-term welfare and that’s disability access needs. That’s a very large number of people that are struggling and trapped in poverty. I want to pick up more work around being able to help people get off long-term welfare and be made feel empowered. I’d also like to sort of thing that we can have a lot more integration with the sector now that we have our new ministry and the new ministry is going to be a critical part of the work going forward. |
| Sally | And I guess joining those two points together, now that there is a Ministry rather than an Office, there may well more clout or the option or the possibility of getting a bit more traction on for example, some of those recommendations that came out of the report.  Tēnā kōrua, thank you both so much for coming in or Mary, joining us on Zoom, and sharing your very wide ranging expertise on this topic. |