|  |
| --- |
| Speak Up - KōrerotiaDisability advocacy and inclusive communities20 May 2020 |
| Male | This programme was first broadcast on Canterbury’s community access radio station Plains FM 96.9 and was made with the assistance of New Zealand on Air. |
| 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 whāTēnā koutou katoaNau 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.Kia ora, this is “Speak Up” – “Kōrerotia”. Today we’re talking about disability advocacy and inclusive communities. I’m really, really looking forward to this panel. We’ve got a lot of people here in this studio - the most people we’ve actually ever had in the studio - who are going to be sharing the different things they do towards fostering inclusive communities for people with disabilities. Let’s start with some introductions.  |
| Caroline | Kia ora, my name is Caroline Quick. I’ve got down syndrome. I’ve got a lived experience in the disability sector, that’s my main role in the disability sector and advocacy.  |
| Sally | And you’re involved in Enabling Good Lives.  |
| Caroline | Yes I am, yes.  |
| Sally | If you could maybe tell us a little bit about that.  |
| Caroline | Enabling Good Lives is… we’re trying to transform the disability system across New Zealand.  |
| Mark | Hi, my name is Mark Lewis. I have got cerebral palsy and I am living independently at Hōhepa. |
| Racheal | Kia ora, my name is Racheal. I am a mum of four amazing children and I have three children with autism and a few other add ons. And I am also part of the Enabling Good Lives system transformation leadership group. I represent families and whānau on that panel and the goal is to think about how we care for people with disabilities and the funding that they receive and making sure that the system is better.  |
| Rich | Hi, my name is Rich Feldman. I’m the father of Micah Feldman who has an intellectual disability who is now 36 years old and I’m very active in community building and in creating inclusive communities and an inclusive social movement in Detroit and around the United States and just really honoured to be here.  |
| Sally | Thank you Rich. And in fact your visit to Christchurch is what sparked this panel, both you and your wife Janice.  |
| Janice | Well that’s a lead in. Kia ora, my name is Janice Fialka, married to Rich Feldman for 40 years, we have two adult children - Micah, who Rich mentioned, and also our daughter Emma who is a second grade teacher. We come from the States, she is in Boston, Massachusetts, doing full inclusion in her classroom, so she has children with and without disabilities in her classroom as well. And we’re excited to be here and on this panel. Thank you.  |
| Sally | Talking very broadly here, but what is disability advocacy and why does it need doing?  |
| Mark | I find disability… I think it’s one of the things why having a go at things, if you have got quite a challenge that you don’t know whether you can do then you can always get someone to help you through with making choices, making small decisions and it if it’s quite hard ones then we can [get support] to jump in to make those kind of choices for you.  |
| Caroline | In my personal view, it’s about helping other people for those people who can’t be able to talk on behalf of themselves. That’s where advocacy comes in. I am a trained advocate so if any other people doesn’t have a voice, then I step in on behalf of them if they need any help or assistance in any way.  |
| Janice | And it strikes me as how when we support each other’s voices, our own voices become stronger as well. I think a part of advocacy, too, is a sense of pride for who you are. So in the United States we’ve been involved in what’s called the Disability Pride Parade and when I was a mother of Micah when he was just a child, I don’t think I ever thought of putting those two words together and my transformation has been really understanding disability as a difference and not a deficiency as an identity. So I think for me, that’s part of what advocacy is, is that transformation.  |
| Rich | I think in the same spirit of advocacy, I always ask advocacy for what and where are we going. And I think for our son, and for growing numbers of people with disability that we encounter and work with in the United States, it’s so much about creating a community that includes everyone. I mean the phrase, “Nothing about me without me,” which comes from the South African anti-apartheid movement but emerged as a disability theme. And so much about how do we challenge the larger society to realise that the gifts every human being has, regardless of ability or disability, regardless of ethnic background. The folks with disabilities are leading the journey for transformation of a whole culture and it’s the best way and most important way for us to stop the othering that goes on in our society so easily.  |
| Racheal | I agree, for me it’s about community inclusion and for me with young children, it’s about being able to go into an environment and not fear that the children are going to be judged or excluded because of their challenges that they face. I would like them to be embraced because of the gifts that they bring and the richness of the way that they see the world is valued. So it’s not just making it a tokenistic statement - “We’re an inclusive community” - but actually living as an inclusive community and schools as well being more inclusive in New Zealand and embracing that children with disabilities aren’t a nuisance or something to put up with but something to be embraced and celebrated.  |
| Caroline | Being part of your community is very important to keep a connection between the wider community around you. You need to have the sense of safety and belonging and that’s what is really important of being inclusive.  |
| Janice | It’s such an honour to be here and to be having this conversation, is that it isn’t always easy. It’s not just about being nice and tolerating as you had said. Advocacy, I think, requires being able to have those difficult conversations.  |
| Racheal | Brave conversations.  |
| Janice | Yeah and you know, we challenge each other. We need to be able to be challenged to understand what does it really mean to be an inclusive community.  |
| Rich | And that’s what it means to break the silence and difficult conversations and not believing you’re an inconvenience because that’s how society changes.  |
| Sally | Racheal, you touched on schools, it would be great if we could talk a little bit more about education and the education sector.  |
| Racheal | You talked about the class having one door in and Micah wanting to go in the other door and you hearing him say that and making his dream of being included in the school come true. I guess that’s for me as well. So we are mainstreaming our children which is very much like what you’re daughter is doing - so there’s abled and disabled children in the classroom - and it’s about accommodating that need within the classroom without it seen as… what’s the word… a pity thing. Yeah, it’s about accommodating their needs because it’s the right thing to do and for it to be demonstrated to the other children that because we have people in our communities that need something else, it’s not a bad thing, it’s a thing to embrace and to see how can I help my friend or my peer or my colleague and that will live with them hopefully for the rest of their life. That skill of seeing that there’s something that somebody else needs to be able to come to their level and being able to do that. So that’s not been my experience up until recently, that schools have accommodated the needs of my children in the school but it’s changing and it’s changing for the better and it’s great to see, so they are able to be mainstreamed and go in the same door.  |
| Caroline | In my lived experience, I’ve been through mainstream all my life and I… yes, I found it tough and yes, I did get bullied in some of it but some of it is inclusion. When I first moved over here, I found it very easy going, very easy to make new friends, very easy to make friends who have got the same disability as me which is fantastic. The only thing that has brought it down a bit was I didn’t get any ORS funding and so my mum and dad had to fight and so I was only at school for about three years over here. And so I left school when I was 19 and then I went on to polytech and did a two year course which I really enjoyed. Then I did further studying, I did a barista course, hospitality course, I’ve done retail and yeah, I’m enjoying life.  |
| Sally | I’m sitting here thinking oh, I hope my coffee is good enough, you’re a barista.  |
| Caroline | Nice coffee.  |
| Sally | Well we might have our first song and then we’ll come back and talk a little bit more about disability advocacy and inclusive communities.  |
|  | **MUSIC BY STAFF BENDA BILILI – MARGUERITE** |
| Sally  | This is Speak Up – Kōrerotia and today we’re talking about disability advocacy and inclusive communities with Caroline, Mark, Racheal, Rich and Janice. I’d like to start this section off by thinking about labels and how labels can be quite harmful and I open that up for comment.  |
| Caroline | Labelling for me is quite difficult. I found it very hard to accept that I’ve got down syndrome. But the only way that has got me going, the way that my parent has taught me, is to put my disability second. So my parents has taught me you are Caroline Quick who happens to have down syndrome.  |
| Janice | One of the things that I’ve said as a mother, is that all the labels that our son Micah has received over the years distract me from seeing the child that I knew and I bore. You know, that all those labels sort of plastered over his face and what I found is that the way I can let go of those labels is to tell stories about Micah and hear stories about who he is as a person. So the stories become who Micah is. So when in third grade, when one of his teachers called and said I just want you to know that Micah counted to 30 today, that there were no more labels, it was just his ability to move forward. So labels can get us services that we sometimes need, or supports, but they don’t tell the whole picture of who we are as an individual.  |
| Racheal | Interestingly, one of my children would actually wear his label with pride. So again, it shows the diversity of how each person may think about who they are and how they identify themselves. So an interesting wee story - and I’m sure he won’t mind me sharing it because he’s let me share it before - is recently there was a lot of debate going on about vaccinations and he asked me why are people so concerned about vaccinations. I said to him well there was a study done a long time ago where a doctor associated vaccinations to creating or causing autism, lots of people believed him and then they found out that he had told lots of lies about the study and that there as no connection between vaccination and autism. Then when my wee boy piped up - and he’s only six or seven at this stage - said wow wouldn’t it be amazing if there was a vaccination that could give you autism because then you would have a brain like me. And I thought that was incredibly amazing. So he wears his label with pride because he sees it as a benefit in life because he can see lots of things that other people don’t see.  |
| Rich | Labels are what other people and usually those in power, give to others. Identity is what you choose and we choose to be the kinds of human beings that we aspire to. The T-shirt people have in the States is “Label jars not people.” But it’s the identity of who we are and where we want to go that allows us to be human and that’s what we’re all struggling for, and that’s why society would rather have labels, so they don’t have to deal with all the complexities of being human because that’s scary to people. They don’t know how to grapple with all these relationships and all these differences, this diversity.  |
| Caroline | There’s one motto that I’ve always thought about, it’s “Nothing about us without us.”  |
| Janice | Yes.  |
| Caroline | And that motto has really empowered me to become of who I am today and I got loads of friends and family who are around me, it’s really helped me to accept of who I am. The main ones has made me of who I am today would have to be my mum and dad and my sister and my grandma, they’ve been a huge inspiration in my life.  |
| Mark | I think the people who have actually been supporting me has got to be the staff members of Hōhepa. They’ve been wonderful and helped me out to try and find a job, they’ve been helping us out with doing shaving and stuff like that as well and they’ve been helping us with more like the hardest [*inaudible*] that we’ve got at the moment and hopefully that they can continue doing that over the years. To my mum and dad, they’ve been wonderful to me as well. They’ve been helping me out. To my sister, without her I would not have been here without her because without her I would not have been able to raise a little niece which is just wonderful.  |
| Racheal | Mark’s dad did an amazing fundraising event last year.  |
| Mark | Oh yes, my dad has… he’s actually done… my dad was a real estate agent and he has decided to fundraise a motorcycle race and it was actually quite far away. I think it was actually from Australia all the way over to the finish line and he actually managed to get it done and was… that was actually quite a hard thing for him but he actually put it through and made it happen.  |
| Racheal | He rode a mail motorbike.  |
| Mark | It was a postie bike challenge and he was riding a little Honda, my dad got injured at some stage but he was OK to get back on the bike and managed to complete the whole challenge.  |
| Racheal | So they rode through the Outback for a week.  |
| Mark | I think it was.  |
| Racheal | So that’s what parents do, they get on motorbikes and they ride long ways and they raise the awareness of disability as well as raise some money.  |
| Rich | I was wondering Caroline; how would you share with other young people and their parents what your parents did that was supportive of you becoming the person you wanted to become? What are some specifics you might think about or share?  |
| Caroline | It’s to have faith and independence and for other people to let other people… give them support. If you can’t find any support, then go to a friend or a close relative or go to someone that you trust to be able to help that person out if they need it.  |
| Janice | That is something that our son Micah has really taught us and I think the disability justice movement, is that to have the dignity to be able to ask for help and see it as a strength and not a weakness. And learning how to ask for help without apology but with dignity and intention as well. So I’m grateful for that lesson and still learning it as well. I remember when Micah was having to fly by himself - and he doesn’t read or write in the typical sense - so he was at the Chicago airport which is massive and he had to get from one gate to the other and he arrived at the gate that he needed to be at and was kind enough to remember to call me, because I was sitting wondering how he was going to get there. So I asked him this question, I said how did you get from one gate to the other and I could almost hear him rolling his eyes, right. And he said, “Mum, I just asked for help.” So I think we spend so much time not asking for help, if we can move into that that’s a better way.  |
| Sally | I also like this idea of asking for help, asking for support, and the idea that I think you guys are quite keen on is this idea of interdependence rather than just independence and recognising that humankind is all about connections to everybody.  |
| Racheal | So I’ve got a wee story about that. The dignity of risk and allowing our children taking a risk and giving it a go and as a mum you worry that that risk is going to end badly. And for me, we have a daughter who was hit by a car last year on Columbo Street and so roads are a big fear of ours and it’s a reality because you know, it’s happened, she was hit and in hospital. But my wee boy has decided that he wants to scooter or run to school which is three kilometres away from our house to the school and it was that taking a big breath, and he was going with his really great friend, that they can do it. And I said to him - same conversations! - how do you know how to get across the road? And he said to me, “Well my friend says ‘Run, run, run, run, run’ and I run when she says.” So I’m just holding faith that it’s going to work and giving that dignity of risk that he wants to do that and even though his wee sister was hurt on the road, that he will be OK and this is a really nice thing for them to do.  |
| Janice | Cheers mum, it’s hard to do.  |
| Caroline | It was hard for my mum to let go when I first moved out of the family home and went flatting. It was hard for me leaving the family home for the first time and a bit later on, when I went onto Facebook, my mum wrote on Facebook saying half of me I am happy for my daughter, the second half of me, I’m going to miss her. And it was like letting go to let me have the freedom that I want. And then I’ve been flatting on and off and it’s been an incredible journey knowing that I’ve got the support that I’ve got. I know that I’m going to be OK.  |
| Janice | The phrase that I’ve learnt for families or for parents and caregivers: It’s not about letting go, it’s learning how to hold on differently. Because we never totally let go and that has been helpful for me to think about: How do we encourage in a different way than just holding back? So hats off to your mum and dad allowing that to happen.  |
| Caroline | My parents have been amazing throughout all the past 31 years.  |
| Rich | I think the question for parents often are challenged with is, what do we mean by security, how do we create security and also acknowledge the importance of risk and interdependence. Micah is now 36 years old.  |
| Janice | 35 dear.  |
| Rich | 35 years old. 1984. He’ll be 36 in September. And he lives 410 miles or almost 700km from where we live now with supports in Syracuse, New York. We live in Detroit. And I think the three principles that guided our vision and were important that Mike taught us was 1) having great expectations which clearly all the families sitting around this table have had and you have for yourselves and your families have had. 2) education was a lifelong process and we didn’t just mean schooling, we mean education of life and growing. And the third was it wasn’t just about how Micah changed, it was how the community around him changed because the security of Micah depends on other people becoming much more conscious, compassionate, caring, recognising that they become better human beings because they know our children, because they know a broader, larger perspective of humanity and now their own narrow just go on their own little stream of I’ve going to take care of myself. But the ‘we’ becomes very important. So it’s that community building that allows us to take risks and knowing that there are people out there to be support of and with us.  |
| Sally | I think we might have our next song and we’ll have Mark’s choice.  |
| Mark | OK I would have to choose ‘Rocket Man’ by Elton John.  |
|  | **MUSIC BY ELTON JOHN – ROCKET MAN** |
| Sally  | Welcome back to Speak Up – Kōrerotia. We’re discussing disability advocacy and inclusive communities here on Plains FM, 96.9. We’ve touched very, very briefly on this idea of disability justice. Janice maybe if you could fill us in: What is disability justice in a kind of a definition way and then maybe we’ll open it up for how you all personally see disability justice.  |
| Janice | Yes well I’m still learning and growing on that. But I think what I’m learning is disability justice is so much more than just access to being in the world. It’s not just about building ramps or making sure that there are laws - which of course are important - but it’s really about redefining what it means to be human. We can enter into the world and create a world from very different perspectives. There’s a quote out there that disability is an ingenuous way to live, that it takes imagination and so that respecting that there’s so many different ways of being in the world. So that’s part of it.  |
| Rich | I think we’re often familiar with disability advocacy, even becoming more comfortable with disability pride, disability rights. Disability justice is a deeper interconnection between the fact that folks to have disability justice in our society, need to transform our culture and our systems that have been based on often racism and capitalism and patriarchy and all the ism’s that go together and that disability justice, separate from that, can’t exist. As a friend recently said, inclusion doesn’t mean I want to enter a house that’s really burning. I don’t want to enter a culture that’s very destructive. We need to create a new culture. So disability justice is about the transformation of a culture, of an economic system, of a way of thinking. Of saying what is success, what does it mean to be human and that means creating ‘beloved communities’ as Martin Luther King talked about. In Detroit, that’s somewhat being expressed through our commitment to create inclusive housing for people with and without disabilities in an ecovillage, so people can create sustainable communities. So it’s about a transformation for all of society and not only of how do I get access into this society that has been so painful for so many people.  |
| Caroline | One thing that I have noticed in the community is discrimination against people with disabilities. People with disabilities need to try and find a voice and to tell people that lived experience around discrimination act. Discrimination against people with disabilities is one of my main concerns in New Zealand and I actually feel sorry for those people who are getting treated in that kind of way. The other side of it in the disability justice is to get accessible housing around our community and to make housing in New Zealand to be a bit more cheaper because some people with disabilities may not be able to afford it and it needs to be reached within their budget. All housing needs to be accessible, all the buildings need to be accessible especially for the people who have got higher needs like wheelchair users, elderly with walking frames and other people who are travelling with children like in their pushchairs and stuff, it has to be accessible to meet the criteria for them to be able to move around in the community and how to be safe in the wider community.  |
| Racheal  | We’re doing that work at the moment too with the Enabling Good Lives project, looking at the way disability funding is allowed and you know, disability justice is about making sure that it’s fair and equitable. We were talking before we came in how many different ways people are funded in New Zealand and it does create an unjust system for many people, especially if you have a barrier to accessing it. So maybe English isn’t the first language or education and people aren’t getting what they are entitled or the system isn’t working in a fair and just way which is what Caroline and I are doing in our leadership group, looking at how disability funding, the system is working here in Canterbury in the entire New Zealand.  |
| Caroline | I did forget that I am one of the disabled reps with the Regional Leadership Group with Enabling Good Lives, I forgot to add in that I’ve been involved with Enabling Good Lives since the very beginning. It’s been really helpful; it’s given me a learning curve and different principles of enabling good lives.  |
| Sally | We’ve touched on physical accessibility with wheelchairs and walking frames and pushchairs and things, and you’ve touched on funding - some things that New Zealand is doing well in some ways and some ways it’s still got to improve.  |
| Racheal | So even things like disability justice in terms of people having rights to open bank accounts and there’s lot of barriers for a person with a disability to have the same rights to even open a bank account through all the other legislation that’s happening at the moment, bank laundering - there’s all these types of ID that you need, for example. So you would need a drivers licence; well, most people with a disability don’t have a drivers licence because that’s not their reality so they’re excluded by that or forced into another route to get other ID which is expensive, simply to open a bank account. I think we need to consider the real needs of people with disability around common sense legislation and how that creates barriers for our community. Lots of other things… Can you think of anything, Mark? What about getting on the bus with your support person?  |
| Mark | Getting a bus is another one, that you all have own Metro card and that with it. But you’ve always got to make sure that everyone is [*inaudible*] because there’s [*inaudible*]. |
| Racheal | [In Canterbury] if you have a support person with you on the bus, the person with the disability and the support person both have to pay for the bus. Whereas in other parts of New Zealand they don’t see that the support person is there because of the person needing the support so therefore they shouldn’t have to be paying as well. It just makes it more expensive for people to get around and it’s not fair or just.  |
| Sally | We’re talking about accessibility, being able to move is important.  |
| Racheal | Yes absolutely.  |
| Caroline | The other thing is the health sector as well although we’ve got a few free prescriptions and I’ve also noted that the doctors have lowered their cost, but before that it used to be really expensive. The health sector needs to be more accessible for people to use and to get the right information from their doctors. Sometimes they’ve been for a support person to come in to be able to understand what the doctor needs to do and to me, that’s important to be included in that sense… in that sense of safety and knowing where you are is another important thing for me as well. Knowing who you are, how to express yourself in the community and I find that very important.  |
| Racheal | Caroline raised a good issue, another barrier is that safety of knowing where you are or who… you know, having a mobile phone is critical often to the safety of people with disability yet generally it cannot be included as a disability related cost, having a mobile phone. Yet we absolutely know and good common sense again, you know, it’s essential for people to have a phone for safety.  |
| Janice | Yeah I don’t think I’d have been able to support Micah taking two buses up to the university if there wasn’t a phone. The story of Micah and many of other students in the United States with intellectual disabilities who are learning on a college campus and there was a lot of interest generated by people who want to support this to occur here in New Zealand as well. So when Micah decided that he wanted to go to college, initially that just was not acceptable because he didn’t read or write, couldn’t take the required test but we were able to create a fully inclusive college experience for him on a campus. And as I said he took two buses up and was on campus for a number of years. At that time, ten years ago, there were just a few individuals who were learning and continuing their learning on a college campus; now, in the United States, there are over 285 programmes so it’s really grown exponentially. So we’ve been excited to have conversations with individuals about how do we begin to move this forward into New Zealand as well. So I think that’s a whole other opening up the stream. And it not only supports someone you know, with an intellectual disability, it changes the whole campus because we are learning to live together, not waiting for someday for that to happen.  |
| Caroline | Since I’ve got down syndrome I was delayed in my speech. So I learnt the old fashioned American Makaton sign language for me to communicate with my family and my peers, and when I started talking I was about maybe five, maybe six and now people tell me to shut up sometimes because sometimes I talk too much. The other thing that I was delayed in was my walking. Back in those days they didn’t have any prenatal tests to show that I’ve got down syndrome so they got told in the doctor’s office that I’ve got down syndrome.  |
| Rich | I just think that’s the question. How do people get their rights? Every country is different.  |
| Caroline | There are human rights put in place now and they’ve put down quite a few principles. Like from the CDHB [Canterbury District Health Board] with all the rights that needs to be covered within the health sector, they’ve got a right to make a complaint if they want to.  |
| Rich | I think this is correct from just being here a short time, that folks in Christchurch and in New Zealand were very active in creating one of the first suffrages, women’s suffragist movements in the world, right to vote. Have been very active in… was very active in the anti-apartheid movement against the violent racism in South Africa and very active in the nuclear disarmament movement. Our son Micah has had a chance to go to college - and we’re not saying everybody should go to college, that’s not the point - but a chance to live the dream that he wanted to live because a woman named Judy Heumann led a sit-in in 1977 for 100 activities, for the longest sit-in in a federal building in the United States, that led to a law called the 504 being implemented. Which meant that there has to be access, they said in law there should be access but they never gave money to make it happen. So we have all these brochures and all these human rights declarations but they don’t put the funding behind it to make it happen but it took a sit-in.  |
| Janice | Of disabled activists, I think that’s… |
| Rich | Disabled activists were part of it.  |
| Janice | They brought in with their oxygen tanks and their wheelchairs and their interpreters and they stayed in the building for 28 days as well. So yeah, so that’s part of it because see right, it’s being able to really put your body on the line in a sense too, not that everybody has to make that choice.  |
| Rich | And the American’s Disability Act got passed in the United States partly because folks went around and they got all the stories and brought them to Congress, but also because there was mass demonstrations of people with disabilities in Washington DC. So I say that to say that how does a movement help us get our rights. Advocacy is both within the system of getting law makers to do stuff, it’s also challenging them to realise we’re not going to be silenced, we’re collectively acting and we’re collectively engaging in a social movement and I think that’s a critical lesson from our experience.  |
| Sally  | Well we might have our final song and we’ll get back and wrap this all up.  |
|  | **MUSIC BY JEFF MOYER – DO YOU SEE ME AS AN EQUAL** |
| Sally  | To wrap up our conversation on disability advocacy and inclusive communities, I’d touch briefly on technology and how it can enable inclusion.  |
| Caroline | Technology is very important in New Zealand to keep in contact with family and friends especially when if we have a natural disaster, to know people where they are and to see if they are safe.  |
| Mark | If we didn’t have one, I would not have been able to contact our parents to make sure that they were OK or friends or inside. Especially good to keep in touch with them just in case our friends if anything were to happen, like an earthquake. It is very important to make sure that you get provided with… their need for the internet or something like that is very important, to make sure that you can keep people in the loop at all times.  |
| Racheal | My wee chap at primary school has just been identified as having fine motor skill deficiency, I guess, and we are going to go down the avenue of getting OTs in to do speech-to-text. And it wasn’t something that had been sitting in my mind because he seemed capable and was doing OK but it was actually to dig deep and see what was going on under the surface and finding out that the amount of energy that he was putting in to just write and if we could save that energy for other things, we might see an improvement in other areas of his life. So technology isn’t just about doing what they can’t do but supporting the energy stores to put it where it needs to be. So that has been a really interesting development in our own family’s life, how we’re going to need to go down that technology route.  |
| Janice | Yes you described that so well, I don’t think we had the awareness but we sort of moved with that with Micah and the other piece of that, the energy piece which you articulated so well. The other piece is that if we can move closer to what we can do, it became clear that he wasn’t going to read in a typical way, his ego wasn’t smashed either. The sense of himself and his abilities was strengthened through the technology because if he would have stayed with continuing to try to read, that would not only have taken away his energy, but also made him be aware of what he couldn’t do as opposed to what he could do. So yes, that’s been very important. The caveat is that technology doesn’t mean that we have to be like everybody else.  |
| Racheal | It also fits beautifully with what you were saying, it’s about asking for help. So it’s using technology as another means for asking for that help.  |
| Rich | I can by voice, ask my cell phone to go somewhere: How do I get directions? I can ask about the suffragist movement in New Zealand. I can ask what disability organisations I can work with; I don’t even need to be able to read in the traditional way. We’re in a technological revolution in many ways. The other thing about technology is if we can imagine building a house with someone who understands technology and fabricators and the ability to bring in the new technology, we could build a house. We don’t have to be hammering every nail. If we can imagine it, you can create it on a computer and you can produce it and that means people can become responsible for their lives and for their communities in ways that we don’t have to rely on someone else building our chairs, building our cell phones, building our cups; it’s a whole different way. And 50 years from now, what’s possible? It’s all in what you talked about: support for your own self-respect.  |
| Sally | So this is a perfect segway into just the final concluding points. Your visions and what you’d like to see happening as we go forward.  |
| Janice | Well I’m going to just leap in, my vision is that there be a wonderful radio show on a weekly basis because I think this kind of discussion publicly needs to be on a regular basis.  |
| Racheal | I would just like to agree, I think having the voice of people who are living and living well with a disability. I think that voice needs to be heard more.  |
| Mark | Totally agree because without a voice, when we’re inside, we won’t be able to talk with friends and also [*inaudible*]. It’s actually quite a good idea.  |
| Caroline | I think this is very exciting especially talking on the radio. Having a voice.  |
| Rich | In that same spirit, I would love to project a vision that one day in New Zealand and one day in the United States, governments will be run by people with disabilities, people who come from the Māori culture, because that’s when it will be an inclusive world that we’ve created.  |
| Sally | Perfect place to wrap it up. I’d like to say kia ora, tēnā koutou. Thank you so much for coming in and this has been a really enjoyable, uplifting discussion.  |
| Group | Thank you.  |