



TRANSCRIPT:

Joint Standing Committee Inquiry into the Capability and Culture of the NDIS

Hearing Date: Friday 4 November 2022

CHAIR, Ms Libby Coker MP: Thank you very much, Ms Hewett. All the best to you. Now I'd like to invite Emily Caska to come forward, please. We appreciate your time. Could you please just for the record, for Hansard, provide your name and the capacity in which you're presenting today?

Ms Caska : Absolutely. I'm Emily Caska, and my capacity is a bit mixed. I'm the CEO of Down Syndrome New South Wales, which is amazing, but I'm also a sibling. I have a sister, Lucy, who is awesome and loves McDonald's and is very persuasive, but she has a severe intellectual disability. I have an uncle with a psychosocial disability, and as of last year I have a brother with a physical disability, quadriplegic from a motorbike accident. We're from a regional area, and I've got an ageing carer mom. So I think we tick all those boxes.

CHAIR: You look very positive. Good on you, Emily. Would you like to present, please?

Ms Caska : Absolutely. A little bit about Down Syndrome New South Wales, probably to your point, Dr Freeland, we were started 40 years ago by parents who were told, when they had a child with Down syndrome, either to terminate or to put them in an institution and tell their families they had a miscarriage. We were started by a group of parents who said, 'No, we're not going to do that; we are going to raise our children at home,' and we're still here today off that legacy, which is amazing.

Dr FREELANDER MP: I can remember as a young resident going around with a paediatrician who told a family exactly that—that they should institutionalise their child and get on with life.

Ms Caska : My dad is a doctor, and my uncle is a GP, an obstetrician. They are in that generation as well, sadly. But thankfully times have changed. Again, probably to your earlier point, we do have the NDIS to thank for a lot of that. I did work at National Disability Services when it was being developed, and it really is revolutionary. I know these inquiries focus at times on the negatives, but there is a lot of good in the system, and in my submission I'm very much separating the system from the agency, because they are different things and there are different issues. But we do certainly commend that the NDIS has given people choice, voice and control, and that is at the core of its philosophy. Obviously the implementation of that is a little bit mixed, and the agency is at the core of that implementation. We're really thankful for this review, because often it is about the system, not so much the people that are running the system and the culture, so I thought the topic of this inquiry was actually really interesting.

In addressing the terms of reference I want to share for our community why the culture and capability of the NDIA are so important to people with Down syndrome and their families. Down syndrome is the most common genetic condition in the world, and it's caused by three sets of

chromosome 21. It is also the most common cause of intellectual disability, so for about 15 per cent of people with intellectual disability it is caused by having Down syndrome. There is still no national data collection, surprisingly, on the number of people in Australia with Down syndrome, and I'd probably put that forward as a recommendation to the committee that, if the agency themselves don't know the number of people and the type of people they're supporting, that's going to make their job quite hard in the first place, without that baseline data. But the best estimates are that there are somewhere between 13,000 and 15,000 people in Australia with Down syndrome, and around 12,000 of those do receive the NDIS. New South Wales has the lion's share of that, with about 30 per cent. Down syndrome does get by and large automatic eligibility into the NDIS, and that's great. However, probably to your earlier question, Dr Freeland, about the length of plans, every year people with Down syndrome are asked, 'Do you still have Down syndrome?', as are quadriplegics and others. So that's quite an interesting nuance in the system that continues.

Again why the culture and capability of the system are so important is that we know that nine out of 10 families who have a diagnosis of Down syndrome choose to terminate. So only one in 10 babies still to this day are born with Down syndrome, and we know that in part this is due to ongoing negative attitudes of medical practitioners around Down syndrome. They're given commiserations, not congratulations. But also in part families tell us it's because they don't know what the future looks like and they don't have confidence in the system, and obviously the culture and capability of the NDIS would be a part of that. We also know that 46 per cent of students with Down syndrome are mainstream schooled and 46 per cent are in special units and special classes. But for those that are in special units, the vast majority of parents want their children to be in mainstream education. We know again the NDIS is critical to that, because we know that therapies and things it provides allow for inclusive education, and that's why, again, this inquiry is so important.

We also know that only 34 per cent of my friends with Down syndrome have a job, whereas 76 per cent of my friends without Down syndrome have a job. But probably most strikingly, only eight per cent of people with Down syndrome are in open employment, where they have a regular job with a regular wage—eight per cent. Again, under the NDIS there are supports for employment, and it is the people running the NDIA that help our guys get those services and supports. This is why it's so important to us.

Lastly, life expectancy of people with Down syndrome is now 60 years plus, which is incredible. When I was born in '83, it was 25, and in the forties it was 12. We know that this has increased so much because of systemic changes, obviously access to medical treatment, but also through better opportunities, and again that's why this inquiry is so important to our members, because this is a milestone to be celebrated. People with Down syndrome are living longer. But I think what it's going to mean for the agency and what I hope it means for the agency is that, as they're outliving their carers, they're going to be speaking to people with Down syndrome more. We want that, but we know that there's a gap in their understanding around that. That's why, again, this culture and capacity inquiry is so important to us.

We've currently got a survey out to our members, and specific to this inquiry I've asked three key questions. Firstly, what do you want out of the NDIS? Why did you get it? What life do you want? Secondly, how would you currently describe the culture and capability of the agency? And thirdly, what would be the ultimate culture that you would like to tell the agency about? To the first, and I don't think this is too different to probably what my list is, to be honest, they want to live, work, finish school, get a great job, socialise, be happy and healthy and live a normal life, just like my siblings. They want to be valued, pursue their passions, help others, have their own home and fall in love. I know that if we can get those things right for people with Down syndrome and all in the NDIS, then hopefully that system will start to fade away, as it should, and the culture and capability is obviously a key enabler of this, because to us this is more than just a HR exercise and it's bigger than the current capability framework that the NDIS has, which none of our members have ever heard of; this is actually one of those really life-changing moments where, if we can get the culture right, I would anticipate the longitudinal effects of that is that we'll see more people with Down syndrome in the community, as we should, doing the things that you and I get to do, which is amazing.

Interestingly, of everyone we surveyed, only four per cent are NDIS managed. Now, we didn't really dig into that in the survey, but that's a really low number and that would tell me that's speaking in part to the culture and capability of the staff to manage their plans for them. What they currently describe the culture of the NDIA as, unfortunately, is a bit on the negative side, but they feel that it's a process where the NDIA are wanting them to have less support. There's a lack of understanding of Down syndrome, as well as the compounding impact of multiple diagnoses. There's a lack of personal experience with disability. NDIA staff are certainly stating that things like speech therapy and muscle tone therapy aren't needed, because people with Down syndrome won't ever develop, so why bother? Other words that came up were 'minimising', 'variable', 'inconsistent', 'disinterested', 'power over, not power to' and a lot of comments about high turnover, inappropriate use of language and a very unsettled and confrontational culture. That is how it was described.

However, there were pockets where it did work—never fear; there are some. Looking at that and why it worked, it was definitely down to continuity of staff or having a known and informed contact, particularly in regional areas, the role of LACs as a really important conduit or buffer between the agency itself and the person with disability and their families and, absolutely hands-down, lived experience and training in disability. We asked our members to rate their current satisfaction with agency staff and made it clear it was separate to the system, and they rated it at 2.8 out of five on average. Looking to the future, we asked them to state words and values that they would like us to put forward in this, and there were really common themes. First was lived experience of disability or as a family member, transparency and how things work, customer service skills, absolutely mandatory disability education—that came across very strongly—data informed, a committed leadership and an openness to new ideas, unusual scenarios and innovation. But above all, consistency, reliability and clarity are what came through, all underpinned by compassion, empathy and listening to understand, not to react.

In summary, one parent told us, and I think it really sums it up well, that for their child they just want a decent and sensible life where the NDIS is a light footprint but an enabling one. What we're finding from our members is the NDIS and its staff, and in the previous submissions as well, have



become all-consuming for people and are dragging on so many resources from every angle, from a government angle, from a family angle, and actually the staff and the NDIS need to sit at the periphery to give people a good life, give them their life back, give them a better life, whatever their goals are. Thank you for the opportunity to present. It is honestly my hope that if we can get this right, to my earlier example, for every one friend that I have with Down syndrome, I would honestly hope that we see the other nine born because there is confidence in the system that's going to support them across their lifespan, and the culture of the NDIA is absolutely critical to that.

CHAIR: Thank you very much for an excellent presentation. You obviously have experiences, because of your relationships with others, which mean that your insights are really valuable, and we do appreciate that. Do you want to add anything, Dr Freeland?

Dr FREELANDER: I do, if I can. First of all, thank you very much, Ms Caska, for your extraordinarily articulate explanation of where you come from and where the Down syndrome association comes from. I just want to ask you a couple of things. I completely agree that it just seems really poorly thought through to have plans reviewed so frequently, particularly for someone who has a known disability such as Down syndrome, and we need to change that. And I do agree the NDIS has been a remarkable thing for families who have kids with disabilities, giving them some certainty about the future, but we undermine that a little bit by frequent plan reviews and the anxiety that causes. I just want to ask you how you feel and what the general feeling from families is about the training of planners and how we could improve that.

Ms Caska : Absolutely. To your first point, we are actually starting to see some families come through with two-, three- and five-year plans. That's quite a new thing, and the feedback on that is really great, because obviously Down syndrome is not going away. You're not going to outgrow it. But also generally, depending on the life stage, their needs are fairly consistent, and you could do it more on a change-of-needs assessment or things like that. To the point about education, we are the peak body for Down syndrome in New South Wales and we also conduct training, and we've never been approached by the agency at all to do any training in Down syndrome.

Dr FREELANDER: Is that right?

Ms Caska : No, never. We've not done any, and we do a lot around communication styles, learning profiles and obviously just about Down syndrome itself, to my earlier point. We've not known of any, and our members would like the broader disability education. That's one overarching level, and they were very clear: mandatory; obviously Down syndrome specific, because Down syndrome often will get lumped in with intellectual disability, and it actually does have very specific needs; and again, exposure to lived experience, so not just the classroom-style education. I think if you took that three-pronged approach, that would certainly help.

Dr FREELANDER: So you would welcome the opportunity to provide some education services to the NDIA?

Ms Caska : Absolutely. We can tailor everything from one hour up to full-day training sessions around understanding Down syndrome, and we've got fact sheets and resources galore. But we've not sent them to anyone in the NDIA yet.

Dr FREELANDER: Perhaps that's the first step. I think that would be good. Due to my own particular bias, I'm a believer in inclusive education. Not everybody agrees with me, of course, but I just wonder if you feel the NDIS is helpful in supporting education systems for kids with Down syndrome.

Ms Caska : I think it has helped insofar as it helps with the precursor to it, so around providing the early intervention, supports and therapies with a lot more certainty and a bit more consistency than what we saw before. That said, we're not seeing it yet correlate through to the statistics. I wouldn't say in the last few years there has been a big jump; it's still sitting around that stable 45 to 46 per cent mark that are mainstream educated. Again in part that comes down to the previous speaker's issue, where there's that nexus between the state and federal systems coming into play and what you can access through the NDIS—as well, though, in part education. As with everything, one good thing with the NDIS is that, whilst we want consistency, the flexibility is also nice. There are some capacity-building pockets that we've been able to tap into, through the NDIS, to better educate state-based schools, but it's certainly not in the main.

Dr FREELANDER: My last question is related to the equity of the system. I see a variety of kids with Down syndrome, and their NDIS plans can sometimes be dramatically different. You're very articulate, but I'm a little concerned that people who are not as articulate are not getting as much support for their child through the NDIS as those that are very articulate. Are you seeing evidence of that?

Ms Caska : Absolutely, and not just Down syndrome; with any type of cognitive disability or intellectual disability, those initial stages around access and information are not there. Then we're also seeing it particularly with the ageing carer cohort. They're not online. They don't understand what they can and can't get. They're still, by the agency, told to think in previous service provider terms, like respite, day programs, group homes. We're also unpacking some of the emotion around that. But it is really hard for our families to know what's available and then articulate what they are wanting and dream big. Again I know this personally. My sister's 38. She still lives at home with my mum, who's 76. You would think that we'd be across it, given what I do, and to this day Mum has never been afforded any accommodation funding through the NDIA. She doesn't know what it's about. She doesn't know that she can get it. So there's still a lot to be done in supporting parents and people with Down syndrome and disabilities themselves to understand what's possible. The way that we're finding it happens at the moment is we run a lot of workshops that are more parent-to-parent, which is great, but it almost feels like it's a secret society where we're telling each other, 'I got this, so try for that.' It's still not in the mainstream at all, and I think it came across in the feedback from our members: it feels like a system—and I get it; it is an insurance system. It does have to be rationalised to some degree, but our families are saying it feels like they're wanting to take less from us and minimise the expenses.

Dr FREELANDER: How can we change that, though?



Ms Caska : I think you could provide, through the agency, more consistent case studies and best practices around what is possible and some good news stories about what has been achieved. Families love hearing from other families, and that's not really being circulated by the agency; it's more being done in pockets by organisations like us. So I think the agency has a role to play. I think that the price list as well, which is probably moving to system rather than agency—gosh it's long, and it's kind of saying all of the same things, with lots of the same prices, but it's just so granular and broken down. I think that could be uplifted a bit, because to me it just reads like the old service provider language, pre NDIS. So there should be some more real-life examples and more forums for families and people with disabilities to share what they've been able to do—that the agency staff have to attend as well, though. That's the problem. We had a conference earlier this year where we had all the parents presenting on different ways they've used their accommodation funding. Not one agency staff member attended, and we invited about 30 of them.

Dr FREELANDER: To be fair, though, I can remember going to a meeting of the Down syndrome association where the NDIS staff did attend. But over time there's been less encouragement for them to do that, and I don't quite understand why.

Ms Caska : Yes, it does seem that, I agree. Across a range of forums that I sit on, not just Down syndrome, it does feel like the agency staff themselves are quite constrained. Again, I get it. I've worked on the government side as well. But I think it would be nice to have them at the table for a lot of things, and I know families in particular would like to see some faces to the names.

Dr FREELANDER: Absolutely. Alright, thank you very much, once again.

CHAIR: Thank you, Dr Freeland. That was an excellent discussion. Thank you for your contribution.

Ms Caska : No, thank you for what you're doing as well.

CHAIR: It's much appreciated.