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The Federation
of disability information centres

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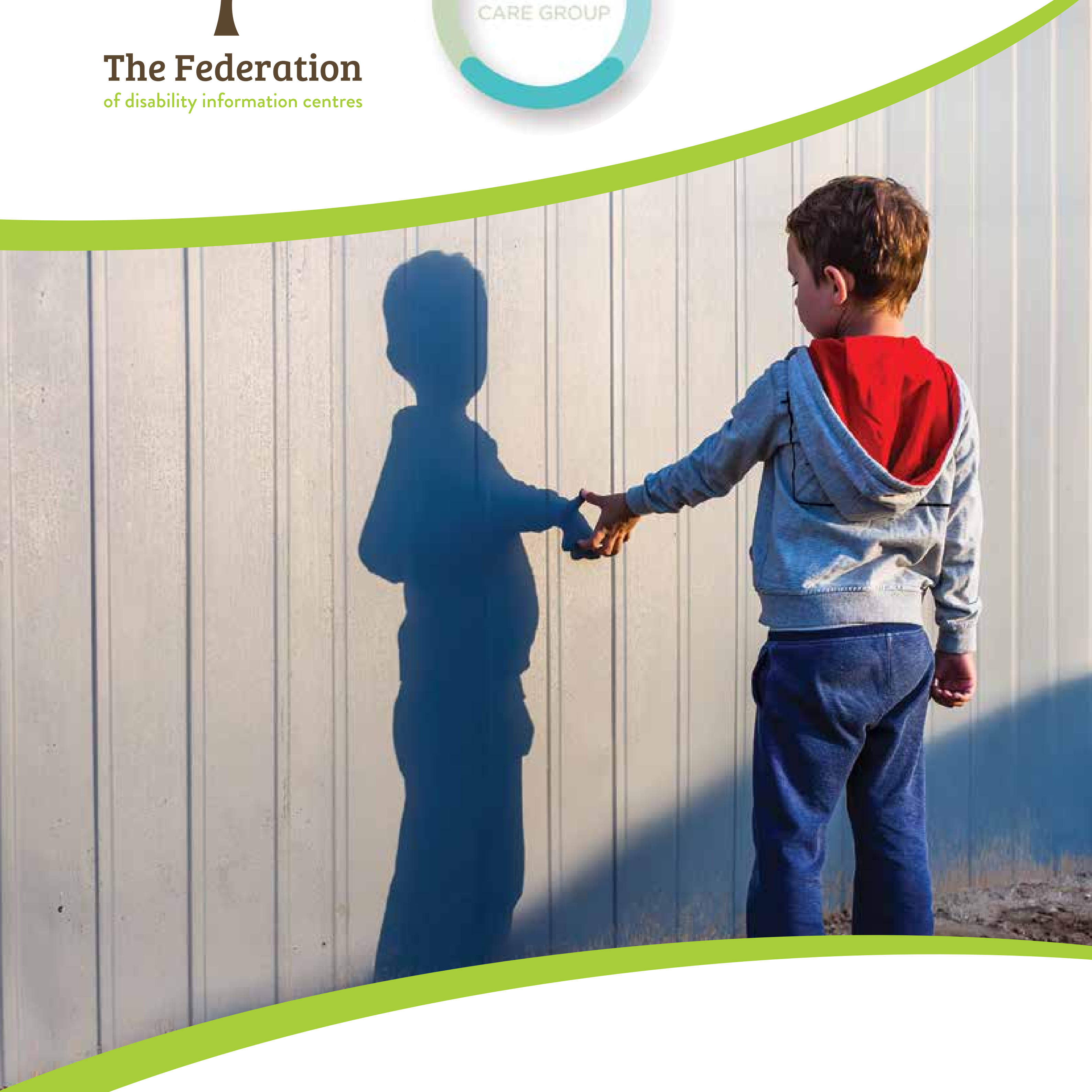

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Voices Project Report

Lisa Martin

The Federation
of disability information centres

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Executive Summary

This collaborative project of the Federation of Disability Information Centres and Complex Care Group revealed findings which will be of interest to government and disability sector organisations.

The Voice of the severely disabled, those with very high and complex needs, the non-verbal - is 'spoken' by parents and those who know the disabled person well and can communicate with them effectively. In order to ensure New Zealand has a future system of disability support which is appropriate for ***all*** disabled people - including the most vulnerable disabled New Zealanders - these voices must be heard. This report contains a plethora of valuable insights into what works, and what doesn't for the profoundly disabled and the families supporting them.

Parents' concerns focused on these three overarching areas in particular:

- Lack of targeted and practical supports, particularly respite
- Eligibility criteria which is misaligned to some severe disabilities and needs
- Desperation that despite trying to raise awareness of their circumstances and submitting their concerns to decision makers, the issues parents raise are not addressed.

Introduction

To source and validate the Voice of those with severe disabilities has always been an enigma in the New Zealand disability sector.

Those with very complex disability needs, particularly intellectual impairment, often do not have a Voice. They may be non-verbal, use Assistive Communication Devices or may have profound intellectual disability and/or communication impairments. Very often the Voice of these disabled people is spoken by their parents, family and very close trusted support people. Yet over the last 12-15yrs this modality of parents Voice, on behalf of their disabled child, has not been widely accepted by the disability sector and Government.

The New Zealand Federation of Disability Information Centres (the Federation) is a nationwide peak body for providers of disability information and support.

The Federation promotes and supports the local provision of generic disability information and referral services that are community integrated, needs driven and focused on achieving the aims of the New Zealand Disability Strategy document. The objective of the Federation is to provide an impartial information and referral service, through a network of independent community Centres nationwide that operate according to established National Standards.

Complex Care Group is a national Disability Information and Advisory Service based in Auckland. Complex Care Group provides information and support for families and carers who are providing an intensive level of support for a disabled child/young adult who has either multiple disabilities, a serious, ongoing medical condition and/or behaviour that requires a high level of support. Complex Care Group aims to provide a collective voice for these carers and an opportunity for them to network with other members, as well as raising awareness with the Ministry of Health, funders and service providers of the specific issues that face this community.

The New Zealand Federation of Disability Information Centres and Complex Care Group collaborated on this project to address a lack of recognition of parents' voices, speaking on behalf of their severely disabled loved one. We wanted to know how this came about – it wasn't always this way in New Zealand - and in many other countries parents voices are listened to. We sought information from parents about what they do know about various supports and services, and probed feedback about what they might not know. We asked how well they understand the overall disability sector environment in New Zealand including health and education supports - and funding supports which might be available. We enquired as to their knowledge of the Enabling Good Lives principles and the practical applicability of these principles to their lives. We asked about their knowledge of the United Nations Convention on the Rights of Persons with Disabilities. Most importantly, we asked if parents felt 'listened to'.

In October 2016 Sapere Group completed their 'Disability Information and Advisory Services and Needs Assessment and Service Coordination Review: A Proposed Design and Framework' - for the Ministry of Health.

Mindful of the findings of that review, in 2018 the Federation wanted to further explore what modes of communication and information sharing work best for the families of the centres we support (eg: websites, booklets and print material, blogs, meetings, etc). The Federation quickly concluded that families of those with very high and complex disability support needs had unique Disability Information and Advice needs. This formed the first phase of information gathering in 2018. Two meetings were held in Auckland and Dunedin, attended by several parents of children with very high and complex needs. The feedback from those two meetings could be summarised as a belief amongst many parents that their voice was not heard. They were concerned that whilst they are unarguably the 'experts' in their child's needs that their knowledge (willingly offered to agencies) did not translate into practical useful supports or services for them. Parents were concerned that "you don't know what you don't know" – reflecting their worry that there might be supports and services they are unaware of, and frustration at not being given fulsome information by agencies and services. Importantly, families felt they were regularly asked to attend workshops and forums or provide feedback to the sector, yet seldom was this feedback acted upon.

This prompted the Federation to obtain funding in 2019 to progress this area of concern. A collaboration with Complex Care Group – who specifically support disabled children and young adults and parents/families within this demographic - was agreed. This project involved a survey to which 70 replies were received. Ten interviews were conducted throughout New Zealand where parents had an opportunity to expand upon their concerns. This report is the culmination of the over-arching findings of the Voices survey, narrative and interviews. This report is directed towards government, Ministries and Ministers as well as service provider organisations, Needs Assessment Service Coordination organisations and interested sector stakeholders. All parents who participated in the interviews have also been offered a copy of this report.

Methodology

The target demographic of the Voices project was parents and family members of those with significant, high and complex disability needs, particularly parents of those with intellectual disabilities, who are closely involved in the care of their disabled loved one.

These parents are the voice of their children – they speak on their behalf.

This is because their loved one may be non-verbal or have communication challenges or be unable to communicate their opinions and preferences effectively or in a traditionally accepted format such as forums, workshops, surveys, submissions to government etc.

We did not seek to engage directly with the disabled person themselves, though three were present for part/all of the interview with their parent. There was no age limit for the disabled person being cared for by the parents who participated in the survey and interviews.

The online survey was created using Survey Monkey and comprised of 39 questions – some multi choice, some inviting narrative responses. Participants in the survey were given the opportunity to provide their contact details if they wished to have follow up contact to explore information on certain supports or services.

The survey was released via Survey Monkey on 8th October 2019 (see Appendix 1). It was distributed to the Complex Care Group database and the 23 member centres of the Federation of Disability Information Centres. It was also distributed to key sector groups likely to support families within our target cohort including Disability Connect, Independent Living Charitable Trust, IHC, Cerebral Palsy Society, Autism NZ, Children's Autism Foundation, Vaka Tautua and others. Accompanying the survey was an Information sheet and a Background info sheet with more detail (see Appendix 2 and 3). These information sheets, as well as the survey and call for interviewees covering email, stated the target demographic of this project are parents or family members supporting a loved one with very high and complex disability needs. 'Print ready' versions of the survey were included in the distribution email.

70 copies of the survey were completed mostly via the Survey Monkey version (a small percentage were completed manually and posted back). For data collation purposes the posted versions were entered into Survey Monkey to ensure accurate data graphs, etc. Data from the survey was aggregated into a report and analysed. Bar graphs and pie graphs capturing important statistical data are included in this report. Narrative data was analysed for common trends as well as unique issues. Numerous anonymised quotations from the survey are included in this report.

Ten interviews were completed from 15th October 2019 to 9th January 2020. Eight of the interviews were conducted in the families' home, one was conducted by telephone and another was conducted in an extended family members home in a different city to where the parents normally live. Interview participants were from:

- Auckland (x5)
  north=1, south=1, east=1 and west=2
- Warkworth (x1)
- Whangarei (x1)
- Dunedin (x2)
- Napier (x1)

The majority of interview participants accessed Ministry of Health Disability Support Services (DSS). One interviewee's son was predominantly supported via ACC.

Interviews ranged in duration from 36 minutes (telephone interview) to 3hrs and followed a conversational style of interview. Parents were invited to express their greatest concerns for current or future supports – and were encouraged to focus on the issues they found the most challenging. Parents were also invited to share potential solutions to these challenges or changes they would like to see in the disability sector. Other than for clarification, few questions were asked by the interviewer, preferring instead to encourage parents raw commentary.

Prior to the interview commencing Lisa Martin (the interviewer) provided parents with the Information and Consent form and allowed time for parents to read this and sign/date the form. One Consent form was scanned back. Participants were also provided with information about the Voices project report and how, where and to whom it would be made available. Participants were informed they would be able to obtain a copy of the report if they wished. Interviews were transcribed (with the permission of the parent) directly at the point of interview by Lisa Martin. Most interviewees preferred to remain anonymous. Quotations were also captured in the transcription and parents agreed to the anonymous use of their quotations.

Background

In 2008, soon after the process of de-institutionalisation was complete in New Zealand a Social Services Select Committee Enquiry into the Quality of Care and Service Provision for People with Disabilities was completed.

The enquiry was in response to worrying gaps and inadequacy of support for disabled New Zealanders including some of the most vulnerable members of our community.

Internationally a widespread shift occurred from the 1960's to 1990's - from the medical model of disability to the social model whereby the disabled person did not have to be "fixed". Prevailing beliefs were – and rightly still are, human rights oriented. People might have impairments but it is the environment, inappropriate supports and attitudes which are disabling. Concepts of inequality and inequity were emerging in New Zealand.

In 2001 the New Zealand Disability Strategy was created. The strategy was devised from a rights based approach and strongly emphasised the drive for an inclusive New Zealand. Objectives of the strategy included access to a non-disabling community, access to education, employment and economic development for disabled people. Also access to recreation and cultural activities – promotion of the participation of disabled Māori and Pasifika peoples. Importantly the 2001 Strategy promoted the value of family, whānau and those providing ongoing support to disabled people.

The New Zealand Disability Strategy serves as a goal-oriented reference point for government, organisations and the wider disability sector. The Disability Strategy was updated to cover the period 2016-2026. The Disability Action Plan 2014-2018 and more recently 2019-2023 demonstrates how goals of the disability strategy will be implemented in New Zealand. The Office for Disability Issues was established in 2002 within the Ministry of Social Development as a central point to manage cross-government disability issues and to promote the disability strategy.

The Ministerial Committee for Disability Issues was established in 2009 and is chaired by the Minister for Disability Issues. The committee provides a coherent focal point for disability issues across all of government. In 2010 the Ministerial Committee began to consider a New Model for disability support in New Zealand focussing on concepts of choice and control embodied by easier access to information and support and concepts of personalised budgets.

In 2014 the Ministerial Committee for Disability Issues approved the Disability Action Plan (2014-2018). This signified an important shift towards a collaborative approach between government ministries and Disabled Persons Organisations (DPO's). DPO's are organisations which are governed by disabled people to support and promote the goals of disabled people.

So it was within this environmental paradigm in 2011 the then Minister for Disability Issues Hon. Tariana Turia invited the Ministry of Health and Ministry of Social Development to work together with an independent stakeholder group to develop a ‘clean slate’ approach to disability support in New Zealand. The resulting Enabling Good Lives report 2011 has since heralded a steady shift towards a more person centred, inclusive and valuing approach to disability in New Zealand.

Enabling Good Lives (EGL) embodies these admirable Principles:

Self-determination
Disabled people are in control of their lives.

Beginning early
Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

Person-centred
Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

Ordinary life outcomes
Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Mainstream first
Disabled people are supported to access mainstream services before specialist disability services.

Mana enhancing
The abilities and contributions of disabled people and their families are recognised and respected.

Easy to use
Disabled people have supports that are simple to use and flexible.

Relationship building
Supports build and strengthen relationships between disabled people, their whānau and community.

www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/

The intention and ethos of these principles cannot be disputed. There is however growing concern amongst the high and complex disability community as to the practical applicability of these principles to their lives. This is partly because these principles appear to be aimed at relatively able-disabled people who can implement them (ie: a person who may have a physical disability with no intellectual disability and therefore has a high level of control over their life). Whilst the intention was to include all disabled people, in reality those with very complex disability support needs – particularly those with intellectual impairment – are closely supported by their parents and family.

It is parents who support them with Needs Assessment and Service Coordination, seeking Disability Information and Advice, organising supports, directly providing unpaid daily support, liaising with provider organisations and managing personalised budgets such as Individualised Funding or Funded Family Care.

The issue of applicability of the EGL principles is exacerbated by growing concern amongst the high and complex needs disability community that the “able disabled” are speaking on behalf of those with profound disabilities (particularly intellectual impairments) who cannot speak for themselves. This has evolved in part due to New Zealand’s response to establishing our monitoring mechanism to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

In 2007 Hon Ruth Dyson signed the UNCRPD on behalf of the New Zealand Government. The Convention was ratified by New Zealand in 2008. UNCRPD is a human rights treaty. It does not afford disabled New Zealanders new rights, rather it reinforces the rights they currently have and encourages signatory governments to implement those rights. As part of the Convention monitoring requirements New Zealand established the Independent Monitoring Mechanism. This comprises the Office of the Ombudsman, the Human Rights Commission and the Convention Coalition Monitoring Group (CCMG). The Convention Coalition Monitoring Group was renamed Disabled People’s Organisations’ Coalition (DPOC) in 2019. The DPO Coalition comprises eight DPOs and provides an important voice for disabled people. The DPOs who make up the coalition are:

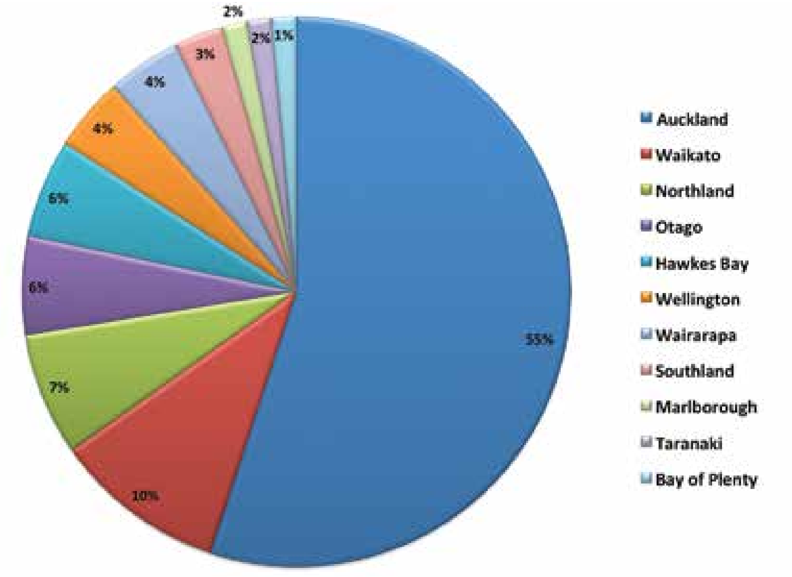
- Blind Citizens New Zealand
- Balance Aotearoa
- Deaf Aotearoa New Zealand
- Deafblind (NZ) Incorporated
- Disabled Persons Assembly (New Zealand) Inc
- Ngāti Kāpo o Aotearoa Inc
- Muscular Dystrophy Association of New Zealand
- People First New Zealand

The DPO’s within this Convention Coalition Monitoring Group (now called Disabled People’s Organisation Coalition) perform admirable work and are an essential part of the monitoring mechanism. What appears to be missing from this group is an organisation representing those with very high and complex disability needs (often intellectual disabilities). Commonly, people with such profound disabilities are represented by their parents.

Parent/family member groups do not generally meet the criteria for being a Disabled Persons Organisation (ie: being governed by disabled people) because their children’s disabilities often involve significant intellectual impairment and communication challenges. These profoundly disabled people (currently represented by parent led disability groups such as Complex Care Group) are generally unable to govern their own organisation in the absence of considerable assistance. Therefore groups such as Complex Care Group do not qualify as a DPO. For this reason the new name of the Convention Coalition Monitoring Group (being Disabled Person’s Organisation Coalition) is problematic as it seems to automatically exclude parent led groups. Therefore, they do not have a seat at the Convention Coalition Monitoring Group. This crucial shortcoming will be explored and demonstrated in the findings and conclusion of this report.

Voices Project Findings

Location of survey respondents:

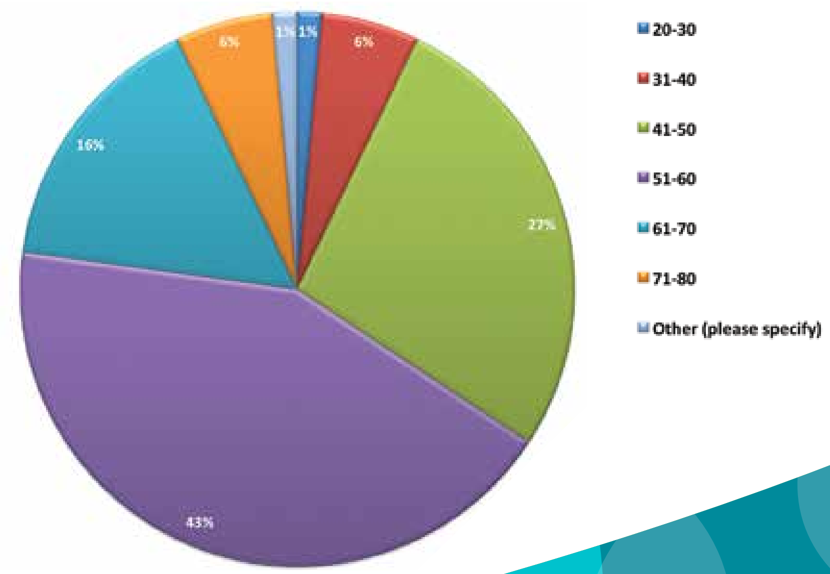


Identity of survey participants:

89% of survey respondents were parents, 5% were an 'other family member'.

Age of survey participants:

The age of survey participants was heavily represented (43%) by parents aged 51-60yrs.

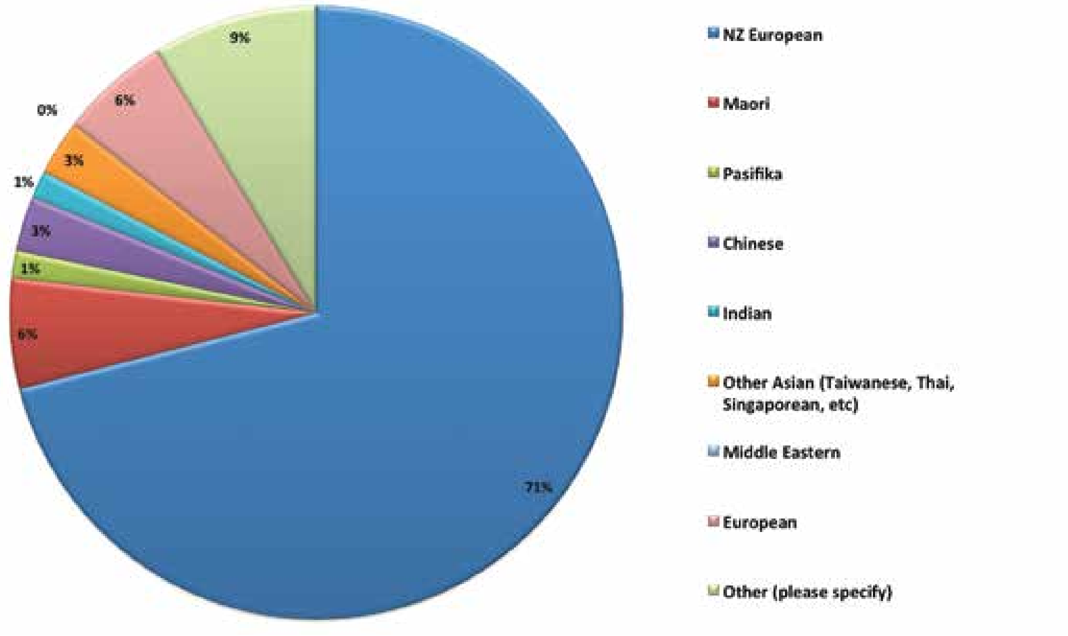


Gender of survey participants:

Overwhelmingly 93% survey respondents were women.

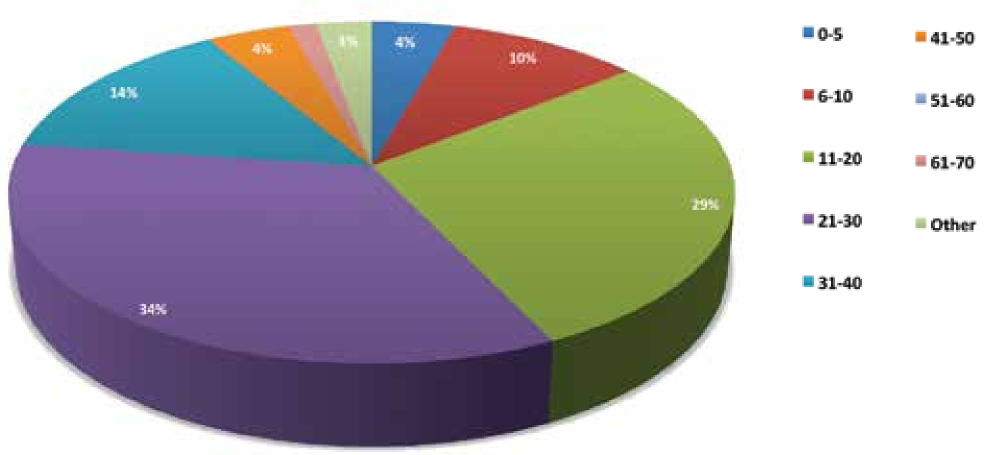
Ethnic identity of survey participants:

New Zealand Europeans made up 71% of survey participants, followed by Māori 6%, Chinese 3%, Other Asian (Taiwanese, Thai, Singaporean, etc) 3%, Pasifika 1%, and Indian 1%



Age of disabled person you support:

The most common age group of the disabled person supported by survey participants was 21-30yrs 34% followed by 11-20yrs 29%.



Gender of the disabled person you support:

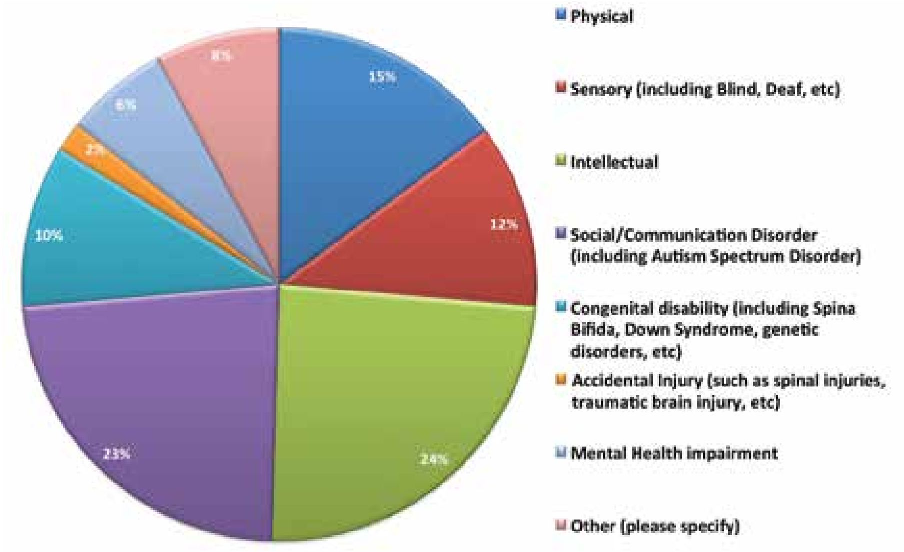
64% disabled people supported by survey participants were male, 36% female.

Ethnic identity of the person you support:

Predictably there was a close correlation between ethnic identity of the disabled person supported and the survey participants themselves. However, there was a higher number of Māori disabled people supported by survey participants at 9%, compared to 6% of survey participants themselves identifying as Māori.

Type of disability(ies) of the person you support:

A significant majority of respondents identified Intellectual Disability 24% - and/or Social/Communication Disorder (including Autism Spectrum Disorder) 23% in response to this question. Physical, Sensory and Congenital disabilities also featured highly. Many of the disabled people supported have multiple disabilities.



A range of other disabilities were also identified within the 'Other' category including Rett Syndrome, Epilepsy, ADHD (Attention Deficit Hyperactivity Disorder), Global Developmental Delay, Behavioural challenges, rare genetic disorders and chronic health conditions.

Enabling Good Lives:

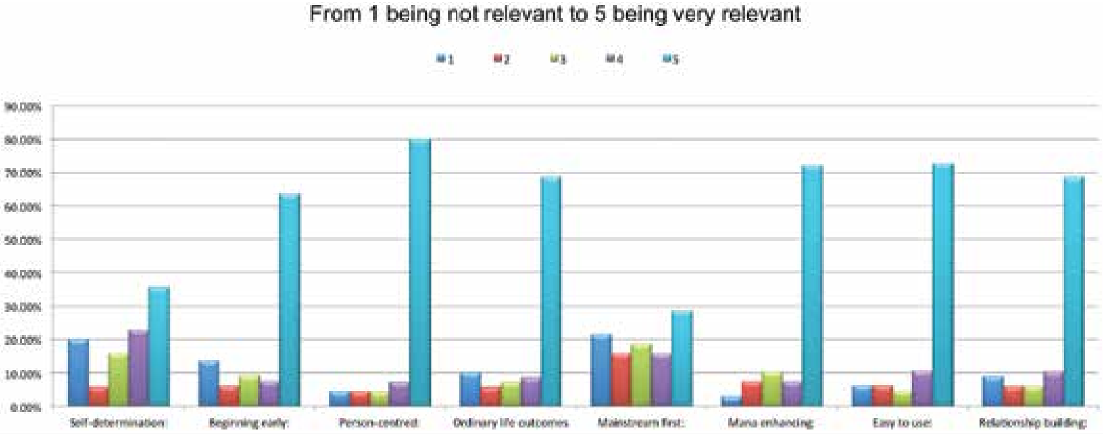
The survey also asked parents to rate the eight Enabling Good Lives Principles of:

- Self Determination
- Beginning Early
- Person-Centred
- Ordinary Life Outcomes
- Mainstream First
- Mana Enhancing
- Easy to Use
- Relationship Building

80% of respondents rated Person Centred as Very Relevant, followed closely by Easy to Use 72%, Mana Enhancing 72% and Relationship Building 69%.

69% of respondents rated Ordinary Life Outcomes as Very Relevant, followed by Beginning Early 64%.

36% of respondents rated Self Determination as Very Relevant and 29% rated Mainstream First as Very Relevant.



When asked how the principles might be adapted to be more relevant for severely disabled people many responses indicated a balanced and realistic approach:

> *"Self-determination. Disabled people are in control of their own lives. I'd like to think this is true… but is it really? A person with severe intellectual disability… autism…. can't communicate etc… are they in charge of their own lives? There's always a danger their support workers, families even, are the ones in control. Sometimes this is ok… often it isn't. Who checks to make sure a very high and complex person isn't being controlled by the very people who are employed or family members?"*

Interviews

The predominant themes from the interviews and survey are captured below.

Voices Project Themes

(including quoted narrative from the survey and interviews)

Understanding of the disability sector

One of the survey questions asked: How would you rate your overall understanding of how the New Zealand disability sector and supports operate? Do you feel you have an overall view of how the system pieces together? Scale of 1 – 5 (1 being poor, 5 being excellent) the aggregated answers to this question revealed a level of understanding at approximately 3.2 (on a scale of 1 – 5).

Responses to this question varied but overall parents expressed concern that they do not know all that they need to know. Parents cited exhaustion and lack of forthcoming information from agencies and services as being negative factors. Also, ongoing changes were identified as challenging:

> *"Though I have been fully involved in the disability sector for 23 years as a very proactive participant, it is still confusing because of all the ongoing changes in funding services, huge regional differences, and all the changes that occur as your child ages. The learning never stops."*
>
> *"The fragmentation of services and constant pilot studies with stupid acronyms that never roll out in the south is bewildering. There are few options here. Also, my son is still at school and under "education" when he should be under MOH. Even so, we have four different physios to deal with for equipment and none of them do physio with him!"*

Several respondents identified their level of knowledge was the result of ongoing research, looking at websites, attending meetings and workshops and regularly talking with other parents in a similar position. This would imply that to attain knowledge and keep up with changes in the sector parents need to be very proactive. This has implications for exhausted parents who are time poor.

> *"...It's horrible to feel as a parent and fulltime caregiver that you are not trusted to receive the funding you are clearly entitled to though have to continually justify like a criminal... my family are neglected and we all have mental illnesses exacerbated by the toll of simultaneously both loving him and hating his disability."*

Information and Support

Survey participants were asked: How well do you feel you understand how the certain key components of the NZ disability "system" work? For example, what is your level of understanding of: Ministry of Education funded supports, Ministry of Health funded supports, Work and Income supports, Post Schooling opportunities (Scale of 1 – 5, 1 being poor, 5 being excellent).

42% respondents rated their understanding of Post Schooling opportunities as 1 (poor) whereas 10% respondents rated their understanding as 5 (excellent).

> *"Post schooling opportunities - no one seems to know anything that we can use for respite, community, residential for our son except for old age centres because of the high and complex needs (including the use of oxygen)."*
>
> *"I used to say to this friend, once we left school and all the education hassles that it would be easier. But it's not."*

Broader comments on information and support included:

> *"In the early days after diagnosis when you discover your perfect little daughter isn't going to have the life you thought she was going to have – you then have to go out and find all this information about what support you might be eligible for. We're legally entitled to be told this information but no one single place or person tells you all this information."*
>
> *"Either you have the choice of doing what everyone else does – special school, then off to Idea Services house, etc. Since we don't want that structure, then we have to figure it all out for ourselves without having the knowledge. We don't know what we don't know. It's sad that in this day and age you are isolating yourself because you're not moving in the circles where established support is. You have your goals and ideals but feel alone."*
>
> *"We learned about the disabled child's allowance from a parent – no one ever tells you about these things."*

Several participants desired a one-stop-shop for information and support – a community hub.

Knowledge of Ministry of Health funded supports were fairly equally spread across the range of 1 (poor) to 5 (excellent) – although only 12% rated their understanding as excellent. In answer to this question some parents commented more broadly:

> *"...it's like the information is sacred and they don't want anyone to find it easily."*
>
> *"I often feel the people trying to provide the support have a lack of understanding just what support is required and the complexity of it. It's just too complex for them to grasp and they pass you on to the next organisation/department ie they pass the buck."*
>
> *"It's not so much finding out about supports, as to the fact that the supports are simply not there, or are declined, or are inappropriate/unsuitable, or the answers given create more confusion, and urgent requests get ignored or passed around in circles with no outcomes."*
>
> *"I know what I know, not everything is shared with you, normally more info from other parents rather than organisations."*

Overwhelmingly, when asked: Are there any particular disability supports you would like to know more about, or are having trouble finding information about? 60% respondents chose 'Finding staff or support workers.' This was closely followed by' Ministry of Health funded supports' (52%) and 'Post Schooling options' (54%). Other sought after topics were 'Housing and Accommodation' (50%) and Funded Family Care (47%).

When asked about other information they would like to have:

> *"What is actually going to be available in the MidCentral region for those non verbal, high and complex needs people."*
>
> *"I would like to know how service providers are moving toward providing services within the EGL framework."*
>
> *"Please ensure the FFC (Funded Family Care) allows for any person who provides care is employed under the exact same conditions as non-family support workers."*

Needs Assessment and Service Coordination

In terms of Needs Assessment and Service Coordination the most consistent concern reflected in this Voices project was around:

1. Eligibility criteria – disabled people with demonstrated need but not quite "fitting the box".
2. Concern that the disabled person is not getting sufficient support from NASC due to lack of understanding about very high and complex disability needs (and thus onus on parents to exhaustively explain the needs in a way the NASC assessor will understand, fitted within the common assessment domains of a NASC).

> *"They took my Carer Support off me because they needed to increase my Personal Care support. Why did they do this? A friend of mine down the road has a disabled five year old and she's got great support in place – what box did she tick that I didn't?"*
>
> *"In a nutshell the need for services and funding exceeds supply, the criteria used to decide entitlement and access to services is not standardised, the decision making processes are not transparent nor are they done consistently and the skills of those making critical funding decisions for families like ours is questionable at best and we experience no real tangible accountability about decisions that affect us."*
>
> *"I disagree with having another criteria to have to meet. Society and government know so much about us already – you feel like you're some sort of criminal. We have to meet so many different criteria and justify this and that."*

Primary, Secondary and Tertiary Healthcare

Several parents reported concerns about accessing General Practitioners and other primary healthcare providers as well as secondary and tertiary healthcare. There is an apparent lack of medical/nursing staff who understand complex disability:

> *"The DHB acknowledges that they don't have the expertise to deal with her, but they won't do anything about it... This is because of the rarity of medical people encountering someone with complex needs... S******'s GP was so desperate for clinical coordination of her care that she tried in desperation to get a geriatrician to take over clinical oversight. There's a huge gap from paediatrics to geriatricians."*

Parents in smaller cities and rural locations cited difficulty accessing healthcare professionals:

> *"It's very hit and miss – if you get a great professional it's great, but if you don't then because we live in Dunedin we have to pay to get appropriate professionals. It definitely seems to come down to the persons attitude. We've had some people who are just incredible because they talk to her like she's a human being".*

Health and Disability Sector Professionals

Many of the respondents were positive about health and disability sector professionals – acknowledging that they do the best they can. However, professionals understanding of the unique needs and implications of having a family member with very high and complex disability were identified as problematic. Also, the impact on parents of continually high levels of support for their loved one:

> *"I had a doctor in New Plymouth say to me I think R**** is autistic. I asked what are the implications of that? He said "you don't want to know"."*
>
> *"A**** has had to take R**** to appointments that I just wasn't aware of because I was too overwhelmed...People don't realise that it rips your heart out having to re tell your story over and over."*

Lack of expertise in autism was identified:

> *"The results of all this have proven to me many professionals have no idea regarding autism, challenging behaviours, particularly behaviours with very high and challenging needs. This was in 2010 and I believe in 2019 it is no better."*

One parent identified communication protocols amongst professionals as challenging:

> *"I then rang the developmental paediatrician to ask her opinion of the medications. She asked me if I'd like her to speak to the psychiatrist about E**** and I said yes, because she could teach the psychiatrist a lot. I learned later that the psychiatrist refused to speak with the developmental paediatrician and instead got her registrar to ring the paediatrician who wouldn't accept his call as she wanted to speak directly with the psychiatrist."*

Education

Challenges across the education sector were broad – issues cited include difficulty obtaining Ongoing Resourcing Scheme Funding (ORS) often requiring multiple applications or appeals. Also, shortcomings in the inclusivity of mainstream class environments:

> *"Mainstream education has a long, long, long way to evolve before we could be safe having our special needs children there."*
>
> *"Even at Early Childhood some kids are only getting 10hrs ESW per week so they don't even get the usual 20hrs per week at ECE."*

Bullying was identified as an issue:

> *"Our son was bullied at school, a unit in a normal school. He came home one day with horrific burns to both his shins where boys had held him up against an exhaust pipe at lunch time. His teacher noticed the burns but just asked if he was alright to which he replied yes. He has high complex needs!!! I immediately took him to our GP who was horrified by the schools' reaction. The school did not take any action and would not believe these named individuals would have done it on purpose."*

And in an eerily similar case:

> *"Bullying is a big problem. R**** came home with deep burns on his shins. I took him to the doctor who was horrified. He ended up having a month off school and having to go to the doctor twice a day to have the wounds dressed. School wouldn't accept that two boys at the school caused the injury. A**** eventually went into the school and got some greater recognition of the abuse. But the Principal protected the two boys as they were sports minded boys. One was a high achiever on the cricket pitch."*

Some parents expressed a desire for mainstream education but cited many challenges to this:

> *"We're not challenging parents… but it seems like our kids are being treated like second class citizens. We're lucky, we've got VHN funding… It's their basic right to be able to communicate and to go to their local school but there's barriers to that."*
>
> *"K**** is at a mainstream high school in a special needs unit - he's been there for a year - we're coming up to his IEP meeting - we're asking what mainstream opportunities has he had and he's actually had none. We're now questioning, would he be better off in a Special School".*
>
> *"It's one thing for teachers to expect to see disability, but it's another for them to actually be able to manage it."*

Some families felt that the ideology of inclusion doesn't match what is happening at the coalface:

> *"We got rid of institutions and there's an intent to bring people out from behind the fence and include them in society but education hasn't reached that stage yet."*

Sensory overload in a classroom/school environment was also a common concern, particularly in large open plan learning spaces:

> *"Because of his ASD, sensory issues, inability to regulate emotions, social and communication issues, etc, my son had "behavioural issues" at school, he was bullied by other kids, his teachers referred to him as "naughty"... We had ORS funding for the first year and a really good teacher so things went quite well, so then they decided because he was doing well to cut the funding and sign him off!?"*

An interviewee cited a particular challenge in her child's classroom whereby the teacher - working to traditional achievement milestones - insisted the young disabled student was functioning at Level 1 mathmatics. The teacher felt the girl's responses indicated she didn't understand Level 1 so she was kept at this level and lost interest. It was later revealed she is functioning at Level 5 mathmatics. This might indicate non-typical responses of disabled students in the classroom, combined with communication challenges of the student, could result in grading difficulties for educationalists.

Wait-listing for equipment is also a challenge – one parent identified trends in educational resources to be an issue:

> *"You have to sit on a waitlist forever to get into Talklink, then once they feel they've got it set up for your child they withdraw. Then what happens is a new-fangled method of communication comes in and the Principal says "right we've going to scrap that one and go with this one" and you're back to the beginning."*

Several families stated success in education was more about the specific professional involved rather than an across-education philosophy:

> *"...the person that you're working with does make an incredible difference - their attitude is crucial but they also need the skills to teach these kids. Ministry of Education website about inclusion is their ideology but schools just don't know what to do."*
>
> *"...a 'them and us' approach - feels like no attempt to gather information or build rapport. It's like they just come in and tick the boxes or their agenda is to do as little as possible."*

Some families cited differences between Ministry of Education protocols and the aspiration of individual schools. One family explained their challenges trying to implement part time correspondence schooling with part time school attendance. Whilst the school was willing the Ministry followed specific guidelines. There were other regional differences identified:

> *"In a small town there's more accountability. If you saw a hopeless professional in a supermarket in a small community, there'd be several parents who'd had a bad experience. Shortcomings are more obvious in a smaller community. In a small community there's literally more consequences from disgruntled families. In Auckland you're an anonymous number."*

Respite

Lack of access to quality respite, particularly for those with medical and complex physical disabilities and/or severe behavioural challenges, was a worrying finding of this project. It has widely been accepted that for parents and family members to develop physical/emotional resilience in order to continue caring for their disabled loved one, they need a break from their caring responsibilities.

Issues cited include lack of respite facilities and concern over quality of care in respite facilities. Travel to access respite facilities, and lack of respite facilities in some rurally dispersed areas of New Zealand were issues of concern. Some families also referred to respite as a valuable opportunity to foster family relationships. Families valued respite for their disabled child in order to do activities with their other child/ren that are not possible to do whilst caring for their disabled child.

> *"...it has been impossible to access suitable respite or day care facilities"*
>
> *"Respite facility unable to care medically for my boys at times needing transfer to hospital."*
>
> *"Not many respite carers or available (unless family help out) so I cancelled mine. Would help if it was a grant that was usable for anything, rather than a painful claim process also."*
>
> *"We receive personal care and household management support through IF, however finding care workers can be difficult. THERE IS NO RESPITE SERVICE IN OUR DISTRICT, we would have to travel to Auckland to access this service, which I understand has large waiting lists anyway. We would very much like to have respite care available in our local area and would definitely use it if it were available. Also, every time we need to look at equipment needs, we have to find our way back into the system."*

Parents also stated challenges around facility based versus in home respite. Facility based respite is a common desire for parents of children with very high and complex needs. Parents of children with autism explained their reasoning for facility based respite:

> *"Even though we had respite allocated, when we first started it was in our own home - a support worker would come but we had to go out. So if it was raining we would run around in that weather - we did all the cafes... even when we had bubba we had to carry him around. There's only so much you can do with a newborn for 4 hours."*
>
> *"When we were at home we were the ones K**** would come to so we had to go out or be out of sight."*

Managing respite using Individualised Funding was also challenging for most parents, largely due to lack of staff:

"It's so hard to get support workers for respite."

Disability Support Services, ACC Support, DHB Long Term Supports; Chronic Health Conditions, and Eligibility Criteria

Narrative from families commonly identified their child's disability not quite fitting eligibility criteria for services or supports:

> *"R**** goes to gym but ACC considers gym to be a lifestyle choice instead of a health choice so they won't fund this."*

Some parents identified lack of ability of existing services to cater to the needs:

> *"On one occasion I had representatives from various organisations including the then provider of behaviour services tell me that they could not cater for E**** because his behaviour was too challenging for them. We had waited for this meeting for 6 weeks and that's what we were told!"*

Comparisons were also made to overseas practice:

> *"There are therapeutic treatments for people like my daughter that have been successful overseas. There is no funding for these treatments in NZ. When I asked the Ministry why there was no funding for these scientifically researched treatments, I was told that this "wasn't appropriate to New Zealand's conditions." I guess it's much cheaper to ruthlessly exploit families as unpaid caregivers."*

Funding to provide appropriate levels of care was also identified:

> *"Adequate funding for the assessed levels of care needs to be provided to allow the disabled person and registered nurses or carers to be safe."*
>
> *"If you've just got a minor brain injury and we can get you into the workforce, then we'll give you some rehabilitation so then you can go out to work. But if you're in the "too hard" basket then there's just nothing."*

Mental Health Support - and Autism

Mental health sector challenges were reported by some parents. Some parents cited lack of recognition and support for their own actual and potential mental health impairments - and worry that their own wellbeing was secondary to that of their disabled child due to their extensive ongoing caring responsibilities. Post Traumatic Stress Disorder was a concern to many parents, the result of years of ongoing exhaustively high support needs of their disabled child. Some parents referred to continually high levels of anxiety, particularly in supporting a child with autism.

Autism was a particular area of concern, partly due to the ricochet effect of some NASC's referring requests for support on to mental health services (including Child and Adolescent Mental Health Services CAMHS) and those services referring the client back to the disability NASC. This reflects problems with eligibility for services, particularly in cases of autism with no intellectual disability.

One interviewee had a particularly harrowing experience of mental health services with their young adult disabled child who has autism and intellectual disability. Preceding this experience, the parents (on advice of medical professionals) adjusted their son's medication due to significant side effects:

> *"Towards the end of 2009 when E**** was 15 years behaviours at both home and school were becoming uncontrollable... by April 2010 we had a house with a hole in virtually every wall. We were battered and bruised parents, and caregivers coming into the house were terrified."*
>
> *"On one occasion after leaving W**** (CAMHS) offices E**** launched across and grabbed the steering wheel. We nearly had a head-on crash attempting to get home. That night, all hell broke loose. The medications were clearly not right for him. He was standing at the top of the staircase grappling with my husband. I was on the phone to adult mental health services. They couldn't help because they had one car and it was on the North Shore."*
>
> *"A suggestion was made by the crisis team that we call the police – what would the police have done? They're not trained for these situations. I had already been told by our community constable that he'd be placed in a cell and the on-call nurse would see him. They are also not trained in ASD and the appropriate medication to calm him."*
>
> *"...they said, don't worry we've rung his respite house and he can go there. I told them don't be ridiculous, there are 4 other clients there who he could harm and he would damage the house. So we brought him home unsupported. We were told we may need to get a nurse into the house to help."*
>
> *"I contacted the NASC and a team of carers were sent to our house – untrained and one of them was six months pregnant. They were meant to be here for 24hrs but they had no idea about autism and behaviours. I told them to go."*
>
> *"One of the most frustrating things for me is that during this whole episode of crisis I was chairperson of **** and if I couldn't get through the pathways with all my contacts and knowledge, then how would anybody else?"*
>
> *"Now in 2019 E**** is living in a residential house in a residential community with 4 other young men with autism. He's very happy, settled, and has mellowed in his behaviour... as long as routine is kept."*

Equipment and Modifications

Several parents identified the importance of physical aides in order for their child to access community. This is particularly important for whole family involvement in community activities.

> *"I want them to stop making us meet their criteria – I want them to meet OUR criteria."*
>
> *"We lost our portable ramps that enabled us to visit some people in the community."*

Impractical and misaligned eligibility criteria was also an issue:

> *"Downstairs F**** has a back-up manual wheelchair. But F**** needs customised seating. So he can't effectively use it. It's gathering dust. But somehow we don't tick the box to get a suitable back up chair."*

Funded Family Care

47% of respondents indicated they would like to know more about Funded Family Care. It was reflected throughout the survey and interviews that parents know little about this possible support.

Parents seek validation for the exhausting level of support they provide for their disabled families member/s. Rather than a parental 'duty of care' approach families expressed a desire that their extraordinary efforts and sacrifices are recognised. Families often reported the care needs of their disabled family member tended to increase with age, not become easier as would typically be the pattern with a non-disabled child. Instead of adult children leaving the family home to go flatting, settle down and enjoy community life, parents of severely disabled children are often still caring for their disabled child well into that child's adulthood. This is in part due to limited availability of facilities which could adequately care for them. Parents are aging themselves and becoming less physically able to cope with the demands of caring.

Funded Family Care was desired by some families – partly as this represented validation and remuneration for a very high level of daily care provided to their adult children. Financial remuneration is particularly important for a parent who cannot work due to their caring responsibilities. Families also expressed concern that in accessing Funded Family Care, the level of funding/hours allocated needed to better reflect the true level of support provided.

> *"... struggle to get family funded care."*

Individualised Funding

Personalised budgets, including Individualised Funding – whilst often desired by families in support of their loved one – need to be sufficiently flexible to purchase the required supports. Furthermore, there is concern that there may not be the types of services available for those with very complex needs to purchase in the community, or staff available to employ/contract to provide these services in the home.

> *"S**** is nursing level care but the social model has taken away the ability to purchase the people needed... "support worker" doesn't meet the mark of care required. Back in the day S**** would have had access to nursing level care."*

Provider organisations may not find services/supports for the very high and complex needs community to be sufficiently profitable or efficient to deliver. Organisations may also be concerned about Health and Safety in support of these people with disabilities.

Some families reported a reluctance to manage Individualised Funding on behalf of their disabled child as this was seen as another layer of responsibility on top of an already demanding caring role. Some families perceived the need for considerable time-consuming research to check what they could and couldn't do and buy using Individualised Funding – preferring instead to seek appropriate traditionally contracted services, albeit these services also did not adequately meet their needs or exist.

In essence though families applaud the control, flexibility and personalising of services and supports which is possible using Individualised Funding.

> *"I value Individualised funding though find the NASC is always slow on renewals etc, the waitlist for Explore is ridiculous and adds stress to parents, the NASC assumes an extreme amount of family responsibility and ability. Many of the 'processes' could be less bureaucratic"*

Staffing – in Providers' Services and to employ under Individualised Funding

Survey and interview respondents consistently expressed concern around lack of suitable staff both in traditionally contracted services (such as Respite and Residential Care) and staff to be employed under Individualised Funding. One parent referred to using Nannies to provide care, purchased using Individualised Funding.

> *"It's really energy taxing to train staff – even when they came from an agency… in the past I've paid an agency… but I still have to train those staff."*
>
> *"We've never found someone we've been happy with… so basically I do it."*
>
> *"So when people were applying to the agency to work with S**** the agency was pinching them and getting them to work with more profitable ACC clients. S**** was the bait. So we ended up employing the support worker directly under IF."*
>
> *"I don't especially like having to manage the staff. I hate confrontations. It's one part of IF that I don't enjoy."*
>
> *"We have this money – but we need products to purchase – products, and services and staff."*

The Care and Support Workers (Pay Equity) Settlement Act 2017 significantly improved pay rates for support workers in the disability sector. Linking of the qualifications framework to pay rates is likely to help attract, retain and remunerate staff according to their qualifications and/or experience.

There is still some concern however that support work in the disability sector (including the education sector) often attracts a 'transient' workforce such as young people 'between jobs' or study. The disability support workforce is also significantly supported by overseas workers. The disability support workforce is dominated by women, and it is commonly said these women are either young mums (for whom the flexible hours are attractive to balance their own family commitments) or older women whose own adult children have left home. In light of immigration restrictions and growing numbers of people with disabilities – as well as 'competition' for quality workers across the DHB, aged care and mental health sectors – more strategies are needed to attract workers to a long term career in disability support work.

> *"He's not under supported at present. We have an awake carer each night. Even though he's well-funded as such finding appropriate staff is a huge issue."*

For parents of a child with very high and complex needs, often one parent finds it necessary to give up work. For sole parents this is problematic and results in benefit dependency. Some parents have found Funded Family Care can assist in these circumstances.

> *"It has been our experience over the last 10 years that using IF works for some parts but not so much for others. I'm a trained OT but I can't go to work as there isn't the consistency of care for her enabling me to fulfil such a commitment."*
>
> *"His current carer has been a consistent since he was 3yrs, and she has a disability herself…"*

A parent of two adult disabled young men who employs their own staff under Individualised Funding, and where that support was provided within the family home, cited lack of privacy as an issue:

> *"I'm concerned that as K**** and his brother get older and bigger, it's even harder to try to attract support workers. Our house is like a train station. When you've got just anyone coming into your home, it's not your home anymore. Tending to toileting needs is very different at 16 then it was when they were 5."*

Family Dynamics – parents, siblings, extended family

In both the survey and interviews many respondents cited challenges with family dynamics and relationships. Some families expressed concern that whilst 'natural' or 'freely given' support was easier when their disabled child was young, it was considerably harder when their child became an adult. This was partly due to physical challenges of caregiving, particularly if this involved lifting, transferring, intensive personal cares or medical interventions. Some parents are affronted by the implication they should use natural support when this is extraordinarily difficult to source for their very high needs, complexly disabled family member.

Some families stated they have few family members available to assist them and that friends, whilst keen to assist particularly parents of young children, do not have the necessary knowledge and skills to assist in the care of a profoundly disabled child (particularly if medical or behavioural interventions are required). Families were also reluctant to involve friends in caring due to fear of being seen as constantly asking for help. Families want typical friendships without an undercurrent of dependency on their friends' practical help.

Families also referred to difficulty attending family events, particularly Christmas celebrations, but also including weddings and funerals and family get-togethers. This was largely due to concerns the disabled child would be easily overwhelmed at busy celebrations or commemorations, have a severe meltdown, behave aggressively, or their behaviour would draw attention/judgement. Some parents referred to only one partner being able to attend events for these reasons.

> *"M**** loves going out, but his sister H**** doesn't like going out. So we have this constant battle, either with H**** or with M****."*

Some families were also concerned about misperception by their non-disabled child/ren that the high level of care and attention given to the disabled child inferred favouritism. Marriage and relationship breakdowns are common in parents raising a child with a severe disability, resulting in sole parenting challenges including financial constraints as caring responsibilities impact on earning capacity.

Social Inclusion

Responses in this category ranged from attitudinal challenges to practical community access:

> *"Stigmatisation, marginalisation and social isolation are probably the biggest challenges, although obviously day to day care needs are also an ongoing and exhausting challenge for both our daughter and us."*
>
> *"We access our local community and our wider Auckland community frequently and often find obstacles to us being able to participate in normal things with our son because of access issues. Whether there are enough mobility car parks and where they are (as they often not in safe to unload a hoist spaces), footpaths that are inaccessible or damaged or playgrounds that have nothing for a disabled child to play on."*
>
> *"Everyone everywhere wants inclusion, we all want the opportunity of having the best life possible but as a society we are really just quite s**t at doing inclusion and ensuring the best life possible is available and accessible to all. This is why the word mainstream for our whānau represents oppression and exclusion. We're done with mainstream, trying to advocate in mainstream life is like trying to move a tsunami of institutionalised ignorance and intolerance... Mainstream is actually societies default status and there is not a lot of room for difference in mainstream."*

Parents concerns also related to practical implications if their child were to have a meltdown in public – would they hurt a member of the public and if so, what would the results of this be. Some parents operate in a constant state of high anxiety, particularly in public settings:

> *“When we go for a walk down the road we are hyper-vigilant – worried about what M**** will touch – whose boob will he grab as he will do that.”*

Several parents referred to concerns about post schooling inclusion in the community:

> *“... future concern is inclusion, included in society after school. There’s not a lot of future planning in place.”*

Parents also expressed concern for their loved one long term, desiring a safe and permanent living environment where appropriate care could be provided:

> *“Look at retirement villages – government says that’s not inclusion – why can’t we have something like that?”*

Protection of Personal and Property Rights Act 1988 (PPPR) – and Supported Decision Making

Whether or not parents use legal mechanisms or depend on supported decision making drew a variety of responses. 50% of respondents depend on good relationships and the principles of supported decision making. There seemed to be good knowledge and use (29%) of Right 7 (4) (c) (ii) of the Health and Disability Code of Rights (where the parents/caregivers voice on behalf of the disabled person – with their best interests at heart – must be considered). 35% respondents do have a legal mechanism under the PPPR Act 1988 in place. There were some identified challenges with the PPPR Act process:

> *“With me being the PPPR holder I wouldn’t say I have a free for all over her life. Every time that’s renewed I have to provide to the court what I’ve been doing and why I’ve been doing it. So she has a solid protection and advocacy through me, under PPPR. Remove the PPPR and it takes away her protection and it puts her back into the model of ‘luck and love’.”*
>
> *“You get a random lawyer who you have to train... they’re nice people but... we prepared the most amazing documents about planning for H****’s future, but I don’t think they ever read it... Nobody gave her a voice, so that’s what I fought for.”*
>
> *“There is no protection, no support, when you go looking for it, when you need it... in the legal system... It’s a gendered gap. Mother love has to hold it all together.”*

Acrimonious relationship separations were also identified as particularly challenging when pursuing legal mechanisms such as Welfare Guardianship:

> *“I have thrown my toys out of the cot and connected with A****’s father and 2 brothers and said they need to step up and what if I decide not to reapply – then what?”*

Parents fears for the future

Parents concerns for the future included their own concerns for their practical ability to continue caring as they age and therefore needing to instil as many skills as possible for their disabled family member:

> *“The skills R**** has that we’ve fought hard to get, we want to retain these as he’s aging.”*

Family cohesion and grief was also raised:

> *“Grief is not a cycle, we’re slipping in and out. It’s about loss of your dreams, not loss of life.”*

Many parents cited concern about who will care for their loved one once they die or are unable to provide care. Inherent in both the survey and interviews was a common concern of parents for the future related to their unheard voice. Parents and close family members and supporters, being expert in the needs and supports necessary for their profoundly disabled person, need their voice to be heard at the highest and most influential level by policy advisors and funding distributors.

The unheard voice of parents

Responses related to this issue indicated a limited understanding of what a Disabled Persons Organisation (DPO) is. Many families replied they did belong to a DPO yet when they named the organisation it was in fact a support or information organisation (not a DPO). Therefore, when asked if they felt their DPO fed back information about its role within the UNCRPD monitoring mechanism - and if parents felt they could provide feedback to their DPO about issues that affect their loved one with high and complex needs - most of the responses were somewhat negative. Understanding of exactly what a DPO is, and their role (particularly within the Convention Coalition Monitoring Group), is a potential area of information provision in the future.

Some families however have a very good understanding of what a DPO is. There was concern though that a DPO cannot speak for all disabled people, particularly those with intellectual impairment:

> *"DPO's have got too big a say. They have a right to talk on their behalf. Generally they have physical disabilities, intellectually perfectly able, they even have university degrees. They think they can speak for people with intellectual disabilities. I think there's a very vocal group. Some of them have made a good living out of government funding to speak for the disabled, but they don't speak for the whole group. They can be very vocal and very forceful."*

When asked how their disabled person communicates the vast majority (69%) responded 'Communication via family member or trusted support worker who understands or can anticipate the needs/wants/desires of the disabled person'. When asked if parents felt listened to the majority (58%) replied 'No'.

> *"Severely disabled persons who are non-speakers are an 'invisible sector' within the disability sector itself. The Disabled Person's Org does not accept family members as members, so our children's voices are not heard there either. We have to speak on behalf of our children, as well as advocate for ourselves and our rights. Currently, neither voice is being heard."*
>
> *"Contribution and voice of the families are paramount in the case of most who have complex care issues!!!"*

However, most parents (70%) felt trusted as a communicator on behalf of their disabled family member.

65% of parents believed they are 'allowed' to speak on behalf of their disabled adult child over the age of 18yrs. Interestingly 49% of respondents depend on good relationships and the use of the principles of supported decision making. 35% of respondents use the Protection of Personal and Property Rights Act 1988 (PPPR) to speak on behalf of their disabled loved one.

68% of respondents indicated 'No' - their young person had never been directly asked by a provider, NASC or government organisation how they feel about things.

Similarly 77% responded their disabled loved one had never been asked to participate in a service audit or review of services. Some parents identified concerns about how/where to raise complaints and ineffective complaints procedures:

> *"There's no real complaint organisation for disability. You try to change things but in the end you can't do anything. You've just got to make the best of a bad situation."*

Caring for the Carer

Some parents in the 41-50yrs age cohort reported being 'sandwiched' between a continuum of caring responsibilities – caring for disabled children (and their siblings) as well as caring for ageing parents. This was in effect a "doubling" of caring responsibilities when typically if their adult children were not disabled they would be leaving (or have left) the family home. This dual caring role increases the need for respite.

> *“I care for my adult daughter and my ailing father and have 1.5 - 3 hours a week to call my own (apart from sleeping) I work over 100 hours a week - yet when I fill out forms I have to put UNEMPLOYED!!! Please do not forget the carers have needs too which if unaddressed can lead to crisis for all concerned.”*
>
> *“I was an older parent, so my parents are older - so I have both ends of the caring scale - for my child and eventually my mother.”*

Respite was repeatedly cited as an important support to enable parents to continue their caring role and hold families together:

> *“The two most important factors that would give caregivers ‘a more sustainable existence’ are: regular periods of respite and a less complicated funding system to manage. The current system does neither.”*
>
> *“I never realised how hard it could get and thought that love and attachment and being cherished were the best foundations for life. Felt like a betrayal. But I had used up every ounce of energy and hope and just had nothing left to give or renew. We had to come to terms with how hard life really was and would be in the future. If there was one thing I could take away from her it would be the hours and hours of loneliness. And boredom. And that’s what I dedicate everything to trying to minimise. But I have also realised it’s partly impossible and inevitable.”*

Parents were introspective and frank about their exhaustive caring responsibilities:

> *“Going to work after 4 hours sleep a night for years and years and years? Shift sleeping with my husband for 19 years? Being a double main caregiver for a 17yr old and a 97 year old, plus 2 other teens…?”*
>
> *“I’m saving the government the $3K per week - and I can’t work - because I’m in the business of my son. I actually don’t want to work 24hrs looking after M****. I want to do what I was trained to do. Much though I love my son.”*

> *“I think if F**** had a voice he would want society to look after his mother. And for people to have better training - to make it more of a vocation than a dead-end job.”*
>
> *“Caring starts at 6.30am in the morning. I can spend up to 2hrs ‘processing’ F****’s caring needs. F**** isn’t toilet trained because the methods were inconsistent between school and home so it just hasn’t happened. Sometimes when it gets to the evening I haven’t sat down.”*
>
> *“30 years ago he would have lived in an institution - the world has come so far with its aspirations but beyond all the rhetoric when the “rubber hits the road” life is still a constant battle.”*

Choice and Control

Many parents value the concepts of choice and control. There was some concern however than to exercise choice and control requires a high level of understanding of supports and services available or how supports could be innovatively designed and implemented. Exhaustion, overwhelm and family/work commitments result in many families simply wanting a trustworthy, reliable and efficient service without having to create and administer it themselves.

> *“The support system is too fractured, we need choice but not so much that we don’t know who to turn to and it’s all overwhelming.”*

Some participants articulated issues of choice and control:

> *“S**** relies heavily on dependence to have autonomy. The value of dependence in her life is huge - that’s what gives her autonomy, that’s what gives her choices, which gives her meaningful life.”*

Conclusion and Recommendations

One of the most revealing findings of this project were the ratings afforded to the Enabling Good Lives principles.

The principles were all graded by participants across a range from Not Relevant to Very Relevant. Whilst ***all*** the principles have some meaning and applicability to parents/family supporting a profoundly disabled person there is clear evidence Mainstream First and Self Determination were less highly valued. This may be because the sophisticated nature of support to enable a very disabled person (and their family) to live a full and ordinary life obscures the concepts of Mainstream First and Self Determination. 'Mainstream First' - the concept of everyday things in everyday places - whilst highly desired by any parent for their child becomes unfeasible and impractical for many, given the level of support required. A high level of community capability building is required before Mainstream First can be enacted for those with very high and complex needs.

Similarly, Self Determination, whilst a coveted and valued attribute in most peoples' lives can be difficult to achieve for profoundly disabled people and the families who support them. This is likely to be in part due to the nature of traditional disability supports and the concept of fitting a square peg into a round hole. Eligibility and access criteria sometimes counteract Self Determination. For example, if a service or support is not available, or no staff can be found to provide it, Self Determination fades. Supports and services need to be designed with the input of the parents and families of those with very high and complex needs.

> *"Until the decision makers experience disability in their family then there'll always be a gap. They can only make up for that gap by their ability to listen, take people at their word, try and have some empathy, understand what it's like to struggle, and struggle and struggle."*

Self Determination is challenging (though certainly not impossible) for those with significant intellectual impairment, and/or communication challenges. Self Determination relates to concepts of decision making and autonomy which might be difficult and time consuming to elicit from a person with a high level of intellectual impairment. Early provision of skills to parents and families, in supported decision-making processes would benefit families experiencing such challenges, and would certainly provide long term benefits for the disabled person. This aligns with the EGL principle of Beginning Early. Personalised budgets (including Individualised Funding) are overall an attractive option for families in which they (and their disabled loved one) can exercise control over how, when and where supports are provided. However, consideration should be given to additional funding within an IF budget for the provision of management services if desired by the family. Whilst not diminishing the overall management/employment responsibilities of families using IF, being able to fund the services of administration management would ease the sometimes laborious aspects of such personalised budgets (recruiting staff, compiling policies, employment contracts, submitting timesheets, etc) whilst not impacting on the overall support package for the disabled person.

Over the last two decades there have been several pivotal reports in the disability sector, each reflecting similar findings. The 2005 Donald Beasley Institute report ‘Evaluation of the Complex Carers Group Project’ which explored the establishment of this specific information and support organisation found:

> ***The emphasis should be on planning services in partnership with families, with a focus on positive planning rather than responding to deficits or crises. Planning itself, however, must lead to actual services to meet the various needs of families. Professional support must be available to meet complex medical need, early intervention services, counselling, and ongoing, available professional advice and support. The alternative is a return to institutions which contain the necessary professional supports.***

Dr. Hemant Thakkar concluded in his 2017 thesis summary ‘When I am no longer alive - parents’ views on the future of their disabled adult children with high and complex needs’ that the Parents as Partners in Policy and Research (PPPR) model is the most reliable way to ensure future disability support models are appropriate:

Parents as Partners in Policy and Research (PPPR) model

This model is founded on the premise that, when it comes to supporting adults with HCN, expert parental input is needed right at the basic policy and research planning level – to get things right in the first place. Mere consultation at the service delivery level will not be of much help if the basic service design itself is faulty. Under the PPPR model, a partnership with the parents could be helpful in the following areas:

- *Design and delivery of services*
- *Design of funding models*
- *Drafting of policy and strategic documents*
- *Evaluation and monitoring of services*
- *Workforce training*
- *Non-verbal communication*
- *Community awareness campaigns*
- *Research and development*

It is paramount that those with intensive support needs who are cognitively impaired and non-verbal are represented on the UNCRPD Monitoring Group by their parents or those who know and understand the unique needs of this population. This would complement the voices already there (Disabled Persons Organisations) and would provide valuable perspective from parents representing those with very high and complex disability needs.

In Jan Moss's 2016 report to the Winston Churchill Memorial Trust 'Hear our Voices we Entreat' her key findings included:

Legislation in the UK and Sweden ensures that severely cognitively disabled, non-verbal adults do have a "voice", and are provided with the necessary support to communicate effectively. It was acknowledged and accepted that where necessary, those who know the disabled person well were able to speak on their behalf. This has ensured that relevant policies and services at both local and national level have been developed to meet their needs and appropriate individuals and organisations representing this population are consulted.

In the same report Jan recommended:

That "nothing about us without us" is applied to all disabled people in New Zealand as it does in the UK, Ireland and Sweden.

And

That profoundly disabled people are provided with appropriate representation in the Convention Coalition reporting on the UN Convention on the Rights of Persons with Disabilities.

Article 33 of UNCRPD states:

Article 33 – National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

United Nations website:
www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-33-national-implementation-and-monitoring.html

There is no exclusion of parents representing the voice of their severely disabled loved one in Article 33 of UNCRPD. Indeed the 2017 Malatest International final report 'Review of disabled people led monitoring of the UNCRPD' suggested an opportunity for strengthening monitoring in the future:

Consider including some other perspectives which are currently underrepresented (for example family/whānau of disabled people, youth, some ethnic groups (Pacific people, Asians), new immigrants). People could be included as permanent members or seconded to the group.

Furthermore, the report suggested opportunities to:

Further adapt the DRPI method to include more perspectives from within the disabled community. Opportunities include incorporating stakeholder consultation, participation of support people, surveys, family/whānau and other group meetings.*

*Disability Rights Promotion International

This would serve to balance the implementation strategies of the United Nations Convention on the Rights of Persons with Disabilities and would help ensure policy and legislative decisions afford due consideration to the rights of severely disabled people. Consideration could then be given to the detailed design of supports and services affecting those with very high and complex disability needs, helping ensure supports are targeted, effective, timely and fit for purpose. This would particularly support parents drive for much needed appropriate respite care for their profoundly disabled child, enabling these parents to get a break and 'refuel'.

It is a human right that all people with disabilities in New Zealand are represented within our UNCRPD monitoring mechanism. Amongst the New Zealand representative organisations for persons with disabilities there are several parent-led organisations including Complex Care Group, which uniquely supports those with very high and complex needs.

Parent led representative groups (such as Complex Care Group) who support parents/family members of those with very high and complex needs deserve a seat on New Zealand's United Nations Convention on the Rights of Persons with Disabilities Independent Monitoring Mechanism. Because the Convention Coalition Monitoring Group changed its name to Disabled Person's Organisation Coalition thought needs to be given to the somewhat exclusionary nature of this important coalition.

It is sobering to reflect that our recommendations have been made several times before by different researchers.

At present the Office for Disability Issues works closely with Disabled Persons Organisations. We believe wider representation of parents' voices - via an existing or new overarching parents' representative group - within the framework of the Office for Disability Issues is also necessary.

In this way the perspective of parents can be reliably heard and considered. Parents of the most vulnerable members of our community – speaking on behalf of their severely disabled loved ones – can then contribute to policy and legislative mechanisms about the issues which will affect them and their family member. We believe that only in this way will New Zealand 'leave no one behind'.

Acknowledgements

The Voices Project was a collaboration between Complex Care Group and the New Zealand Federation of Disability Information Centres.

We would like to acknowledge the following contributors and supporters of this work:

The 10 families who participated in interviews and their family member with a disability

The 70 survey respondents

The Working Together More Fund

Carol Wood, Executive Officer, New Zealand Federation of Disability Information Centres

Disability Sector organisations who distributed the survey and call for interview participants

PDC Creative

The Federation and Complex Care Group would also like to acknowledge the work of the Office for Disability Issues, the Deputy Director General Disability, the Ministry of Health Disability Support Services, ACC, Child and Adolescent Mental Health Services, DHB Long Term Support Chronic Health Conditions, Ministry of Education, Ministry of Social Development, the Donald Beasley Institute, Dr Hemant Thakkar and Jan Moss (Chairperson, Complex Care Group and author of 'Hear Our Voices we Entreat' report).

We specifically wish to acknowledge Disabled Persons Organisations and the valuable contribution of lived experience and expertise they contribute to the New Zealand disability sector and wider community.

We would like to reserve special acknowledgement for all the New Zealanders caring for and supporting their profoundly disabled family member.

Appendix

Appendix 1
Voices Survey October 2019

Appendix 2
Information sheet for Voices Survey and/or Interview Participants

Appendix 3
Additional information about the Voices Project

Appendix 4
Voices Information and Consent Form for Voices Interview Participants

Voices Project Survey

This Survey forms part of a collaboration project between the NZ Federation of Disability Information Centres (NZFDIC) and Complex Care Group (CCG).

This project will explore the 'voice' of those supporting people with very high and complex needs. We want to know if families feel their Voice is heard and is acted upon - and if not, then what would assist this to happen.

It's important we define what we mean by high and complex needs. These individuals may have:

- Multiple disabilities including sensory disabilities, physical disabilities, severe intellectual disability, or serious and ongoing medical conditions.
- Behaviours that may require a very high level of support.
- Difficulty voicing their needs in appropriate forums due to their severe intellectual and learning disabilities

Thank you for your participation - we look forward to your responses.

Please refer to the Information sheet and Background info sheet for further information about this project. If you would like a paper version of this survey or for more information please contact Lisa at complexcaregroup@xtra.co.nz or phone 027 266 7690 or 0800 852 693.

Whilst it is helpful to have your name and some demographic details submitted as part of this survey, the survey results in our report will be anonymous. We do this to encourage your full and frank responses to our questions. Your responses in no way jeopardise any current or future supports you or the person you care for receive.

---

1. **Name of survey participant (parent or family member) - if you wish to remain anonymous please state 'parent' or 'family member' in this field:**

____

2. **Location in New Zealand (please name the town/city or region in which you live):**

____

3. **Identity:**

○ Parent
○ Other Family Member
○ Other (please specify):

____

4. **Age of survey participant (you):**

○ 20-30 ○ 41-50 ○ 61-70
○ 31-40 ○ 51-60 ○ 71-80
○ Other (please specify):

____

5. **Gender of survey participant (you):**

○ Male ○ Female ○ Gender diverse

6. **Ethnic identity of the survey participant (you):**

○ NZ European
○ Māori
○ Pasifika
○ Chinese
○ Indian
○ Other Asian (Taiwanese, Thai, Singaporean, etc)
○ Middle Eastern
○ European
○ Other (please specify):

____

7. **Age of disabled person you support:**

○ 0-5 ○ 21-30 ○ 51-60
○ 6-10 ○ 31-40 ○ 61-70
○ 11-20 ○ 41-50 ○ 71-80
○ Other (please specify):

____

8. **Gender of disabled person you support:**

○ Male ○ Female ○ Gender diverse

9. **Ethnic identity of disabled person you support:**

- ○ NZ European
- ○ Māori
- ○ Pasifika
- ○ Chinese
- ○ Indian
- ○ Other Asian (Taiwanese, Thai, Singaporean etc)
- ○ Middle Eastern
- ○ European
- ○ Other (please specify)

10. **Type of disability(ies) of the person you support - please tick all that apply if possible:**

- ○ Physical
- ○ Sensory (including Blind, Deaf etc)
- ○ Intellectual
- ○ Social/Communication Disorder (including Autism Spectrum Disorder)
- ○ Congenital disability (including Spina Bifida, Down Syndrome, genetic disorders etc)
- ○ Accidental Injury (such as spinal injuries, traumatic brain injury etc)
- ○ Mental Health impairment
- ○ Other (please specify):

11. **How would you rate your overall understanding of how the New Zealand disability sector and supports operate? Do you feel you have an overall view of how the system pieces together?**
Scale of 1 - 5 (1 being poor, 5 being excellent)

12. **Please tell us why you have given this rating to the question above?**

13. **The Ministry of Health funds a range of disability supports such as Respite, Personal Cares, Household Management, Behaviour Support Services, Equipment Housing and Vehicle Modifications, etc based on eligibility determined by the Needs Assessment Service Coordination agency (NASC). If you or the person you care for receive such supports how well do you feel overall they meet the needs of your disabled family member?**
Scale of 1 - 5 (1 being poor, 5 being excellent)

14. **Please tell us why you have given this rating to the question above?**

15. **How well do you feel you understand how the certain key components of the NZ disability "system" work? For example, what is your level of understanding of:**
Scale of 1 - 5 (1 being poor, 5 being excellent)

Ministry of Education supports for eligible children/youths with High and Complex Needs (HCN) (types of support, eligibility criteria, how the support is used at school, etc):

Ministry of Health funded supports for eligible disabled people (types of support, eligibility criteria, how the support is used, etc):

Work and Income supports for children/youths with High and Complex Needs and/or their families (types of support, eligibility criteria, how the support is used, etc):

Post schooling opportunities for those with High and Complex Needs:

16. **Please tell us why you have given these ratings to the question above?**

17. Are there any particular disability supports you would like to know more about, or are having trouble finding information about?

○ Ministry of Health funded disability supports (such as Respite, Residential Care, behaviour support, Individualised Funding, Personal Cares, Household Management etc)
○ Ministry of Education funded supports (such as Ongoing Resourcing Scheme funding ORS, High Health Needs funding, Special Education Grant etc)
○ Work and Income support (such as Supported Living Payment, Accommodation Supplement, Disability Allowance etc)
○ Funded Family Care
○ Post schooling options
○ Housing/Accommodation
○ Finding staff or support workers
○ Equipment, Housing and Vehicle Modifications etc
○ Behaviour Support services
○ Sexuality issues
○ Other (please specify)

____

18. If you would like us to provide you with information about the supports you have indicated above please enter your phone number and/or email address here:

____

At present the Ministry of Health is leading a project to redevelop the NZ disability system (supports/funding will be provided by other government ministries also). The future disability system is likely to involve the key principles of Enabling Good Lives listed below. We'd like you to indicate how relevant each principle is in the life of your disabled family member.

19. Please grade each principle 1-5
(1 being not relevant, 5 being very relevant)

Self-determination: Disabled people are in control of their lives.

____

Beginning early: Invest early in families/whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

____

Person-centred: Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

____

Ordinary life outcomes: Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

____

Mainstream first: Disabled people are supported to access mainstream services before specialist disability services.

____

Mana enhancing: The abilities and contributions of disabled people and their families are recognised and respected.

____

Easy to use: Disabled people have supports that are simple to use and flexible.

____

Relationship building: Supports build and strengthen relationships between disabled people, their whānau and community.

____

20. Please also comment as to how any of the principles could be adapted to be more relevant for severely disabled people or how you are already using any of the principles:

____

____

____

____

The United Nations Convention on the Rights of Persons with Disabilities is a significant driver of human rights for disabled New Zealanders. NZ signed the Convention in March 2007 and ratified it in September 2008. The Office for Disability Issues has a key role in promoting the convention and making information available about UNCRPD.

21. **How well do you feel you understand the Convention and its role in setting best practice standards for human rights for disabled people?** *Scale of 1 – 5 (1 being poor, 5 being excellent)*

22. **Please comment on the question above:**

NZ's implementation of the United Nations Convention on the Rights of Persons with Disabilities is monitored by the United Nations. New Zealand has an Independent Monitoring Mechanism (IMM) in place to track and guide our progress internally so we can report back to the UN. Three groups comprise the IMM – the Human Rights Commission, Office of the Ombudsman and the Coalition of Disabled Persons Organisations. The Disabled Persons Organisations (DPO) are largely managed and governed by disabled people. Some examples of a DPO are People First NZ, Blind Citizens NZ, Deaf Aotearoa etc.

23. **Do you or your disabled family member belong to a Disabled Persons Organisation?** (If No, then go to question 29)

○ Yes
○ No

24. **Which DPO do you belong to?**

25. **How do you rate your ability to 'be heard' by your representative DPO? Does your DPO hold meetings or surveys you can participate in?**

26. **Does your DPO report back to its members about its role within the UNCRPD Independent Monitoring Mechanism (if it does have such a role within the IMM)?**

27. **Do you feel you have opportunities to feedback to the Coalition of Disabled Persons Organisations regarding issues that affect your loved one with High and Complex Needs?**

28. **Is your disabled family member able to complete surveys or attend and participate in meetings themselves in the disability sector?**

29. **How does your disabled family member communicate?**

○ Verbally - clearly
○ Verbally - unclear and needs clarification by a family member or support worker
○ Written communication
○ Augmentative Communication Device or other high tech devices
○ Low tech methods such as Picture Exchange
○ Communication System
○ NZ Sign Language
○ Communication via family member or trusted support worker who understands or can anticipate the needs/wants/desires of the disabled person
○ Other (please specify)

If your disabled family member communicates via another family member please tell us how organisations, government departments, etc validate that communication?

30. **Do you feel listened to?**

○ Yes
○ No
○ Comment:

31. Do you feel trusted as the communicator on behalf of your disabled family member?

○ Yes

○ No

Comment:

____

____

____

____

____

32. Are your concerns taken seriously and acted upon by the agency?

○ Yes

○ No

Comment:

____

____

____

____

____

33. In NZ those 18yrs and over (regardless of whether they are disabled) are legally adults and responsible for their own decisions. Decision making can be challenging for those with very high and complex needs involving intellectual impairment. Often they will need support from family members or trusted support workers. Do you believe you are "allowed" to speak on behalf of your disabled young adult after the age of 18yrs?

○ Yes

○ No

Comment:

____

____

____

____

34. Do you have a mechanism or procedure in place to ensure your voice (speaking on behalf of your severely disabled family member) is heard?

○ No - I depend on good relationships and use the principles of Supported Decision Making

○ No - I depend on Right 7 (4) (c) (ii) of the Health and Disability Code of Rights (where the parents/caregivers voice on behalf of the disabled person - with their best interests at heart - must be considered)

○ Yes - we have a legal mechanism under the Protection of Personal and Property Rights Act 1988 (Welfare Guardianship and/or Property Management)

Comment:

____

____

____

____

____

35. Has your young person ever been directly asked by a provider, NASC, government organisation how they feel about things?

○ Yes

○ No

Comment:

____

____

____

____

____

36. Have they ever participated in a service audit or review of services?

○ Yes

○ No

Comment:

____

____

____

____

37. **We believe real, authentic stories – told or written by the disabled person and/or their close family or support persons – are powerful.**

They inform others with details about the life of a person with severe disability, intellectual impairment or high and complex needs. Sometimes others (including government representatives and providers organisations) who have no personal experience of disability are unaware of the complex issues we face. We'd appreciate you sharing your story with us - about a particular issue you have found especially challenging (regardless of how long or short it is). Please write it here or contact us if you'd prefer a phone, skype or face to face interview to share your story.

38. **Families have expressed in the past that because they are immensely busy and tired, they must choose carefully which meetings or activities they are involved in. Some families have historically reported that they feel they are always asked to "give" (participate in surveys and meetings) but receive little in return by way of updates or real progress. Please comment on your experience re this.**

39. **Is there anything else you would like to tell us or ask us? If you would like us to respond please give us your contact details.**

Thank you. We sincerely appreciate your input whether by survey or interview. Your participation has contributed to securing the rights of, and the value of 'the Voice', for which we are very grateful.

At the conclusion of this project we will make available to you our completed report (including results of survey and interviews). The final report will also be sent to the funder of this project. We intend to share this report with government departments, Ministers and organisations in the disability sector - particularly decision makers and fund holders. In this way we assist these stakeholders to 'get it right' for the most vulnerable members of our community.

In this survey we have asked questions about your understanding of disability supports, policy and legislation. If you would like more information on any type of disability related support (or if you have any questions or you think of additional information you'd like to submit to us) please **contact Lisa Martin at complexcaregroup@xtra.co.nz or 027 266 7690.**

Appendix 2

The Federation
of disability information centres

COMPLEX
CARE GROUP

Information Sheet

for Voices Survey and/or Interview Participants

To learn more about **Complex Care Group** (or to become a member) visit **www.complexcaregroup.org.nz**
To learn more about the **NZ Federation of Disability Information Centres** visit **www.nzfdic.org.nz**

The NZ Federation of Disability Information Centres is undertaking a project in collaboration with Complex Care Group to capture the 'Voice' of people representing those with significant intellectual impairment and/or high and complex needs. The Working Together More Fund is funding this project.

Often for people with such disabilities, their parents, family/whānau/aiga and/or close caregivers are their Voice. These close and trusted support people know the disabled person very well, understand their communication style, body language and behavioural responses.

Often the voice of this community is missing – but it is crucial it is heard by decision makers and fund-holders – to ensure the future support system works for clients and families experiencing complex disability.

Firstly we'll define what we mean by high and complex needs. These children and adults with disabilities are some of society's most vulnerable citizens and may have some or all of the following:

- Multiple disabilities including sensory disabilities, physical disabilities, severe intellectual disability, or serious and ongoing medical conditions
- Behaviours that may require a very high level of support
- A lack of appropriate services or policies to meet their intensive support needs
- Often unable to voice their needs in appropriate forums due to their severe intellectual and learning disabilities
- They are unlikely to be able to work or earn a wage. Their needs may be expressed in such a unique way that only those close to them will understand.

We want to hear about particular challenges individuals/families face – it may be related to education challenges, Ministry of Health funded support, hospital access and treatment, access to support via Needs Assessment, Work and Income support, housing, stigma, etc. The specific topic you wish to share is your choice.

We are seeking willing participants for our survey and interviews. The survey is open from early-October to mid-November and takes around 15 minutes to complete. There are multiple choice answers as well as narrative (written) answers sought in the survey – write as much or as little as you like.

You can access the survey here:

www.surveymonkey.com/r/voicesnz19

We are also seeking 6 or 7 interview participants, ideally spread geographically throughout New Zealand including rural areas. Interviews will take place from mid-October to mid-November 2019. Lisa, Director of Complex Care Group (and President of the NZ Federation of Disability Information Centres) will travel to interview parents either in their own home (wherever that may be in NZ), or at a location convenient to the participant.

Alternatively, interviews can be conducted via telephone, Skype, Zoom or Facetime. There is absolutely no cost to families to participate in this project. Interviews could be video or audio recorded (in agreement with participants) to enable accurate transcribing. We will require participants who wish to be interviewed to read and sign a consent form prior to the interview.

Interview themes and some specific issues (including some quotations if agreed by the parent) will be written in a report at the completion of this project. Interviewed parents can remain anonymous or identify themselves. Interviews can be as long or short as parents prefer – we understand you have many commitments.

Participation in this project (survey or interview) will not adversely affect any disability supports you receive.

For more information or to request an interview please contact Lisa Martin at complexcaregroup@xtra.co.nz or phone 027 266 7690 or 0800 852 693

Appendix 3

The Federation
of disability information centres

COMPLEX
CARE GROUP

Additional Information
for Voices Survey and/or Interview Participants

To learn more about **Complex Care Group** (or to become a member) visit **www.complexcaregroup.org.nz**
To learn more about the **NZ Federation of Disability Information Centres** visit **www.nzfdic.org.nz**

Background: In 2018 NZ Federation of Disability Information Centres conducted a project looking at what type of information and support works well for families and what doesn't. This early work led us to understand those with complex disability needs are under-represented in their Voice to Government, Ministries, Service Providers and the wider community.

This current phase two Voices Project aims to capture real stories from families about particular issues affecting them now or in the past. Real stories of people's experience have a powerful impact on those who do not have a personal connection with disability – helping them understand the challenges we face.

We want to improve understanding of our vulnerable and severely disabled community who are not currently heard via traditional disability sector interaction. Ultimately, we'd like this Voice to be heard at the highest decision-making mechanisms including government and the United Nations Convention on the Rights of Persons with Disabilities.

Please complete the survey here:

www.surveymonkey.com/r/voicesnz19

or request a postal copy if you prefer. Surveys can be returned freepost to Complex Care Group at the address below.

Please contact Lisa as soon as possible (details below) if you are interested in participating in a face to face or telephone/ Skype/Zoom/Facetime interview. Lisa can travel to your location or set up the video or audio interview.

At the conclusion of this project we will make available to you our completed report (including results of survey and interviews). The final report will also be sent to the funder of this project. We intend to share this report with government departments, Ministers and organisations in the disability sector – particularly decision makers and fund holders. In this way we assist these stakeholders to 'get it right' for the most vulnerable members of our community.

Participation in this project (survey or interview) will not adversely affect any disability supports you receive. For more information or to participate please contact:

Lisa Martin, Complex Care Group
Email. complexcaregroup@xtra.co.nz
Phone. 027 266 7690 or 0800 852 693
Freepost 179 329, P.O. Box 11-533
Ellerslie, Auckland 1542

Thank you.

Information and Consent Form

for Voices Interview Participants

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Participation in this project (survey or interview) will not adversely affect any disability supports you receive.

For more information please contact:

Lisa Martin, Complex Care Group
Email. complexcaregroup@xtra.co.nz
Phone. 027 266 7690 or 0800 852 693
Freepost 179 329, P.O. Box 11-533
Ellerslie, Auckland 1542

○ I have read and understand this information sheet about the Voices project. I agree to be interviewed by Lisa Martin and willingly share the information I impart in the interview. I understand I can contact Lisa at any time with questions or for clarification and I know I can withdraw from participation at any stage. I can also choose to keep my interview responses anonymous. I agree my interview may be recorded (I will be told if it is) to ensure accurate transcribing.

Name of Interview Participant (please print):

Signature of Interview Participant:

Date:

Thank you.

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To learn more about the **NZ Federation of Disability Information Centres** visit **www.nzfdic.org.nz**

The Federation
of disability information centres

COMPLEX
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the
WORKING
TOGETHER
MORE
fund

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