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# ‘Being a parent of a disabled child and a disability ally’ – transcript of Imagine Better’s online panel of 13 April 2021

Work continues to improve this transcript and we apologise in advance for any inaccuracies. Please email [info@imaginebetter.co.nz](mailto:info@imaginebetter.co.nz) and tell us about any improvements we can make to this transcript.

Zoom Time and Date: 12 noon, 13 April 2021

The panel was led by Dr. Carey-Ann Morrison, with panellists Bernadette Macartney, Jane Bawden, Rod Wills and Antonia Hannah.

## [Carey-Ann Morrison]

Kia ora kōtou. Hello and welcome to the second panel in Imagine Better’s Disability Ally Campaign. My name is Carey-Ann Morrison, and I am here as both Image Better’s senior researcher and as a parent. I am lucky to have the role of Momma to a young disabled son named Lachie. It gives me great pleasure to welcome our four speakers today, and to welcome those of you who are joining us through Zoom, or who are watching the livestream on Facebook.

Before we get into things, we’ve just got a bit of housekeeping to get through. First off, as this is a Zoom webinar, if you are here as an attendee you won’t show up on screen; you will just see our presenters, me and the New Zealand sign language interpreters. People requiring NZ sign language interpreters should pin the interpreters to their screen. Our NZ sign language interpreters today are Shosh Cleary and Sarah Moss-Kennedy. Welcome Shosh and Sarah.

We have decided not to offer closed-captions to everyone because of the poor quality, but you are welcome to turn them on using the floating toolbar near the bottom of your screen. Please note, there is a bit of an element of ‘buyer-beware’ with this. If you have any questions please use the Q&A feature at the bottom of the screen. Any questions you submit will come directly through to our panellists. We will try to make sure we respond to and publish any questions that come up in the course of today’s session.

We have left the chat function on, but ask that you only use it if you need technical assistance. You can also email us [info@imaginebetter.co.nz](mailto:info@imaginebetter.co.nz) and we will try and check the emails throughout the course of the discussion.

Finally, we will be publishing the recordings, transcripts, Q&As etc. on our website, so please check back there in a few days for these. You will also be able to access material from our last panel, as well as a range of resources related to the Disability Ally Campaign.

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Now, with that done, I want to briefly talk about the theme for today's panel discussion and introduce our wonderful panellists.

The theme for today is the role of parents as allies within the Disability Rights Movement. We know that parents play an important role in the lives of their disabled child or adult, particularly for people with learning disabilities; and we know that for many parents advocacy in relation to education, housing, healthcare or any number of things, is a daily task that can start when the child is very young, and can continue well into adulthood.

At the same time, we also know that parents very tremendously, in their understanding of and commitment to disability activism as expressed by disabled people, and the disabled persons' movement.

In today's discussion, we want to delve into some of the complexities and explore issues of power, privilege and positionality.

We have set of questions that will help guide our conversation, but we want to make sure there is space for the discussion to develop organically, so we can address issues as they come up.

In different ways and in different spaces, all of today's panellists share a commitment to supporting the rights of disabled people, and have contributed to building a stronger disability rights movement. So, without ado, I am pleased to welcome our panellists to say a few words about themselves and provide some context about where they each fit, as the parent of a disabled child or adult, and a disability ally in the Disability Rights Movement.

How about if we start.

Bernadette is directly to my right. Bernadette Macartney, if you could spend a few minutes introducing yourself. Welcome.

### [Bernadette Macartney]

Kia ora. Thank you Carey-Ann. My name is Bernadette Macartney and I live with my family in Wellington. My daughter Maggie-Rose is about to turn 25. I became involved in the Disability Rights Movement from when Maggie-Rose was little, because very soon I bumped up against negative attitudes and things that I thought were strange – happening in education and everywhere for her. I studied about disability rights, particularly in the area of education.

From there, I've become an advocate, and sort of feeling like there's not much support around that; just getting through in order for Maggie to get access to things that were happening at first in education and then since she's left home in the wider world. I have also been involved in helping parents to network together that have disabled young people at school, and also in the performing arts – which is

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an area of interest for my daughter. So, I sort of got more into the practical relational change making as Maggie has got older and I have got more cynical about changing systems I suppose. So, kia ora.

### [Carey-Ann Morrison]

Kia ora Bernadette. Moving to Jane Border. Welcome Jane.

### [Jane Bawden]

Thanks Carey-Ann. Kia ora. Hello everybody. It's such a pleasure to be here. I am based in Auckland with my family. I actually work in the beautiful Waikato, which is where I am today. We have 23 year old twins, one of whom our son has a rare chromosome disorder and significant support needs around that.

When I think about the question of where I fit as a parent of a disabled adult, and the Disability Rights Movement, our path has been very similar to Bernadette and her family. But, I would describe my primary role in his life as being the mother of an adult. It has helped having twins because I always had this example running alongside, of what life should be looking like for him as well; in my role to provide the support that he needs, as someone with high support needs, to live a good life. That ranges from ensuring that he has the space and time to do independently what he is able to do independently, or can learn to do independently, through to ensuring that he has the support that he needs to manage the rest of his life, and that he really importantly is supported to express his opinions and make choices and decisions in whatever way that he can.

I have some examples around that, but later on is a better time for that Carey.

### [Carey-Ann Morrison]

Thanks Jane. We'll move to Rod now. Welcome Rod.

### [Rod Wills]

Thank you for the welcome and the opportunity to participate. I guess like the previous two speakers this journey started around the birth of our daughter Sophie. She is the eldest of our three children. In terms of the deficit labels that can be applied, hers is one of Downs Syndrome. I think what we have come to understand - across a period now of, gosh, this year it will be 37 years - is that there's not a typical pathway. There may well have been for individuals like Sophie in the past, and it's certainly where not so long after her birth I was involved working in Māngere Hospital – the big psychopaedic institution here in Auckland.

We closed the institution down and moved people out to live in the community. I think the impetus behind those sorts of shifts and changes has been really, really important.

Paralleling with those moves was, of course, then the opening up of the right to attend and participate at a local school. Both moves for individuals like Sophie, who had been in the institution, and the inclusion of young children as learners like Sophie in their local schools, has given rise to a whole bunch of questions, that have drawn me in for 30-odd years in a range of roles. For the last considerable

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period of time, I have been teaching and researching at the University of Auckland in the area of disability studies.

My work really, I would say, has been in the voluntary sector for the entire period, and different initiatives in leadership and governance, starting from cross-sector early intervention, to education policy reform, to major policy work there.

Interestingly, like Bernadette, I have spent the last 12 years involved with community arts – people with disability leading an organisation in Auckland, and ensuring that perhaps what people can become, rather than what they can't do, is how they are seen.

Sophie is very clear about this. She's at work today. She sees herself as someone who has a range of things to contribute, both in the work setting as a colleague in a school, and in the area of theatre and dance. Those things are really important.

Where it has moved me though, has been from being the parent, speaking for and to the needs of our daughter, hearing and engaging with others, collectively speaking to the needs of other learners like our daughter; and now over that period of time, coming to the point where with a colleague we see the most important thing we can do is to challenge some of the ablest thinking and notions by working in ways to bring the narrative invoice of disabled people to the forefront – particularly people with learning disability – through a range of creative communication media. We're doing that.

And, I am writing a PhD – finishing that and looking at medical training in general practitioners and how they learn about families who care for people with intellectual disability from the two universities in New Zealand – and it is disturbing. So, there's still an engagement in a number of ways.

I suppose, being privileged with this knowledge and information means I can't sit on my hands. I need to find ways of bringing these mistakes, flaws and faults into the attention of people who may become participants for change. That is really what I am focusing on.

The question is: Can I help? How can I be of value and worth, and can we do this? So, looking in that cyclical way.

Anyway, enough from me for now. That's where it fits, how it roles and what it's about.

[\[Carey-Ann Morrison\]](#)

Kia ora. Thanks Rod. Antonia?

[\[Antonia Hannah\]](#)

:Kia ora. Thank you very much. That's really interesting Rod, Jane and Bernadette. It is the path that I followed as well, branching out from the family – going out towards other people.

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I would say that right from the word 'go' disability has been part of our family. I grew up with an uncle who had a traumatic brain injury from a car accident. We lived with my uncle and my grandparent. That was my first kind of introduction to different minds; also, to a certain extent, different embodiment, because it has affected him physically – and also with his traumatic brain injury.

Throughout the family we've got all sorts of interesting stories. We've got my mother's cousins have Wagner Stickler Syndrome, which basically means you grow up blind. It passes down through the families. My great-great grandfather on my mum's side was a very good musician. He was as farmer and he was a musician. He played the piano for Queen Victoria.

Then rolling forward, I've got a son with Downs Syndrome as well. He is sixteen. His name is Max and he's happy for me to talk today.

I think I have always been interested in sociological type things. I started off my undergraduate was in sociology; so I was interested in it right from the beginning. I then went off overseas and did other work. I got into computers and that sort of thing.

Once Max was born, I kind of got drawn back to sociology. I think that kind of way of thinking was always there. I think that's what spurred me to go on outside the family basically. I've been involved with the Inclusive Education Action Group, and wherever possible been offered opportunities to talk and done it, because I feel like that is something that helps the Movement.

I can't really add any more than that. A lot of voluntary stuff as well.

### [\[Carey-Ann Morrison\]](#)

Fantastic. Thank you Antonia. What a wealth of experience we have here today. I certainly feel privileged as a mum to a young disabled son, just relatively at the beginning of my journey as a parent and an ally of the Disability Movement. So, a real privilege to be able to hear some of your stories and your experiences.

Certainly, what I heard through your stories then was the way in which being a parent and a disability ally is both personal and professional. It's individual and it's structural. It's something deeply felt and deeply connected to who we are. I think certainly in terms of education, I suspect there's going to be quite a few insights that can be shared around that space. We certainly hear from parents that the education system is something that is an ongoing issue for families and for parents as they negotiate that.

We will move onto the questions that we have today, starting with number one.

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We learnt at the last panel that an awareness of power and privilege is central to being an ally. Can you talk about this in your own life, and consider how you remain critically reflective of your position and power?

How about we go back, so let's start with Antonia for this one.

### [Antonia Hannah]

I can talk to this. I think my perspective has got in the way, as a non-disabled person. I'm quite eager, as I said before, to get involved on a political level, but every now and again I sort of thing, 'Hold on a minute! What have I said?'

A really good example was putting together a speech. Bernadette and I were involved in an inclusive education rally and we had to write speeches. Luckily we were in a team of people. We shared our speeches. It was so good, because there was a disabled person on the team and she was able to say, "This is a great speech (about mine) but there are going to be disabled people there and it could come across that they are the thing that's making life hard." It was quite a wake-up call. That was never my intention. My intention was always that it was the system that was making it hard.

So it really helped to have that person on that team and to just put a fresh pair of eyes over the speech. That was a big wakeup.

Then occasionally, people have said, "We've got to go and so some oral submissions. The more people that can do it the better." So, I've kind of gone, "Yeah, yeah, yeah, I'll do that." Then afterwards I've gone, "Oh my god! I've said something there which has come across wrong."

There was one particular one where one of the things that really annoys me is that it's a postcode lottery, in terms of where you can go to an inclusive school. What ended up happening is everyone gravitates towards the one inclusive school that's in the area. I was trying to describe that to the select committee. I was trying to describe the absurdity of that in terms of funding as well, because it doesn't help. You have got to be so careful about coming across as though it's a burden on a school.

It was really good, because those select committee oral submissions are videoed and you can listen to them afterwards; you can listen to yourself. It's a fascinating insight into the slips of tongue that you can make. That's your privilege coming through.

One other thing that I have noticed is that sometimes I think as a non-disabled person you want to barrel in and fervently make change, but I think sometimes if you've been doing it for a long-long time, and it's been part of your life-long experience, you've developed very good skills at doing that in a subtle and strong way. I can't really describe it, but I think as non-disabled people we sometimes need to hone in that energy and maybe negativity as well and the anger, and that sort of thing. Because I have noticed that disabled people are often much more positive in their way of approaching it.

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That's my view. I would be interested to hear what everyone else says.

### [Carey-Ann Morrison]

Thank you. Who would like to continue on from Antonia?

### [Jane Bawden]

The most helpful learning for me has been to read and listen to the lived experience of disabled people. I would think that throughout the life of my son, I have very much tried to put myself in his shoes and tried to get a sense of what his experience of life is like. He's not verbal so it's very much an observational approach. But, there are real limitations to that on all sorts of levels – gender, age, expectation, personal, visionary and all of these things. And, to remind myself to exercise curiosity if I feel triggered or challenged by views that are new to me, or might not sit beside the world view that I have grown up with or have developed over the last 20-odd years.

So, trying to see life through the lens of the experience of his strength, and the marginalisation of others I think is really key.

I have been influenced by the online community in particular of autistic self-advocates. I feel really deep gratitude for any opportunity to read and listen to their voices. Also too, they're explaining repeatedly – with real grace too – queries from concerned parents about what to do about this or that, and the various issues that arise in parenting. That of course has been relatively recent in the life of my son – just because of the development of the internet and digital communities.

When I look back to the contrast of when my children were young, the main influences in my life were medical professionals and therapists; those were the big influences on me. What a change-around that has been for me. I've got to give myself a bit of time and space and just acknowledge that throughout, as for every parent I think who try to do the right thing. We have obligations as human-beings to understand contemporary thought and experience as well.

I also follow a number of family organisations and disability writers and thinkers throughout the world – again online. I seek-out family stories that are relevant to us as a family. Not all are.

One of the other things that we did as a family is, when we were looking for support people. One of the people that we brought into the home was a young woman of similar age to my son, who is autistic. She's a university student. We were able to learn so much from her. She's become a sounding board for me. I can say to her, "I'm thinking about doing this. What do you think that would be like? What do you think the right thing is to do here?" I'm trying to understand certain behaviours. She has been, again, enormously gracious and helpful to me.

That would be my comment: to seek out reviews and experiences of those who are living the life.

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[Carey-Ann Morrison]

Thank you Jane. Bernadette?

[Bernadette Macartney]

Thank you. I think through learning about the social model and Disability Rights views of what's going on in our world, I've sort of just tried to catch myself in the act of maybe being too over protective of Maggie-Rose, and allowing or respecting her choices. I try to keep good networks and sort of a community around us, which includes disabled people. Like you Jane, just sort of cultivate relationships so that I can learn more.

One of the things about the term 'disability' or 'impairment' is that there's so much diversity. Sometimes ableism is everywhere and we're all part of resisting, and sometimes supporting or colluding with it. Like you Jane, I sort of try to be curious and open. We all make assumptions, but I like to think that I'm ready to have them challenged and can sometimes challenge myself – if I catch myself in the act.

I think because the world feels like an unwelcoming (or a lot of the world) and dangerous place for our children – and I suppose I'm talking about adult children here – then, we've sort of got a role in helping to protect them. But, also, sometimes that's a bit of a dance. Sometimes I think families, with our own, it's good to work as a collective with other people like support workers, social networks and organisations; so that we can get other perspectives on what's happening within our family and for our young person.

For example, one of Maggie's friends with Downs Syndrome, he was very keen and excited about Maggie's skills in music and performance. Every time I see him he asks me about how that's going and then suggests other opportunities.

On that individual, just on our family level, I think that having that connectivity and helping each other identify where we might be able to do things differently is really important.

I think it's hard for families because the world is a bit dangerous and inaccessible. Sometimes our goals conflict, parents in particular, with their children; and especially as they are getting older.

One of the examples, of the dances that we are trying to do at the moment, is to respect and encourage Maggie's independence in getting out there in the world, and leaving home at some stage. But, she doesn't want to leave home. We're not going to say, "She can live with us for the rest of our lives then." We are really keen for her to get out there and experience those things that you do when you go flatting. It's quite complex.

[Carey-Ann Morrison]

Thank you Bernadette. Rod, any particular thoughts on this issue?

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### [Rod Wills]

Yeah, a couple of strands really. I'll start with one that I've personally experienced over the last three or four years, with a series of episodes around impaired gross motor function (my own) with an episode of strength loss and then partial paralysis in my left hand. I'm fortunately right handed, but it still has a huge impact. Then, intervention to replace my right knee.

The impact of being seen in my workplace on crutches, and obviously not as agile or able to negotiate corridors and things within the university building where I was located, and requiring a taxi. You're away from driving a motor vehicle for a month and a half, to two months, and so on.

Then, being confronted with notions of risk and cost by my immediate line manager. I had a series of roles I had to complete and undertake within the university (not to do with my own teaching). Initially, he was quite happy to meet part of the cost of my journeying across to Auckland, to go to it.

But, then the point was raised that perhaps it was not safe for me to be there, and the cost of me being there was high for him. Not only did I encounter it from him as my line manager, but whenever I got into a taxi cab and indicated that I would be seeking a reduced fare, producing a mobility card, the taxi drivers would query the legitimacy of the contribution of disabled people to the workforce, because they worked harder, and what about these other people who didn't pay their own way.

I thought, 'Shit! There it is.' Just moving from apparently being able to having these issues of physical impairment, which is sort of transitory, and what crap. At a very minor level, but being reminded of the very surface nature of people's judgements and assumptions they're making about individuals. So, that's sitting there.

But, the other thing that I think, over a long period of time, that has given rise to me to express challenge and speak back, is while I've been involved with policy development and facilitation of change in schools and things that have been very successful and so on, I'm really, really aware about the way we set conversations up as binaries. And, so people can be discussing... the word 'normal' comes in. One of my initial responses is to invite the person and say, "What does that look like? What are you meaning?"

Then of course we get to the disabled binary as well. You might have noticed when I spoke about my background and the connection to Sophie's areas of need. I talk with hesitancy about labelling her with the technical term of Downs Syndrome, because that doesn't convey who she is, what she's about, what she does, the fact that she's a worker, the fact that she has a wage, and the fact that she dances and is an advocate herself.

These are the sorts of things that are sitting in the tension.

For me, in some respects, I'm not sure if it's privilege, but I will be rude and picky and point out to people that perhaps the ideas could be changed. I will openly suggest that we should in fact be thinking

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about disability identity as something to preserve – not to fix, challenge, intervene or ameliorate, isolate or terminate, as the case may be with the options around pregnancy and Downs Syndrome.

It pushes up some other issues. Now, I don't know where that puts me in terms of individual sector groups or particular people with disability, but having the sense over a long period of time of noticing this; and taking Antonia's thing – noticing the social constructs, and the sociological imagination in the way identity formation is accepted and not accepted.

I put myself in the position of perhaps raising up issues and suggesting that there are some things that have to be spoken about, and no longer accepted. I suppose the thing that concerns me the most, because it's evident is, with Sophie with her peer group, with her colleagues, her friends within the disability sector – not so much her able friends and colleagues in the workplace – about early death for people with intellectual disability. Particularly women with intellectual disability. It raises some questions for me about how we see, and how people are seen to be well and supported, and care for and about and participate fully in the community.

I have put myself into that space. A strange one: Who's the advocate at the moment? Actually, Sophie is the advocate at the moment. So, on Friday, she's part of a small applied theatre group Act to Advocate. They have a map of 42 or 43 different schools, locations and services. Six of them go there and they speak through a series of role-plays about their experience of human rights and being disabled.

The best thing I can do is to ensure that Sophie is able to participate fully in that and support her peers and her friends. If that means making them cups of tea, coffee and scones and they come here and hang out, they do. So, we do. I think that's the positive thing; to move towards something where we used to run away from disability. In the future, it almost seems like we hope now to defeat it in some way. I'm not satisfied with any of that. I think these are things that need to be preserved and honoured, and the identity to be held there as being significant and very, very central in our community.

### [Carey-Ann Morrison]

Thank you. I think also what came to mind for me through your conversations as well was, the way in which remaining critically reflective of our position as parents also means thinking about other aspects of our identity, our gender, our race or ethnicity, or sexuality; our socio economic background, our previous education, our religion and so on. Thinking about how that intersects with us as parents, with the Disability Rights Movement and how that impacts on the role that we play.

Just moving onto the next question:

At the last panel, the Disability Rights Commissioner, Paula Tesoriero, described being an ally as “picking up the baton when disabled people ask for that”. As a parent and a disability ally, I wonder if one of you could reflect on how you know when to pick up the baton and when to put it down again.

Perhaps we'll start with Jane.

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### [Jane Bawden]

My situation as a parent of a young man, who does not use spoken language to communicate, means that I have to be super aware of his ability to make and communicate decisions, and do everything that I can to support that. The example there is around supporting him to vote in the election. I know where he is capable of making decisions and not. I have learnt how to present information and the physical means of making those decisions and communicating them.

I see my job as sharing our understanding of his views and his vision of a good life, and promoting that. I have had to take up the baton on many, many occasions, as have so many parents – particularly in the education setting – to ensure that he’s heard; to ensure that his rights are observed; to ensure that he’s included; to ensure that he has access to support services that he is entitled to and needs; to ensure that he is understood and known. And, that we know what a good life looks like for him, from his perspective, and to facilitate that happening in a sustainable way.

Within our home, one of the things he has to deal with is, my husband and I are both taking up the banner at the same time with different views about what that looks like. We have to be pretty careful around that as well. I don’t know what it’s like to be non-verbal and to be listening to one’s life being discussed; but I can remind myself at all times that our role as his parents is very much to support his active engagement and decision-making, and communication of what a good life looks like to him.

### [Carey-Ann Morrison]

That draws in the idea around one of our next questions, which is around the amplification of disabled people’s voices and supporting disabled people’s self-advocacy.

Do any other panellists have any other comments on that issue?

### [Antonia Hannah]

I think exactly what Jane was saying was that there is sometimes a conflict. We are at the point now where Max is at the age and also has got the speech now to express his own views. It’s such a balance between all those roles we have, of really, really taking seriously his view, but also being a parent and making those decisions around perhaps having the age gap and experience you have as you get older, and you can see. For instance, things like sitting on the internet all day – as an older person I might be able to say, “It could, over a long period of your life, be really unhealthy to do.” So, it’s not a healthy activity. If you were to listen to your children they’d say, “No, no, we’re fine, we’ll be fine.” But, they don’t have that experience and knowledge that you get as you get older.

It’s a real balancing act. We’ve got a situation at the moment. Recently we’ve had a situation where I felt that an environment hasn’t been particularly stimulating for my son, or even safe a little bit. We are trying to work through that together because his view is different to mind. It’s really, really hard.

Definitely when they’re younger and there is maybe less understanding of what’s happening, and even less communication and less speech, I think parents do play a big part in trying to express how their child is feeling – especially when it comes to institutions like education.

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I think that would be the only thing. I mean, there's so much more.

Opportunities as parents, as humans, for us to get involved in debate is a difficult one. I would suggest, going back to that 'when do we pick up the baton and when don't we', where possible disabled leaders need to lead those debates. However, on a micro level, for instance at school, they had a debate on the euthanasia bill – which is not an open debate, it was an in school debate. I chose to speak at that debate. I chose to inform myself with a lot of the critiques of the euthanasia bill. I think that is okay. I didn't say I was experienced. I said "This is what I'm hearing when I'm going online, when I've spoken to people who have been involved in that bill."

I think it's a really fine balance basically.

[\[Carey-Ann Morrison\]](#)

Rod, do you have something?

[\[Rod Wills\]](#)

With writing up my doctoral work and looking at some of the issues that are emerging from there, my particular concern is actually the acceptance of matter of fact within Aotearoa New Zealand that people with intellectual disability will die younger. That actually contrasts and contradicts the actions and professional pathways engagement in the United Kingdom and in Australia, where these issues are regarded as being preventable death. And, there's mandatory pathways in training for people who are going to be working in general practice, to act in such a way that in fact the life expectancy, morbidity and mortality issues faced by people with intellectual disability are redressed as far as possible.

So, coming across this work and seeing it, is quite a significant component in my study. I have to choose whether I remain silent to that, or actually call it out, in a way that I connect with the organisations, but more on the medical professional side. There's a crown agency of Quality & Safety Commission.

As a researcher I have engaged with them and said, "Can you please say why you do not report and require mandatory reporting of health inequality for people with disability and particularly with intellectual disability, when you've got all these categories and sub-categories for ethnic identification of groups, and the reporting of their health inequalities? What's going on?"

Of course the answers I got were very interesting. Subsequently there's been investigations. The ombudsman has raised a series of questions. The Ministry of Health have done very little about it.

Being aware of those pieces, I feel I have still got to keep asking the question: "So, what will you do?" If I don't ask the question, and yet I know this is an issue, I don't think I'm picking up the baton that has been left in the dust, that is just being made invisible. It's just assumed that this is the way it will be. "But, coincidentally, gosh we did well."

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One of Sophie's friends, Tim, with his mum, made a very powerful series of submissions and advocated that people with disability should be able to withdraw their kiwi saver funding earlier. I think that's fantastic. But, it sounds to me as though that's a bonus payment for drawing the short-straw and going to die younger in the first place when we decided not to do anything about it.

Somehow, in a roundabout and strange way, I think there are batons on the roadside that have just been dropped and left. You don't see them until you start to put all these pieces together, unless you're doing this sort of work and reading, reading and reading, and thinking and asking questions.

So, I am going to step into that, and I will do that. I feel like, if I don't, what am I doing for Sophie and her peers? Not much. Not much of value. I think the question has to be raised up. But, I don't think it's necessarily a question for a disabled peoples' organisation, unless that is part of their ambit for advocacy and change. They can't carry everything. But, if I'm moving along that pathway and I find this, which is really quite significant, because policy wise it's been ignored, and I sit on my hands on it, then I'm an arse.

### [Carey-Ann Morrison]

Thanks Rod. We're just coming to ten minutes before the end of the session. We might move onto the next question, which does relate to some of the previous conversation we have had.

Around some of those tensions that parents might experience or have to negotiate and navigate between the goals of their individual advocacy for their child, if they are in opposition to the broader aims of the Disability Rights Movement, and the segregated learning settings is a really useful example to think about in terms of that.

Bernadette, could you reflect on anything on that topic?

### [Bernadette Macartney]

For Maggie-Rose, we have 'successfully' avoided segregated education, because we don't believe that disabled people should be segregated. But, there's a couple of things around that. One is that it's been really hard to advocate for her within regular education settings; and that that's taken a toll, particularly on me and my mental health over the years.

In response to the baton question, my first response when I heard that question was that I don't think we ever put the baton down as families. We might pass a baton, or share a baton with a disabled person's organisation, but the baton is our life. I'm trying to be really careful not to make that sound like it's a burden, or a deficit thing in [50.07], because there's a lot of positives as well.

It's really important, like Rod said, that we change the discourse of disability, impairment or difference being a deficit, and really do things to encourage, celebrate and support disability as a positive identity and contribution to society.

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We have suffered through the mainstream, if you like, and that's not Maggie, it's the system; and often very well-meaning people, which makes it quite [50.55] as well. A lot of people with smiles on their faces and actually have what you might you call 'good hearts' do a lot of harm. It's hard sometimes calling people out.

Also, I think I have learnt over the years, because I was very into inclusive education and inclusion – sorry to bandy about these flaky words – but I think that we, for quite a while, not on purpose, but Maggie in some ways didn't get opportunities to spend time with and get to know her specific disability community. We're a lot more aware of that now.

I suppose, in terms of segregation, I think there's a huge difference, obviously, between places that are compulsory and exclusionary, and places [52.00] amongst your own community. I think that we have tried to really support and uplift that in Maggie's life a lot more, than perhaps we did when she was younger.

It might also be because at secondary school she sort of met her peeps. There was a group of disabled students and peers. We sort of tried to keep those relationships going post-school, quite successfully, which is good. I think what often happens to people is that they make connections and develop relationships with people and then all those people just routinely disappear at different transition points in life.

I'm not actually sure how that relates to the question now, but that's where I'll end up.

**[Carey-Ann Morrison]**

Thank you. Just a final question.

I wonder if any of the panellists have any advice or strategies to offer to parents of disabled babies, children or young adults; any advice that you think would be useful for helping them along their journey as an ally within the Disability Rights Movement?

**[Rod Wills]**

Yeah, I've got something. I'll hold it up. What I've got there – and I can send it as a word document – is a sort of continuum that perhaps people might find themselves in when they want to take action; and then the possible reactions they experience because of that. These things can be unexpected at times. They can be very confirming, or they can be very confronting. They may change without any great notice.

So, people who perhaps might have been allies, might become antagonists. Might be in a situation with the opportunity to be consulted or engaged in something, then turns around finally when you work out that you really were being conned along the way; your voice was being taken; you weren't really being invited to join because of what you would contribute, but because it was a way of fitting you under the umbrella that the policy makers or the service was wanting to move towards.

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And, so these strange consequences and outcomes will be part of the journey, I believe, once you start to speak up and become active. It's to work out who your friends are and who your allies are. And, perhaps buy a fire-proof vest along the way and a hard-hat because there will be sudden things that you won't expect, that will emerge, and they will shake you up quite immensely. But, if you hold true to your purpose then this Movement is possible.

It's possible to see change. We can all tell you about that. It's also possible to become – and a really interesting role I think – an accomplice; so working alongside and enabling things to happen, and doing it in such a way that it's not your privilege, your voice and your identity, but change emerges.

I think they're very, very powerful roles. We're not trained or taught in them. Jane is sitting there. The important skillset around listening and speaking clearly, and some of the elements from parent to parent I think are fundamental tools for people to use.

I would simply add (then I will put this down and shut up) that aggression, threat and anger are all very, very low forms of advocacy and lead to very, very destructive outcomes. They're not at all helpful. The louder people bang their pot lids together. For me, a signal is to turn, wave, smile and start to walk quite quickly in the opposite direction.

### [Antonia Hannah]

I will say something though Rod. Sometimes you need to grab onto that anger you feel to spur you on to write something, or do something. Because you get tired and lethargic and stuff and sometimes that emotion can...

But, I think you're right, in terms of interpersonal reactions, and that includes interpersonal reactions with organisations – and trust me I'm guilty – where possible is taking a measured approach. I have noticed that the people that exceed take that measured approach.

The other thing I wanted to add was what Bernadette was saying about the networks and having that network around you, including especially if you are going to get into the right side of things, you do need to be networking in some way directly with disabled advocates. That can be quite difficult in somewhere like Auckland where it's so huge. It's difficult to network anyway. I notice Wellington is quite good for that. But, if possible, that's a really good thing to have on your side.

Always take on your journey, when you're in the institutions... because you're in the institutions and that's where you're actually affecting change. Really, your struggle, your personal and your family struggle is part of the big struggle. You do need people behind you – you definitely do. Even sending an email, or even having a conversation on the phone with someone that's part of a more powerful institution, somehow you need to have someone behind you. You need to ascertain your own skills. If you've got skills to do that, to have those phone conversations and not come out worse, that's fine; but, if you don't have those skills then send emails and make sure you've got a team behind you.

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**[Carey-Ann Morrison]**

Thank you. I'm going to have to stop there. We are bang on one o'clock and it might just cut off before we get to say out thank you and goodbye. I just want to thank you again for joining the second panel discussion livestreamed by Imagine Better. Thanks so much to each of our panellists – Bernadette Macartney, Jane [59.48] and Antonia and Rod Wills, for so generously sharing their experiences and insight to help all of us think about how we can grow in our roles as disability allies.

Thanks also to my Imagine Better colleagues – particularly Suzie Linton, our communication and advocacy manager for all of her work supporting this life event.

Thank you to everyone who has joined the livestream via Facebook.

That is all we have got time for today, but I invite you to submit any questions through Facebook or the website. We do note that several questions came through during the course of the conversation. We weren't able to get to them, but we will do our best to have answers and post them on our website.

This conversation is by no means over. We need to continue talking, reflecting and learning.

If you haven't already, please make sure you are on our mailing list. You can join that through [www.imaginebetter.co.nz](http://www.imaginebetter.co.nz).

Thank you once again. Kia ora.

**[End of recording]**