

What's important for family wellbeing?

1. Introduction

Family well-being refers to a “sense of wellbeing of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.”¹

Families are the foundation of communities and play a critical role in the wellbeing of all family members. Families can only thrive if they are connected to, are valued by and have a sense of belonging in their own communities.² Wellbeing also encompasses the experience of a range of human rights and opportunities. Many families with children with intellectual disability find it hard to get the life others take for granted.

To help inform our advocacy work we talked with representatives of family-based organisations and parents about their perspectives on family wellbeing for families with children with intellectual disabilities. Four key themes were identified as important for family wellbeing - attitudes, belonging and inclusion, fair systems and being able to plan with confidence and good support and connections. Drawing from these areas we propose some indicators and possible measures for wellbeing for families with children with intellectual disability.

We would like to thank and acknowledge the organisations and people who took part for their time and the wealth of information that they provided.

2. Background

SuperU's 2015 Family and Whānau Status report identified the significance of family functioning for the wellbeing of family members in the statement “if families are doing well, then so is society”. The report emphasised that families do not stand in isolation but are connected to schools, communities and other supports. The domains used to measure family wellbeing include family structure, health, relationships and connections, economic security, housing, safety and environment, skills, learning and employment and identity and sense of belonging. Particular attention is paid for Māori to whānau rangatiratanga principles – whakapapa (descent, kinship, the essence of whānau, hapu and iwi), wairuatanga (spiritual and connectedness with the wider world), kotahitanga (collective unity), manaakitanga (duty and expectations of care and reciprocity) and rangatiratanga (leadership, authority and whānau empowerment).

Families and family life have a central place in the Growing up in New Zealand study. This longitudinal research is tracking the development of nearly 7,000 children from birth until they are young adults. The conceptual framework and measures used aim to capture the dynamic interactions between the child, families/whānau, physical environment, informal society (friends, peers, neighbours), formal society (educational institutions, community

¹ Zuna, N., Summers, J.A, Turnbull, A.P., Hu, X., & Xu, S. (2010). Theorizing about family quality of life. In R.Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice*. Zuna, Summers, Turnbull, Hu & Xu, p.29

² Pippa Murray (2011) *Developing family leadership*, p.2

organisations, government agencies, social supports) and wider culture and government policies.

Increasing attention has been paid to understanding family wellbeing and quality of life for families with children with intellectual disability. There has been a broadening of interest from a limited focus on stress and burden of care to a wider range of aspects of family and community life. A tool that has been developed to provide a more comprehensive measurement for families with disabled children is the Family Quality of Life Survey – (FQoLS - updated version 2006). The survey covers nine areas: health; finances; family relationships; support from other people; support from disability-related services; influence of values; careers and planning for careers; leisure and recreation; and community interaction. Each of the areas is explored in relation to importance, opportunities, initiative, attainment, stability and satisfaction.

3. What we did: Method, participants and questions

A total of 21 people participated in the study. Interviews were conducted with the representatives of family based organisations and parents to gather information on their perspectives on wellbeing, where the gaps are, what's working and what could be done better. The focus was on families with children with intellectual disability who were up to 25 years of age. Interviews were held over the phone or in person. Supplementary written responses to the questions asked was also provided from four parents.

Fourteen representatives from organisations who provide support and/or advocacy for families took part. Ten of these participants were also parents of children with disabilities. Seven parents of children with intellectual disability who responded to a request put out through organisations also participated in the study. These participants were parents of children between the ages of 3-25 years old.

Areas covered in the questions asked included (questions adapted for individual parents).

- What do you see as being important for family wellbeing?
- What are the common hopes and expectations you see from parents for their children and families (What are your hopes and expectations for your children and family)?
- What happens when things are going well for families (for your family)?
- What negatively impacts on wellbeing?
- How well do policies, funding and practices consider and respond to families?
- Are there gaps in what is currently happening?
- Have you noticed any changes in
 - Attitudes?
 - Flexibility of options available to families?
 - Accessibility and responsiveness of government agencies and service providers?

4. What we found: Key themes

The areas identified by participants as important for wellbeing were consistent with research and what families have told us in IHC's advocacy work and Start Strong campaign. These were the same as for all families alongside some specific areas experienced by families with children with intellectual disability in relation to attitudes, being included and getting support.

Responses to the questions asked reflected the interconnected nature of child, parent and wider family wellbeing. As expressed by one participant *"When things are going well for families, everyone is able to be who they are and has a sense of their tūrangawaewae"* by another, *"What happens to the child has flow on effects for the family"* and *"If things are not going well for the child, whether it is at school, with a service provider or in the community, it impacts the wellbeing of everyone in the household"*.

That children were healthy, happy and safe was seen as integral to wellbeing. This occurred alongside children having a *"sense of belonging"* and being able to *"participate in a variety of different activities"*. All participants saw as important for wellbeing that children with intellectual disability are included as valued and respected members of their communities.

Parents expect that their child with an intellectual disability would be able to live a typical life and reach their full potential, like their siblings and all children. They want their children to go to school, take part in community activities and be involved in decisions that affect them. Looking to the future families want their children to *"go flatting, get employment, have networks outside of the family and be as independent as their capabilities allow"*.

Participants emphasised the diversity of families' situations and experiences and that *"each family was on their own journey"*. The balance of what's important for each family changes over time with different developmental and life course stages and experiences for the child and family. As an example one parent reflected that their families' expectations for their children have increased over the years as they have realised that *"the sky's the limit, anything is possible"*. Changes for families included when older siblings left home.

Positive relationships, support networks and connections in communities were reported as making a difference and being present when things are going well for families. These connections and relationships were often with other parents or families, extended family, community, cultural or volunteer groups, early childhood education centres or schools. Many parents stressed the value of connecting with other families in similar situations. These relationships and connections help to strengthen families and ensure, as one parent said, that *"every family is not an island"*. Families said that their social networks are also useful for obtaining information, learning or sharing ideas with other parents.

When things were going well for families, they had consistent and reliable support that took into account the preferences of their child and family. Access to good quality preschool, primary school and high school and post school options were also in place when things were going well. Many participants talked about the importance of early support and early intervention services having a positive approach and being able to point families towards the right information.

Participants drew attention to the additional challenges faced by families with children with intellectual disabilities. These included extra costs such as buying communication devices or other expensive equipment, taking time off work to support their child, not being able to work

because of lack of support for their child, devoting considerable amounts of time to navigate the system and facing discriminatory attitudes and practices in the community. Negative impacts on family wellbeing were identified when families became “*tired and worn down*” from continually having to fight battles to get help. A number of interviewees also identified a compounding of difficulties that were experienced when families were isolated and/or lived on a benefit or low income.

Four main themes were identified as being important for family wellbeing – attitudes, belonging and inclusion, fair systems and being able to plan with confidence and good support and connections. These areas overlap and are interconnected. Not surprisingly the things that were seen as helpful for achieving good outcomes for family wellbeing were typically the opposite of the things that got in the way of family wellbeing.

Attitudes

A warm and welcoming attitude from community members was something that all participants identified as contributing to the wellbeing of children and their families. Positive approaches where a child or young person was seen as a valued community member made it easier for families to comfortably engage with people providing support or education.

A number of participants noted a generational change in attitudes. They expressed a general belief that the younger generation had become more accepting and in turn, this has made it easier for children with intellectual disability to participate in activities considered part of ordinary life and belong in their communities and schools.

What is helpful?

- Accepting disability as part of human diversity
- Warm and welcoming attitudes
- Seeing the child not the label
- Strength based approaches
- Not making a big deal about adaptations/accommodations – it is just the way things are done.

What gets in the way?

- Seeing the child as ‘other’ and as defined by a label – “*We’ve had one of **those** children here before.*”
- Looking at disability through a deficit lens
- Focusing on what a child can’t do
- Seeing children with intellectual disability as a drain on time and/or resources.

Belonging and inclusion

Positive attitudes from others contributed a sense of belonging in families and communities and inclusive practices. Community participation was identified by all participants as being essential to the wellbeing of their children and family. For parents, participation is not about being an observer or a “*tourist in your own community*”; it is about inclusion and active involvement in “*ordinary*” family, community and cultural activities. Parents wanted their children and young people to have the same access to opportunities and places as their non disabled peers. This was viewed as critical in developing friendships and a sense of belonging as it does for all children.

Many participants said that when things are going well they “*feel welcomed at community spaces, like schools or recreational facilities*”. A number of examples were given by participants where a commitment to accessibility and inclusion in the community was extremely helpful. As stated by one parent, “*It is essential that children and young people are provided with opportunities for community engagement and have opportunities to feel good about something they’re doing*”. For this to happen, many participants said that this must be underpinned by a social acceptance, awareness of difference and seamless inclusive practices.

Several participants discussed that there can be cultural variation in expectations and that this is important to take into account when considering how to support families. For example, organisational representatives who had met with families observed that some cultures prefer to keep care in the family, rather than seek external support.

What helps?

- Seeing the family as a unit
- Including siblings
- Having the same access to opportunities as non disabled peers
- Welcoming community spaces and seamless inclusive practices
- Understanding of how to include people with a variety of abilities.

What gets in the way?

- Seeing the child in isolation from their family
- Not valuing family knowledge
- Not respecting cultural preferences
- Making a big deal of including children with intellectual disability
- Not making adjustments.

Fair systems and being able to plan with confidence

The third theme to emerge from the interviews concerned having fair systems and families being able to plan with confidence. This section refers to the ways systems, funding and services are organised and encompasses aspects of what the 2015 New Zealand Productivity Commission report on effective social services refers to as system stewardship and architecture.

Fair systems are equitable, transparent, and work in ways enable families to have choice and control. Participants reported that families wanted to be able to get support without having to rely heavily on services that may be precarious, have long waiting times and/or are not responsive to changed circumstances. Policy makers, funders and services need to realise that when people with intellectual disability gain skills, they may require help to maintain them. For families, it is important that supports are not immediately taken away once things start to go well or when short term goals are reached.

Many participants felt that government agencies needed to communicate better with each other about the needs of children and young people with intellectual disability and their families, instead of thinking in silos. Families must navigate different agencies and funding streams, which can add to stress. Struggles to find information combined with having a lack of informal or formal supports make things harder. As noted by one participant *“there are not equal opportunities to access support, particularly if you have a lower income.”*

Several participants said that options for services and support vary regionally and that this creates a disparity in what can be accessed. Speech and language therapy and behaviour support services were highlighted as areas where there are gaps. Many participants considered that funding was not filtering down to people who needed it most. Often those parents *“who shout the loudest are the ones that are heard, other people who may not have the energy, time or resources to shout fall through the cracks.”*

When there was a failure to deliver or follow up, many parents found that their expectations were lowered. A number of participants commented that such experiences may make families less likely to push for better things because they have already dealt with so many barriers. Some participants felt expectations were lowered because the solutions offered *“had a one size fits all approach”* and did not see the individual child and their family.

A number of participants commented that traditional residential care is no longer an option that many families want for their adult children. They would like their child or young person to have more of a choice and help with transitions through different life stages. Thinking about what will happen when parents' age is an additional challenge for families because often, they have to do extra things for their child for a longer period of time and *“have to step up if there is a lack of supports in place.”*

While there are a number of initiatives underway trialling more individualised, flexible and integrated approaches concern was expressed at the disjointed nature of these with *“pilots dotted everywhere lacking a vision of what a society in which everyone has a role to play would look like”*. Questions were also raised as to whether there would be sufficient and sustainable funding so that the changes to improve outcomes indicated by projects such as Enabling Good Lives could be implemented nationally.

There were mixed comments about individualised funding. Some parents talked about the benefits that the added flexibility had given them and that this was working well. Others felt it gave “*no care, but all responsibility*” from government funders and added extra stress for families. Participants talked about families not having time to organise the practicalities such as employment contracts or timesheets. The comment was made that when families “*who are already exhausted*” take on total control and responsibility over care “*it can be overwhelming for some.*”

Sometimes families have preconceived ideas about what services are like and may as a consequence just stick with what they know or be hesitant to try new options. Resorting to the tried and known “*instead of lifting the bar of what is possible*” can place constraints on adopting different approaches. Several organisational representatives identified this as a challenge to overcome.

What helps?

- Easy to find services and supports
- Good communication and information
- Flexible and integrated services and supports
- Early access to support, services and intervention
- Respect for family as active decision makers
- Being responsive to family needs and changing circumstances
- Transparent processes for allocating resources

What gets in the way?

- Siloed thinking, funding and ways of working
- Disconnect between policies, funding and disjointed pilot projects
- Have to negotiate complex and difficult to understand systems
- Policy makers having a lack of understanding of families situations
- Having to be in crisis to get help
- Difficulty in disentangling funding pools
- Precariousness of funding and not being able to plan with confidence
- Long waiting lists

Good support and connections

Good support and connections are grounded in positive attitudes, belonging and inclusion and fair and enabling systems. All participants place high importance on the quality of the relationships that families have with the people who support them. As one participant said, it helps when families have people around them who support them to “*step up and step out*”. Many references were made in interviews about the value of having good support workers (Appendix 1 provides a more detailed summary of these comments).

All parents (mostly mothers) interviewed said that when things were going well, they felt supported. This meant that the family was seen as unit and “*siblings and fathers were included in the process and not left behind*”. Participants spoke about the need to get a good balance so parents had time for their other non disabled children and for themselves as well. Getting supports in place early was identified as being helpful as was timely access services.

Strong networks and positive relationships make a difference and are present when things are going well for families and families. Building up social connections in the early years, made it easier to develop a range of natural supports. Good connections can help to strengthen families and help them see they are not alone. Contact with other families who had or were experiencing “*a similar journey*” was particularly valuable for many parents.

All interviewees said dedicated and skilled support workers, professionals or educators to help their children thrive. Many parents expressed that they want to be able to work alongside professionals and support staff they can trust and have confidence in. Families talked about trust being built over time when people make an effort to get to know them and are “*able to keep their promises*”. Families said they appreciated professionals, educators and support workers who went the extra mile to understand their child and who worked in partnership with them. One participant stated that she did not want to see support workers, educators or professionals “*treat children as commodities*”, but as “*individuals with the same feelings and thoughts as all children*”.

The value of a key person who families can communicate with was identified by many participants. This key person is someone who listens, effectively solves problems, is respectful, empathetic and strives for positive outcomes, rather than someone who gate keeps. Parents talked about this key person, whether they were at school or with a service provider, as being committed to understanding the individual needs of their child and using their initiative to create opportunities. Having someone who walks alongside families enabled parent’s “*to move into the driver’s seat*” so they can help their child reach their full potential.

Participants discussed the need for agencies, professionals and other supports involved in their child’s life to communicate with families and with each other. The importance of a team approach where parents and other supports in the child’s life collaborate, but the family lead the way was highlighted by participants. One parent said that a “*co-ordinated support infrastructure that ranges from medical to educational to social support*” would be helpful towards “*producing positive outcomes for the whole family*”. Parents said that sometimes they feel an imbalance of power when their concerns, expertise and opinions are sidelined and not taken into account.

Several participants spoke of the need to better support children and young people with high and complex needs and their families. They highlighted that children and young people who are non verbal or have limited communication can be in vulnerable positions as they find it

difficult to express themselves and their concerns. One participant thought that policy makers had preconceived ideas about high and complex needs, without making an effort to understand the children and young people concerned. Other experiences that often are not well responded to are where the child or young person has a dual diagnosis of intellectual disability and a mental health condition, or has a chronic health issue or when a primary caregiver develops an illness.

Many participants expressed that there is a strong need to develop and better train the workforce. This does not just include support workers, but other professionals and educators, so they know about intellectual disability and how to accommodate diverse needs. In addition to this, education for frontline customer service staff, such as Work and Income, was identified as necessary to more effectively respond to the needs of families and discuss with them the support they can access. It is no longer about *“providing children with nice activities, but giving them the same opportunities for participation and engagement that their non-disabled peers have”*. In addition to universal services, many families identified the need for better access to specialist supports.

Unpredictable service provision was problematic for families. One example given was that of a mother having to change her commitments at a moment's notice when the support worker does not turn up. On the other hand, many parents said that it may be difficult for support workers, educators and case workers to fulfil their roles as they may not have enough support in their job or may have enormous amounts of work, meaning that some families may miss out because service providers are over stretched.

What helps?

- Professionals who know and understand the child and their family
- Good communication with families and between involved professionals and agencies
- Working in partnership and being directed by family preferences
- Families having a key contact person
- Trained staff with the right attitudes and skills
- Investing in support for staff

What gets in the way?

- Poor communication (from professionals, educators, service providers, agencies and Ministries)
- A lack of information about what is available
- Not having timely, quality or flexible supports
- Educators, professionals, support workers and any other support staff not listening to families
- Lack of support resulting in a crisis situation

5. What we found: Indicators for wellbeing

Better capturing and monitoring the dynamic and interconnected areas that contribute to family wellbeing will enhance planning, commissioning and funding practices, community and service development, provision of effective supports and services, policy evaluation, benchmarking and tracking outcomes for individual children and their families. It is beyond the scope of this report to cover all indicator areas, sources of information and measurement tools or to canvass the methodological issues involved. Our aim is more narrowly focused on drawing from the areas highlighted by participants to propose some possible indicators and sources of measurement.

Getting good information has been a longstanding issue both in being included in data about all children and families and in the collection and analysis of impairment specific information. Currently there are some areas where information is collected, others where it may be collected but is not analysed and some areas where data is not available. Some of the possible measures in Table 1 are just that, they could potentially be used as sources of information but would need to include disability as a variable or disaggregate data in order to be meaningful and robust wellbeing indicators for families with children with intellectual disabilities.

Table 1: Indicator areas and possible measures for family wellbeing

Themes	Indicator areas	Possible measures
Attitudes	<p>Feeling welcomed and accepted</p> <p>Being seen as part of the community of all children and families</p> <p>Reasonable accommodations are made without a fuss – it is just the way things are done</p>	<p>Feedback/self report from family members</p> <p>Standardised surveys such as FQoLS</p> <p>SuperU families and whānau status reporting*</p> <p>NZ Disability Survey**</p> <p>CRPD monitoring mechanism reports</p> <p>Analysis of complaints to the Human Rights and Children’s Commission of discrimination and non inclusionary practices</p> <p>IHC Buzz Survey - sections on attitudes</p>
Belonging and inclusion	<p>The family is seen as a unit, whatever the family structure is</p> <p>Families feel welcomed and connected with their communities</p> <p>Children with intellectual disability and their families have the same opportunities and take part family and community activities as non disabled children and their families – spending time with friends, invited to birthday parties, joining clubs, going on holidays</p>	<p>Feedback/self report from family members</p> <p>Standardised surveys such as FQoLS</p> <p>SuperU families and whānau status report*</p> <p>NZ Social Survey*</p> <p>Growing Up in New Zealand Study</p> <p>NZ Disability Survey**</p> <p>ECE participation rates for children with intellectual disability/ developmental delay same as those for non disabled children</p>

	<p>Children with intellectual disability participate in early childhood education and schools on an equal basis as their non disabled peers, school and communities</p> <p>All family members feel safe</p>	<p>School ratings on Index of Inclusion</p> <p>Analysis of complaints to the Human Rights and Children's Commission of discrimination and non inclusionary practices</p>
Fair systems and being able to plan with confidence	<p>Family preferences and culture are respected</p> <p>Families are aware of their rights and entitlements</p> <p>Transparent and fair processes for resource allocation</p> <p>Equal access to universal services – health, education</p> <p>Timely access to quality disability support and specialist services</p> <p>Seamless transition across preschool, school age and post school systems</p> <p>Adequate income and housing</p> <p>Families with disabled children not over represented in those living in poverty</p>	<p>Feedback/self report from families</p> <p>Standardised surveys such as FQoLS</p> <p>SuperU families and whānau status report*</p> <p>NZ Social Survey*</p> <p>Growing Up in New Zealand Study</p> <p>NZ Disability Survey**</p> <p>Health data using NHI number and integrated information under development</p> <p>Quality of IEPs and goals achieved, NCEA qualifications,</p> <p>NZ labour force survey*</p>
Good support and connections	<p>Family preferences and culture are respected</p> <p>Professionals and services work in partnership with families</p> <p>Families have good information so they can make informed choices</p> <p>Families have timely access to reliable supports and services</p> <p>Families have a key contact person</p> <p>Supports and services are responsive to changed needs or circumstances</p> <p>Workforce with the right attitudes and skills</p>	<p>Feedback/self report from families</p> <p>Standardised surveys such as FQoLS</p> <p>SuperU families and whānau status report*</p> <p>NZ Social Survey*</p> <p>Growing Up in New Zealand Study</p> <p>NZ Disability Survey**</p> <p>Integrated plans and agreed outcomes achieved</p> <p>All practitioners and disability support staff have initial and ongoing training in working with children with intellectual disability and their families.</p>

* Disability would need to be included as a variable

** A decision was made in 2012 that there would not be a Disability Survey alongside the 2018 New Zealand census

In 2015 a Disability Data and Evidence Working Group was established to identify high priority areas for data and evidence. One of the objectives of the Working Group is to ensure that informed decision-making underpins disability policy formulation and service planning. In the future, there may be improvements in the availability of information from changes initiated by this working group that will usefully inform indicators of family wellbeing.

6. Conclusion

The selective sample group of participants and small size place limits our findings. However, the key themes identified in this work are consistent with those highlighted in research and by families over many years including in IHC's Start Strong campaign. The indicators of wellbeing for families with children and young people with intellectual disability are the same as for all families. In addition some specific indicators are needed to more fully capture the experiences of children with intellectual disabilities and their families.

Further work is needed so that families with disabled children are included in research on wellbeing for all families and children. Alongside this information on specific indicator areas for families with children with intellectual disability needs to be collected and reported on.

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Appendix 1: Perspectives on good support from support workers

Good Support

“Ask yourself, if you walked in the shoes of the person you supported, would you be happy with your life?”

Organisation representatives and parents identified that having the right support is essential to the wellbeing of families and their children. Participants talked about having someone who walks alongside them and enables them to move into the driver’s seat so they can help their child reach their full potential. When things are going well for families, they have a good connection with whoever is providing the support they need.

Many parents talked about the value of a key person who they can communicate with about their child and have a good connection with. This key person is someone who:

- Listens to the family and child because they have a wealth of knowledge
- Effectively solves problems
- Is imaginative
- Have a flexible approach
- Has good values and attitudes
- Realises that their role is to go the extra mile and make a difference, not just provide the basics
- Supports children and young people to be participants in their community, not “tourists”
- Builds relationships based on trust and honesty. Many parents said that an enabler of trust is the quality of the relationships between family members and support workers.
- Is respectful and empathetic
- Strives for positive outcomes that enhance child and family wellbeing, rather than someone who gate keeps.
- Has an in-depth knowledge of the child’s specific needs
- Sees the child as a whole person, not as the disability label
- Uses a strengths based approach to help the child grow as a person, instead of looking at their weaknesses
- Has an eye for detail, notices subtle changes in the child or young person
- Has a partnership with the child and family
- Does not come in with a pre-existing agenda or preconceived idea of what they should do

All parents noted that a positive and welcoming approach towards their child or young person made it easier for them to comfortably engage with people providing support. Many parents said it was valuable to find core support workers and stick with them because their values and attitudes aligned with theirs. In addition, this core support worker did not use a *“one size fits all approach”*.

For all parents, being able to openly express any concerns or voice any queries they had was important to them. Parents talked about this key person, whether they were at school or with a service provider, as being committed to understanding the individual needs of their child and using their initiative to create opportunities. Several parents talked about the importance of a team model, in which parents and other supports in the child's life collaborate, but the child and family lead the way. All parents said that they needed dedicated and skilled support workers to help their children thrive. Families appreciated support workers who went the extra mile to understand their child and who made partnerships with them.

Several participants talked about the strong bonds they had developed with the person supporting their child. They said that the caregivers or support workers they hired become part of the family. One participant added that this level of trust is a very powerful thing for a family to have. For parents this kind of trust is enabled when support workers have an understanding of life for children and families or work to gain an understanding of their lives. Many parents recommended that the people who provide support should take time to observe family dynamics, see the child or young person in the context of their family and ask questions. One participant said it was helpful when a staff member just came to her home, observed family life for a few days, saw how the family supported the child and took direction from them.

The importance of having flexible home support staff that not only can support the child but if necessary can step up and assist the family was highlighted. One participant said that it is helpful when support staff ask you, *"what do you need?"* This participant also talked about home support workers being constrained by rigid rules and unable to help around the family home if necessary, as the environment directly affects the child.

Where are the gaps?

Many families identified that if the right support staff were not present, things could go wrong quickly and negatively impact family wellbeing. As many parents said, the wrong support staff would have the opposite of the qualities listed under the heading "Good Support".

Many parents said that the barriers to trusting support workers could be the bad approach of one staff member. Parents said that one bad experience had the potential to damage their view of an agency, service provider or organisation. Families talked about trust being built over time when people make an effort and are *"able to keep their promises"*.

Many parents wanted reliability and consistency with the support they were receiving. Several parents talked about dealing with unpredictability and having to cancel appointments because support workers have not turned up.

Supporting children to participate

Many participants said that support workers are an important part of supporting young people with intellectual disabilities to participate in community life. Several parents said that they want to know that supported community living options will provide a level of community engagement and give their young person an opportunity to feel good about something they're doing. Parents did not want support workers to just do the bare minimum and only

focus on meeting basic needs. Many participants pointed out that for support workers, it is no longer about providing children with nice activities, but giving them the same opportunities for participation and engagement that their non disabled peers have.

Understanding complex needs

Parents said that it becomes complex when in conjunction to an intellectual disability, a child has a chronic health or mental health condition. Several parents said that there is difficulty finding support workers who understand and can accommodate these needs. One parent said that it becomes harder as your young person gets older as the only options available are residential care. They said that when they only went on holiday for a few days because it was so difficult to organise support. They added that they would pull out of their holiday early if something went wrong and she didn't want to write "*a manual*" about how to support her child.

Attitudes

Several participants observed that even though institutions had closed, there were remnants of the institutional culture. They said that even though new support workers are coming through, the attitudes of older generations still linger. Parents reinforced the importance of support workers having good values and attitudes. Several participants said that families were reluctant to use respite care and residential care because young people would just be "*left in front of a T.V*" and not engaged.

Many participants said that there was a gap in how support workers are trained to work with specific people and their attitudes towards them. Parents want support workers to value their child and their life. One participant said that she did not want to see support workers "*treat children as commodities*", but as individuals with the same feelings and thoughts as all children.

Investing in support workers

Many parents expressed that they want to be able to work alongside support staff they can trust, have confidence in and who are effective in supporting not only their child's development, but also the family. Many families and organisations identified that there is a strong need to develop the skills of support workers so they know about intellectual disability and how to accommodate diverse needs. Several parents talked about providing support workers with more individualised training so they can meet the needs of specific people they work with. One participant talked about having outreach for support workers in rural areas so they could continue their training.

On the other hand, many parents said that it may be difficult for support workers to fulfil their roles as they may not have enough support in their job or may have enormous amounts of work, meaning that some families may miss out because they are over worked. Several participants said that support workers need to be working in good environments and feel valued and supported in their jobs. Many parents said that a barrier to creating strong relationships with support workers was the high turnover of staff. In conjunction with this,

even when parents could access the funding they needed to pay for support workers, they found it difficult to find suitable people to fill the roles. All parents said there were not enough trained or highly skilled people.