EVIDENCE CENTRE
TE POKAPŪ TAUNAKITANGA

Appendix Five: Understanding children with disabilities in the Family Start programme

September 2019

ORANGA TAMARIKI
Ministry for Children

EVIDENCE CENTRE
TE POKAPŪ TAUNAKITANGA

Aurora Centre, 56 The Terrace, Wellington
The Oranga Tamariki Evidence Centre works to build the evidence base that helps us better understand wellbeing and what works to improve outcomes for New Zealand's children, young people and their whānau.
Email: research@ot.govt.nz

Authors: Paula Pereda-Perez, Senior Analyst, Research and Evaluation

Published: September 2019

ISBN: 978-0-9951239-6-0

If you need this material in a different version, please email us at research@ot.govt.nz, and we will provide it for you.

Citation guidance:
This report can be referenced as Oranga Tamariki Evidence Centre. (2019). *Understanding children with disabilities in the Family Start programme*. Wellington, New Zealand: Oranga Tamariki—Ministry for Children.

Acknowledgements:

Thanks are owed to the large number of people who contributed to this research in some way.

All Family Start workers survey participants for contributing their time and experiences, and the Family Start providers who made this work possible.

Ann Walker, Carmel Daly, Penny Gault (Policy).

Josephine Ryan, Kanchana Subedi, Eyal Apatov (Evidence Centre)

Robert Haig, Paul Arts, Janet Dean, Grecia Mcnamara (Pa Harakeke Family)

The authors owe a special acknowledgement to Valmai Copeland and James McIlraith for their peer-review contribution.

ORANGA TAMARIKI
Ministry for Children

APPENDIX 5: RESPONSES TO OPEN-ENDED QUESTIONS

Reasons for services and support for families with children with disabilities being especially helpful

My clients I work with have impairment issues. The majority of these whānau have substance issues, criminal behaviour, mental health, family violence, left school at a young age history.

The family I am working with has two children with [....] syndrome. Solo mother, no family, financial problem and suffer from time to time with depression. Her respite care is what gives her the strength to keep going. She does not have enough, unfortunately.

Many of the whānau we work with live in isolation and are unable for whatever reason to access support, with the Early Learning Payment the children can start Early Childhood Education earlier and often their disabilities are picked up through this.

Early intervention is paramount for all children with disabilities, to ensure services are in place as soon as possible.

Children suffer from in-utro harm through drugs/alcohol that is difficult to diagnose leaving a child suspended from support from services designed to support their inner and outer wellbeing.

Psychologists, I believe can support whānau to unravel the historical harm weighing on children and look for ways to introduce 'usual whānau practices' that don't involve harm to self and others.

Financial assistance is important and practically helpful, particularly if a parent cannot work, as they have to look after a child.

The support that is offered financially for whānau is a significant help for them as this allows the affordability to be able to provide appropriate care, some whānau with children with disabilities may need to be a home carer for their child where the financial support is beneficial.

Support services in home and community offer the support required for the whānau.

Low-income whānau benefit from any financial assistance, Early Childhood Education is where issues/difficulties should be recognised; early intervention can possibly address issues before the problems intensify (before it is a major piece of work to support)

A co-ordinated approach is preferred in combination with a comprehensive needs assessment to ensure the best and right supports are accessed. Early intervention is essential to ensure the children get the best start and intervention to help ensure they reach their full potential. Financial assistance and time out re childcare also help reduce parent’s stress, which has a positive impact on the child.

Often the families we work with need the support to come to the home as sometimes they do not realise the importance or the difference it makes to their child's life when they cancel or miss appointments. Also, this gives no excuses not to be able to get the help/support the child needs.

The family needs to be released from commitments to high rental payments, and have their own place with low rent so they can deal with everything else to ensure the rest of the family are stress-free and relaxed to take the pressure off the parents trying to compete with and find suitable homes with low costs.

Mothers especially need quality homes, appliances, strong community support, and access to a range of free full-time childcare and holiday care and respite.

The family felt a lot supported when they received a house support worker so mum could have some time off. So, she could do some chores.

Mobility parking was helpful as it is very difficult to find parking in the public service. Also, mum could not carry a child and walk all the way to the hospital appointment time.

Child disability allowance was helpful, as mum could not go back to her work. Only dad had income and family needed to pay all the living expense for such a large family.

The tamariki are included in early childhood and school.

Parents feel overwhelmed with the stress of caring for a disabled child. With the support of childcare, the parents are able to get some time to themselves, the child is in an environment that is supportive, and helps encourage their development. Childcare and respite are necessary for families who are already feeling overwhelmed. I also put the benefit payments in there as most of these families are struggling financially.

Early intervention to give children the best start in life whether that is a referral to family start, speech and language, therapists, psychologist, etc.

Behaviour support services are important to give stakeholders strategies to understand behaviours including behaviours of concern and how to mould them into something positive or less harmful to themselves or others.

NASC to be able to get the funding for early intervention supports.

Early Childhood Education to give whānau respite and have another support avenue and the Early Learning Payment to be able to reduce the financial strain on families.

Early intervention services are key to supporting families with these challenges. Child disability allowance. Families who cannot work because the children have high needs. They need this.

Preschool is a helpful support for both mother and children, and they work alongside other agencies needed, eg, MoE Speech-language Therapists.

Home and community support are helpful for whānau who struggle with transport. Respite for carers is a need so they can take care of themselves. Child disability allowance for financial support. Early intervention teachers to support the children at school and behaviour support services around behaviour strategies at home and school.

Child Development Team as they can refer to needed Doctors and Services, community services can also be helpful; travel is needed for lots of appointments, benefits to help with costs.

Early services can mean early identification of needs for both child and whānau, this includes support with can help reduce stress on the families both financially and emotionally and prevent abuse and neglect.

Most of these services offer childcare/respite so parents can get a break.

I would like to say that the early intervention services through group special education, child development team, ASD coordinators, and behavioural support services, are the most helpful for my young clients and their whānau. However, this is not the case. The waiting times are too long. Many of these services are naming a problem rather than having effective strategies for addressing it. The interventions when they do come are minimal and extremely slow in coming. And often the people delivering the services do not have relevant training or experience to do the work.

Ensuring that the families access the appropriate support available to them in the community, which includes financial support through WINZ. Also, families often feel that the children need more support at school and there is a lack of respite for the families.

Early intervention services – this is important as parents need to know what they can do to support their child's development and help them to reach their potential. The is a risk that parents muddle on and later less helpful behaviours having to be un-learnt.

Home and community support – Having someone in the home to see what is happening a understand the difficulties is helpful for parents and professionals who are trying to work with the children.

Carer support- respite hours – This is more important for some families than others. Where the disability is causing frustration for the child and the parents are unable to handle the behaviours, and the child is not able to go to daycare/school, parents can become overwhelmed.

Disability allowance – There can often be a lot of extra hidden cost for parent/s transporting the child to and from appointment being one of the biggest ones.

Early intervention teachers – Research shows that supporting children in the early years is more likely to have positive results.

Families with children need financial support and information access to support services that will meet the needs of their child and family.

Allowances help the whānau out financially. These services put support in place for the children. Allows the caregivers time out and allows parents to find employment.

Services that allow children access to education and support.

Because they were responsive and collaborative

These supports enable the family to live and cope with their circumstances, especially the supported living payment. The early intervention services available is essential for the children to have the best possible intervention in place long before they go to school to give them a chance for their future. As Family Start is able to support and advocate for the family/children, it's very much appreciated to also received the support and help from the professionals so we can continue to provide the best support we can as workers at the most important time for their young children and their parents.

Child Disability Allowance permits the parent/s to pay for additional services for their child to enhance their well-being.

Having a diagnosis is the beginning of the journey to getting the appropriate supports put into place for the child.

Specific supports enhance the child's developmental potential.

Being able to access Early Learning Payment enables parent/s to enrol their child into an Early Childhood Education centre without financial strain benefiting both the parent/s and the child.

These are the main things whānau need help with when they or their children have a disability.

Extra finances help my family's financial situation as the father is no longer in the picture. Also having a community services card gives them access to other services (discount on insulation for housing etc).

Because I have personally tapped into these services and have been very happy with their responses.

Respite services would be a great service but unavailable in the district.

It is imperative that children with disabilities have their needs identified correctly from the beginning and then can access the relevant services.

Access to affordable/appropriate childcare/respite services allows the caregivers time and energy to expend elsewhere. It’s an exhausting job just to be a parent added in the mix a child with disabilities. So, respite and or childcare services are essential to the well-being of the parent/caregiver as well as the obvious benefits of socialisation and education for the child.

Behavioural issues noticed and an autism diagnosis completed asap would support mums so they can get the resources and services best to support them.

Having a child with a disability can draw on a whānau's budget, whether it's having to buy specialised food or anything else that their child may need

It empowers whānau to achieve best outcomes for the child

Provide funding and assistance for the whānau with costs.

Our whānau would prefer and probably benefit more, from of a hands-on, face to face and individualised support.

Some of the forms they need to complete could be worded better/made easier to understand.

Whānau is tired looking after tamariki especially those with disabilities -A little time to themselves (parents/caregivers), the more support in the home the better.

Yes, the services are helpful when you don't have a long waiting period

The families having a disability need more supports.

Child Development Services – a visiting neuro Therapist is visiting the home fortnightly and co-coordinating services to support the child's development. They have also built in referrals to support the family, and it was this service that referred to Family Start. They also work with the Paediatrician.

Counselling has also been useful for the parent to assist them with the loss associated with their son's diagnosis.

There are often extra expenses involved with having a child with a disability. Accessing appropriate services is often difficult. Having time out is crucial, depending on the nature and severity of the disability. Needs assessment can help access the services they need. People are often not aware of how the disability will impact on the child and their family.

They are active within the community

Not all professionals are helpful. Family/whānau sometimes opt out of seeking help due to the lengthy paperwork and repetitiveness when filling in applications. And sometimes, family/whānau do not fully understand what they are being asked.

Services needed that most for easier access.

The parents/families need a rest from these busy children; they also need knowledge to how best to support their child.

Quick service, referral response is made within 3-week gap. Continued support of service is easy, and understanding for parents to engage.

Helps alleviate financial stress.

This ensures families are getting all entitlements necessary to accommodate extra costs to hospitals on a regular basis and to allow us as family start to support them into Early Childhood Education.

They work with caregivers at the level of the caregivers.

To increase the ability of rural families to meet their costs. Pre-school attendance gives parents a break and allows other professionals to support the family.

Early professional intervention will help children to achieve more if they are supported from early stages.

Hands-on, real and practical support for whānau and Tamariki.

The parents get a break when the child/ren go to Childcare. Disability allowance helps them manage the extra costs. Early Intervention Teachers are well trained and can offer support plans in the home and preschool. Speech and language Teachers are crucial in the child's development.

The families that it directly involves have other children; this can be stressful to care for their disabled child while ensuring that they are meeting basic needs. The services that have become available to the family have been very helpful. This has alleviated stress in the home environment.

Pre-school services & financial support to extend the children's learning capacity and support the parents care for their children in their homes.

I think these services are the ones that can make life a little easier for the families with disabled children, by putting things into place that will help with situations, like more money for power when a child is not well.

These are in regards to the whānau, which I have the pleasure to support, not all whānau would need this combination as all whānau's needs and experiences are different and affect whānau differently. There services which I have named work towards the child's whole wellbeing and provide both a clinical and non-clinical perspective for response to the needs of child and whānau.

The financial costs of having a disabled child and the fact that any other children in the home who miss out if the costs place the whānau in critical mode.

By receiving the benefit, they have a little more flexibility.

Coordination and knowledge of supports available via NASC is invaluable.

Financial Supports very beneficial for all family's I support as all living week to week.

Additional Support in the education setting vital for children with challenging behaviour to keep themselves and others safe.

Home and Community Supports if coordinated well.

They are all helpful in a different way. For children, it is important that whānau have a safe place for their children to go when they need a break and that they get the support they need in education.

The biggest challenges for families appear to be their need for respite care, which gives each party time out, coordination of services as families often, have multiple services involved, which can be challenging and financial assistance due to the financial strain placed on families caring for a child who has a disability.

These families tend to have additional costs due to their child's disability, and there are unique ways of managing their behaviour than standard parenting services. Families find it helpful to get a diagnosis for their child for understanding and support that may come with it. For tamariki with severe disability, respite is helpful – the families I have worked with often do not have their own social supports or have exhausted them. Parents/caregivers become burnt out from the day in day out the needs of their children.

The disability allowance is most important because it provides the funding that allows parents to get to services/support, Early intervention services for the diagnosis and referrals to other agencies, SLTs to help the children with development and access to other supports in the school systems, Early Learning Payment subsidies to help give parents a break, Behavioural Support Services to help with diagnosis and support/education for parents

After school care can allow the parents/caregivers a break. Subsidies make after-school care more available to families. Disability allowance means more income for extras. Carer support is good but only for those that have a diagnosis.

Child Disability allowance is helpful as it is providing additional financial resources as normally for families of children with a disability; there are always additional financial needs. Child Development Services are normally the first service that the families come in contact with and they can point them in the direction of other services they may need and then move them onto Early Intervention, which is important to give children the best possible starts. I have put Early Learning Payment in there as it means that parents can access good quality preschool education for their children, which means they can interact with this peers and equipment modifications are important to help a child lead a full life.

Financial assistance is necessary for these low-income families.

Families who have children with a disability often face additional costs particularly with transport to appointments. As the children get older, the early intervention services provide expert support to the families and to the childcare providers

They are helpful because they work around the families in terms of transport, they will come to the home, and the assessments done with the family are thorough and effective.

I've worked very effectively with two children with Speech-language therapists and found them easier to access than Early Intervention Teachers and with useful strategies for helping the children communicate at school where this has been an issue – the funding available for many of these children to settle them at school is wholly inadequate and does not enable them to fulfil their potential. The criteria to receive teacher aide funding alone is so prohibitive that students miss out or are forced to do half days as they cannot get adequate funding for longer-term support/longer hours.

Community support services are helpful as they visit families within their own home (environment) this allows whānau with transport/money challenges to access help even though they cannot attend appointments.

Parents require financial support as well as respite and childcare supports

Money is the biggest issue as people primarily on benefits or the working poor are struggling under the best of circumstances, let alone the financial drain of having a child with a disability or impairment.

The families want to see an expert first to give them some answers usually; they want to know what services they can access to help support them. Finally, what financial help is there for things like transport to and from hospital visits, medications, specialist appointments etc.

The services are offered via family doctors.

The whānau I support do not have access to a vehicle and because their baby has high medical needs, getting to appointments has always been hard; therefore, transport is the biggest gap we found we had to fill. Public Transport is always an option; however, a particular type of car seat needs to use for transporting baby. Family Start also found the whole Early Intervention team within the hospital worked in together with the whānau and ensured that all community services for this whānau were engaged before discharging from the hospital.

Helping at the home was also better for whānau as mentioned above transport is always a battle. Having the speech therapist and other organisations coming into the home also gave the whānau more comfort in discussing the needs of baby in private, rather than in front of an audience of people.

EI Services support the child and family to improve outcomes, ensuring they are school ready and helping them to integrate into some sort of 'normality'

Community support workers go into the homes, which are often where areas of greatest vulnerability are identified. It also helps as we build up a rapport with the families and are able to identify when there has been change or worsening of circumstances that other professionals may miss in a clinical setting.

Availability in our region and access. Being a remote area, we sometimes do not have services appropriate for the needs of our families

All support begins with Needs Assessments, so this is important. Money is tight so the Child Disability Allowance can help slightly (it's not very much). CDS, EI teachers and SLTs are all of equal importance in providing home base support and early intervention.

Because this is the only supports my family are using at the moment a child is still very young and it is not known what he will require as he gets older.

Respite care has assisted the parents to have a break and work on their self-care plans. Also, to assist them both to keep calm and be more positive parents.

Being on a benefit the disability allowance has helped them to buy the appropriate food, which assists to balance the behavioural issues present.

Home modification has enabled the family to be more relaxed as the safety issues (such as running away and getting up during the night) have been alleviated a bit.

For most of my families, having their children in an early learning environment and having some respite care appears to be extremely helpful in their getting by day by day. Makes it easier for the parents to take care of the children and themselves, if they the children have been taken care of during the day and they then take over in the afternoon and evenings.

The chosen ones are the ones that our families have access to somewhat

Effective professional support to help improve/manage child's particular disability

Financial support if family is finding it hard to manage re providing child's extra needs

Childcare support

To provide relevant information to caregivers to better care for the children.

Families who struggle with children with children's behaviour need support through early intervention so that the family gets the support they need early on and not when they have already been struggling for a long time.

The disability allowance has allowed the mum I am working with to put in place the things the family needs in a more autonomous way.

Main issues faced by families with children with disabilities

Impairment- whānau that have dealt with their child being assessed by a practitioner. The child they were told that the child was ok. The two older siblings however witnessed a lot of family violence, and childhood neglect. The younger child was too young to understand what was going on.

The whānau were told the two older children have behaviour issues and that is it.

The whānau have finally been heard and now they both children are being referred to a service that will hopefully help them.

The process and systems in place are putting extra stress on the whānau, as they are the ones that are dealing with these issues every day.

Information and ongoing support.

Finance appears to be the whānau' main issue at the moment since its one source of income.

Not having time to clean and cook when the children require 24 /hours supervision and not having any support around like family. The family has to rely a lot on the help of church people

Not knowing where and how to access help, acknowledging their child may have a disability.

Appropriate child time framed diagnosis. Services are unable, due to funding criteria unable to assess children for support.

Difficulty diagnosing + receiving the appropriate supports in a timely fashion.

The whānau who doesn't have appropriate support in their home face the daily challenges of these aspects – depending on the disability. Financial hardship may arise, as the caregiver may not be able to work due to the child.

Poverty, lack of skills to cope with the disparate issues associated with the disability, lack of cognitive ability, inadequate support.

Waiting list and delay in needs assessment and coordination of services and supports, not being heard and delays in supports puts more stress on parents and children.

Lack of understanding regarding children's needs and follow up supports, not informed enough about child's condition, language barrier (culturally appropriate professionals/services/support), financial support i.e.; transport and costs, motivation and drive to ensure all needs are addressed appropriately for the child and family. Meeting and making appointments, frequent change of phones and address.

Parent’s lack of sleep, lack of assistance in the home – need professional workers in the home to assist the cognitive and other developmental issues the child is facing, to support the mother to know how to deal and set up routines, monitor etc, the family

Family had difficulty to search a childcare, which can accept disabled child. Family had to wait until the daycare find a person who works with a child one on one. The child waited longer time than other children.

Parents are feeling tired to take children's appointment which has very often (hospital, GP and DHB professionals) at least 1, 2 or 3 times a week. Family also had other appointments for other children and family start. It was very tiring for mum. It would be helpful if there is any transportation support or reduce/combine some appointments.

Parents often struggles to look after other children when they have a child with disability and siblings. It would be nice if there were any extra support for siblings such as school walking buss, available after school programmes and after-school home workgroups.

Extra cost.

For the East Coast Whānau it is being able to access these services, as distance is an issue. Also being aware of the support services available to them.

A lot of families, as well as the workers, are unaware of the benefits or services available to these families or where they can go to get the support. As the child grows, there are new obstacles. Rather than seek help some families try and cope on their own.

Funding to be able to access services more promptly. Not enough access to Clinical support over a longer period of time and one on one support in Early Childhood Education, School etc.

Respite.

Financial support.

Transport to appointments.

Support with behaviour management.

Knowing how to support the child, eg, especially so with Autism.

Getting support needed at school.

Lack of extra support either in the home or respite.

Poverty.

Low income.

Lack of community supports.

Lack of transport.

Homelessness

Family harm/DV

Accessing support.

Depending on where they live, accessing services and professional services and cost of travel.

Help – respite care, knowledge of what services can help them out.

No Respite care in our own community.

From my experience, I think that the disability support services in this country are poorly calibrated. In other countries, people do jobs that they have the experience and training to do. For instance, if we are looking to improve a child's behaviour and learning capability, then people from a psychology background who understand learning theory and behaviour do this type of work. For issues around language and speech, a language pathologist is engaged. Children who have sensory issues are seen by an occupational therapist who will frequently design exercises and a sensory diet for them.

In New Zealand, social workers seem to be tasked with a lot of jobs for which they do not have the relevant experience or training. Furthermore, in the education setting, almost everything is done by teachers. Teachers do minimal training on learning theory, and most have a limited understanding of behaviour modification when it is applied to children who are emotionally and behaviourally complex and challenging. Some schools are open to learning about how to work with these children, but most are not. Thus, we end up with a vast majority of children with additional needs, who are not being properly catered for with our education system.

Lack of respite for families and respite care workers.

They do not know where to seek help.

There are often a number of complex social, emotional and physical issues happening for these families. Adequate housing, lack of positive support, history of trauma or disability for the parent.

Funding and access to appropriate resources and information to meet the needs of their child

Getting the right supports in place within a reasonable time. Often some services are not listening to the needs of whānau; therefore, their needs are not being met within a reasonable time frame.

Poverty, lack of adequate services.

Being seen and heard

Being heard, recognised, and understood.

There are still gaps in the system, especially where there are learning and behavioural disabilities. I have supported a mother whose child was diagnosed with Dyspraxia, her journey in trying to get supports into place for her child both before he started school and afterwards was horrendous.

Likewise, a mother whose daughter was on the Autism Spectrum. Because she was not on the high end trying to get the support she needed at school (Mainstream) to assist her learning was extremely difficult. After a year at school, the child still could not write her name.

Lack of services that are actually helpful.

For my family, the health professionals have struggled to diagnose what was going on for their child. There were concerns by health professionals that the mother was neglecting her child but was then diagnosed and is now receiving some support.

That whānau are unable to utilise these services 24 hours. It is during the hours that these services are not engaged with whānau that they really need their support

Accessing services.

Lack of inclusion in mainstream services.

Lack of funding, resources, the process it takes to diagnose and then access funding. The eligibility criteria can be exhausting and does not guarantee a positive outcome. Whānau that sit just outside of the criteria are not catered for and can be/are forgotten about.

A holistic approach, where the whānau is catered for, and not just the child would be more beneficial.

Waiting too long for an official diagnosis and to see a specialist. Finances-extra income is needed for parents with children with disabilities.

Having their children diagnosed by specialist, having their concerns being heard

Not knowing what resources are available to them

Lack of knowledge of support services in the community.

The time it takes for things to be followed up and put in place

Seeing different people – having to explain over and over.

More shared information for transient whānau needs to be made available – proper support can be put in place sooner rather than later.

Long waiting times for appointments – 16 months max.

Free transport for those who have no vehicles.

The eighteen-month-old has had CDA approved, but Work and Income are disputing this on grounds children of this age require supervision. However, I believe this should be payable as health issues, and disabilities lead to additional costs for the whānau.

From working in the disability sector for a time, it is very complex to navigate to all the supports that are out there and how they can be accessed.

I worked for many years in the disability sector prior to working for Family Start. Families struggle with judgement, marginalisation, telling their story, again and again, and working with people who have no idea of what it is like for them. Trying to pretend it's ok when it isn't, minimising their struggles, grief and sadness, which is ongoing. Relationships often crumble under the strain of raising their children. Loneliness.

Isolation and limited access to appropriate resources/support in a timely manner.

Lack of support and funding

Not being heard.

Do not meet the criteria.

Not understanding what is being asked of the family/whānau.

They are not sure as to what supports they are entitled to

Services not engaging with families fast enough to be helpful they always come when the situation has reached crisis point

Financial support into services that will help parents' children grow and develop to their ages and stages

Having respite care for children

No respite care for the whānau or for the child

Travel costs, transport, vehicle maintenance, family support, food, parent stress and health, etc. Services do not explain to families properly what their role is, and some do not follow through or follow up. GP and nurses are not helpful to clients, and this means they need more appointments waiting in waiting rooms to address the problem.

Inconsistent professionals.

Enough knowledge from professionals to meet their child's needs, especially for unusual conditions.

Usual life pressures, such as financial, relationships, mental health, are harder if also managing children with higher needs.

To access the necessary support agencies

Isolation, judgements and ignorance from others, lack of understanding, 'professionals' telling them what they 'need'.

Time out. Transport to and from childcare.

Recognition, time out, a break.

Financial support and resources, for example, a modified vehicle to get their child to and from school/respite while ensuring that the family as a whole is involved.

Access to timely services, eg, assessments and thus earlier access to intervention services.

Not knowing where to go.

Supports and services being put into place quickly enough for the families, at times the diagnoses can take a while and until this is completed, services cannot be assessed.

Funding and access to regular respite care.

Lack of respite services in the rural area, the cost of travel for those who live on the boundary of being entitled to travel expenses mean that a number of families miss out on essential services.

The limited number of therapists that service the smaller towns and rural areas.

Financial – Poverty.

Access to Services – Waitlists.

Community Access.

Access to Appropriate Housing.

Rural Isolation.

Social Isolation.

Discrimination from schools and people in the community.

Lack of support and knowledge.

It takes a lot of time and energy to care for a child with a disability, especially if no other practical or family support is available, the financial strain on families can also impact negatively on the wellbeing of family members. Coordination of services in terms of a strengthening family's approach ensures the whānau have a voice and clarity around the services involved, their role and who can help with what.

Lack of understanding and (practical) support from others including professionals such as school staff; exhaustion from the day-to-day high needs of their children; the school has all the support but not so the family.

Funding, transport and education around how best to support their child and know what's available for them in the community.

Accessing services to improve the quality of life for the child. Lack of monetary resources in agencies that help.

The main issue is being able to access the most appropriate services and equipment for their children as there are always waiting lists and I have one Mum who has been told that Speech-language Therapy will not look at preschool children until they are three even though her son already has a definite delay. Also, there is an issue with parents often getting a diagnosis, and then there being nothing following that to help them cope with the diagnosis or to give them information and parents have to go searching for this themselves.

Financial support

Adjusting to the additional needs of their child.

Accepting that their child has a disability and learning to accept they may not meet developmental levels at the same time as their siblings or that their developmental level may be different.

Grief at the losses they and their child's face.

Housing, finances, and education.

As above- criteria are too strict for Special Ed Grants etc, and not enough teacher aide funding to support children with additional needs at school. Also the stigma of dealing with children with disabilities in a mainstream system of overfilled schools- I have witnessed this several times where schools and support teachers become exasperated at the lack of funding, and the parent feels their child is a 'burden' on the system as they don't 'fit in' with a mainstream model, in particular, one that proscribes open plan learning situations where there are so many issues for hearing and communication impaired children,

Need for respite care.

Lack of money to access vehicles that are suitable for children with disabilities.

Childcare and financial

Lack of support and advocacy within health professional domain

Respite support and access to financial assistance.

Funding and support, is challenging to access

Our rural community without public transport makes it difficult for families to obtain the services, and then they have actually to know about services – so lack of knowledge of what is available.

Adequate housing and transport options.

Isolation.

Discrimination.

Judgement.

Grief.

Acceptance.

If you are limited in education as a parent, this can also prevent you from seeking the appropriate services; therefore, baby misses out on some services that could benefit them and the whānau.

Being judged by others and feeling guilty that their child is disabled because of something they may have done.

Isolation stress tiredness frustration.

Lack of social support networks when finances are tight. Often the added stress of having a child with a disability can lead to social isolation or worsen issues around maternal/paternal depression

Accessibility and costs.

Managing all the extra needs of these children and the strain it puts on parenting other children and the parental relationship.

Ongoing grief and loss issues.

Stigma and negative judgement from the wider community.

Lack of understanding from the wider community.

Inclusion problems at schools and preschools.

Piecemeal professional support from an overstressed specialist work front.

Advocating for their children to ensure that disabilities are picked up early, feeling listened to regarding their children. Knowing what services are available to their children.

Frustration regarding the behaviour of their children and not having the skills to cope with/deal with behaviours that are challenging. Often this results in anger towards the children.

One family are being asked to work when there is one child with high needs as well as the father having high health needs – We are often asking the mother to go to working/trainings. Financial assistance (disability payments etc) can be hard to get and maintain.

Lack of support. Child disability intervention almost feels non-existent, or you need to jump through loopholes and can spend months trying to find the right intervention for the children and parent.

Access to services and expectations of providers do not match.

Lack of adequate support – have to wait so long to see paediatricians/ psychologists etc.

Long term support is also not available – services tend to be short term.

Children with disabilities don't always get adequate support in the education system.

Families financially disadvantaged by extra needs of child/children with disabilities especially if they are unable to return to work because of children's needs.

Getting the appropriate support – unfortunately MOH, MOE can be difficult to get to provide the appropriate support and want us to fund services privately because the children are in our care.

Not getting access to support quick enough. Families have to wait a long time on waitlist to get any form of support from specialists.

Families face a lot of discrimination.

Crucial services such as paediatricians, physiotherapists, speech-language therapists and other services saying that children need to be urgently seen but they are overloaded, and the children cannot have an appointment for months. Several times I have seen appointments that children have been waiting months for, then be delayed for another few months because a worker goes on leave/or resigns. Then I have witnessed the family being told that the long-term outcome for the child could have been more positive if the child could have been seen earlier. Also, health professionals saying they will refer to other services and not following through and when reminded months later shrugging and saying they forgot.

How children with disabilities and their families could be better supported

A better system needs to put in place. Creating a system where children are being fully assessed from 0-16 years. This would be monitored by a service, which will monitor the developmental changes that are taking place with that child.

By the time they transition to school, supports will be in place for that child. From primary to high school, the next stage will be the same. If no change, to continue with support for that child.

Create a form where whānau can find out which is the right service for their child.

By open communication between whānau and services involved.

During school holidays, having more free programme for them, so the mother gets a break. She has two other children.

If I could talk about GSE in our area, they do an amazing job when they finally get to meet with the families, however, waiting lists are way too long. So clearly, they are understaffed, Teachers in Early Childhood Education and Schools are not always educated around identifying when something is wrong, and it is often put down to behaviour.

Services designed to support the current needs, impacts of poverty, alcohol and drugs, and family violence, especially intergenerational. Frequently services are available for whānau once there has been a crisis. When the worries and observations of the whānau and NGO services working with the whānau try to get preventive support in place for whānau, before the crisis, there are limited supports available.

Shorter waiting lists for services and assessments + income support for parents.

Community support, financial support, travel assistance for whānau who have to travel to hospitals etc.

whānau support is always key. However, some whānau do not have this, unfortunately, where support systems would be beneficial. – Group counselling or other significant support groups would benefit whānau who are going through the same thing.

More qualified early intervention staff, whānau/tamariki can quite often fall through the cracks, parenting education that can cater for parents who have cognitive issues of their own

Home visits too not having to come into appointments were possible making access to support and services more accessible.

Need housing to be free and good quality.

Parents are supported by professionals in the home not at another service – In the home to monitor and assist with how to develop routines etc.

Need free childcare for 40 hours to enable parent’s time to rest and deal with the child when they come home.

Need support groups in the community for constant and regular support they can meet their needs and share.

Great support was close communication and suggesting available support from school (the school from siblings), health professionals (for the child with a disability) and family. Parents seemed to be relieved that school understood the family's situation, DHB's suggestion of some financial support (disability allowance and home support) and extra school's support. Made a plan together and achieved the goals.

Extra finance.

Information sharing and communication.

Better support from families GP, Plunket and community nurses that see concerns and problems first hand and can make initial referrals. Services being pro-active to refer to specialised services if they cannot also support for disability services to speak to families about their entitlements from Work and Income and utilising interpreting services. Community workers to work collaboratively with one another to better support the family's plans.

More funding.

More respite.

More money.

Transport.

Extra financial support that recognises the extra expenses.

Better access to respite.

Monitoring parental mental health.

Having the right supports at school and more time one on one in the class.

More residential respite and help in the home

Better support services

In-home support who can navigate on their behalf

Depending on where they live, my whānau live done the coast but otherwise, there are lots of services available.

Respite – either by carers or by getting kids involved in activities to get them out enjoying life and giving the whānau a break also. These need to be at no cost to the whānau. A lot of children with disabilities miss out of things because the whānau cannot afford it or they have to go to support their child

Not having to wait months for appointments and assessments

Listen to the whānau and the people with disability to find out what they require. Get the right people into the right jobs. If they need help with behaviour problems, find a person who understands how to address behaviour problems effectively and ethically. Do not hire a speech and language pathologist for the job, or an occupational therapist, or a social worker, unless they have a good few years of experience in the field and appropriate training.

Do not minimise disability such as dyslexia because literacy difficulties are a key factor in youth suicide. And here in New Zealand, we are the highest for youth suicide 15 – 24 years of the 34 the OECD countries.

More hours and availability for respite. More holiday programs for children will include disabilities and one on one support at school.

Reaching out for them and informing them with appropriate supports.

Early detection and correct support.

Information and funding families can access to support them with the care of their child.

More collaboration between services could help with this process.

More targeted services.

Being heard, with understanding and compassion

There needs to more understanding around disabilities. The mother whose child was on the Autism Spectrum was viewed as being a 'bad mother' because of her child's behaviour by the staff of the daycare centre. They had no understanding what so ever of autism which is concerning.

Being able to access learning support in schools needs to be easier for parents.

Parent/s applying for the Child Disability Allowance have to jump through many hoops, it is a time-consuming process. Surely, the process could be streamlined and made less stressful?

Faster diagnosis and faster help for the children and their whānau.

Understanding the family’s situations and keeping them informed as much as possible. Sometimes clients feel like they are being kept out of the loop.

Having a 24-hour contact service would be helpful for these mums and their whānau.

Services visit whānau instead of expecting whānau to always travel to them.

Absolutely – I have none on my caseload at the moment and think it would be beneficial to many families.

They could be better supported if they feel they have been listened to and that their fears and anxiety are taken into consideration. Whānau feel as though they are just 'moving through' a system that is not their own and are often a number as opposed to a human being. Money is a very big factor, and unless the appropriate boxes are ticked, you will get nothing.

Faster diagnosis from specialists.

Listen to the concerns of the caregivers (Parents) they are with their children 24/7 if anyone knows the child they do. Don't discount the knowledge that they have.

Whānau to be made aware of resources that are available to them.

Provided with better information on support services so that they can gain help earlier to better help the children and furthermore the wider whānau.

Yes – consistency of workers/support. More Multiple Disciplinary Team meetings so all involved with the whānau know what is going

Shorter waiting times for families.

More funding.

A more coordinated one-stop shop to advice on supports and services.

Better financial support eg, CDA

Free counselling

Working with people who are aware, empathetic, supportive and kind. People who will work 'with' them, rather than 'do' to them.

Rather than having to go all over town – or even the country – having an advocate/navigator to work alongside them to ensure they received all the support and services they need. Why do whānau have to go searching or support & services when they need them most?

Appropriate funding.

By being listened to.

To fully understand processes of any given agency or organisation.

What are their rights? What are the entitlements?

Being referred to the right agency or organisation.

To inform them of what they are entitled to and the process of what is involved.

More hours engaging with professionals and services.

Better response from respite care.

The family are given a social worker that has the capabilities to organise appointments effectively, so it doesn't impact on the parent's daily routine, organisations have shared knowledge so that the parents do not repeat their story.

More services in the home.

Automatic services and entitlements rather than having to make an appointment with WINZ. GP Medical needed only. It is our responsibility to support workers to refer families to the correct services, which mean collaboration with other services and working together for the best outcome.

Less professionals, more coordination of professionals, instead of 3 meetings per week, how about on meeting.

Accessible respite for parents/carers.

Having access to in-home mental health support or counselling alongside medical needs. Having to go out to appointments all the time can make things more difficult and often parents need a place just to offload even when they are generally coping.

More money.

For them to access support groups for helpers.

Listening to nga matua more effectively, give them real support.

More frequent home/ community visits.

Free services that eliminate financial stress; more support with respite to allow the family to have a break.

Better timeliness of services and resourcing.

By them being in engaged in the correct support service. Having a referral to other services rather than just a medical expert.

Maybe things could move a little bit quicker.

For community agents who are involved with whānau from day dot such as well-child, LMC, GP connecting whānau with the supports earlier on, to allow the whānau to have support from the prevention perspective rather than intervention when the situation becomes more complex.

By removing the kilometre range from the service provider to a service that supports financially for the families who may have two or three appointments a week. These whānau should be able to receive payments when they travel over 50 kilometres a week.

The cost of parking at the hospital is very expensive. A number of people do not know how to access the parking concessions, and they are not informed by the service provider

Person-centred supports rather than task oriented.

More financial support around accessing schools and the community.

Quicker response times from Early Intervention and Access to Services

Early intervention, in Early Childhood Education, extra funding for one on one teachers for children with disabilities and behavioural problems and more training for teachers, health professionals and social workers.

By giving them the right information about the services available.

Longer respite hours and financial support.

Support to establish and maintain their own social supports; better understanding/awareness of their struggles/needs from the community including from professionals.

More funding around transportation and Early Learning Payment for longer hours (not just 20hrs) for children living with disabilities

Giving a better monetary resource to those children in need so they can have a better quality of life and not feel like they don't belong.

When they have a diagnosis, it would be good if there was more follow up from social workers ensuring that they are getting the right supports and information or telling parents where they can get that support or information from. They would be better served if parents could access services earlier too if needed such as speech-language therapy.

Access to practical support.

Children under 2 are not eligible for respite care I have found. This is a difficulty for a single parent who may be living in the community without supports. It also places the expectation on their family to provide support, which may put them under financial pressure.

All entitlements received secure housing and wrap around support with educational resources for the specific disability/condition.

Better funding at schools and support. More support around activities for the children outside of school and more assistance from agencies contracted to set this up for families and manage it. They are given large sums of funding and not much help in how to get the best from this. Also long waiting times for specialist support and even to be seen in the first place for certain assessments (autism) and also help for early intervention teachers- the waiting list where I live is ridiculous- I have families in need who were told 9 months and their children are barely able to communicate.

More respite services.

Having more respite, or in-home support workers

have specific advocacy services at medical establishments that can accompany, support, reinforce and help parents gain a complete understanding of their child's disability or condition, understanding options, feeling confident to challenge thinking or miss-understanding with regards to diagnoses and feelings of being dismissed.

Streamlining the process – half the battle for families is the paperwork, assessments, explaining the condition, meeting horrific criteria, appointments far from home.

Have the services visit them at home, services being culturally competent.

Government agencies that gate-keep lengthen the process adding more stress to families.

Community support services, funding for education

Provided clear information on what services are available. Free health transport.

Prioritised for HNZ homes.

Seen by specialists and diagnosed with related disorder to ensure needed support can be granted.

Educate staff in Family Start about disabilities particularly if they have never had to deal with whānau with disabilities, then think about how the whānau who do have disabilities feel when they get someone from Family Start who has no idea (not a good look).

Always listen to the parent when dealing with their children with disabilities, they live with them 24hrs and know them better than we do.

Always promote respite for the whānau and encourage them to accept it. Whānau tend to be whakama.

Yes, by being able to access supports regardless of where they live and receiving whatever is needed for that child rather than what is available for that child.

Be given free counselling so they can process all that sits underneath from having to be so strong.

Better funding for community support workers- meaning we can spend more time on these families both at a practical and organisational level.

More information about entitlement and access to appropriate services/ resources for their needs.

Enhancement of community understanding

Deeper understanding of the ongoing issues of grief and loss these families navigate every day.

More home-based support.

Development of 'I stop shops' where families can access all support and interventions at one place.

Maybe more localised focus groups for parents with children who have particular issues (eg, Down syndrome).

Maybe more localised focus groups for specific issues (eg, language development groups).

Do not know as this child is very young and is being well supported at this stage.

For the children with hearing impairment a follow up on the language development would be useful as they are often behind in this area and not meeting milestones.

More Child Disability Intervention preferably after school in the school. Being able to include the parents in the support so they can learn how to take care of their child, whilst they are dealing with their own mental illness and/or disability.

Getting the support and easier to access and maintain support.

Supports more effective, timely and ongoing.

Better financial support for families.

Better support at Early Childhood Education and schools.

More coordinated approach from professionals involved.

Families need to get support early on before they struggle for too long. Families also need ongoing long-term support and not a quick in and out service.

Children with disabilities being able to be seen by health professionals in a more timely manner so interventions can be put into place. I have witnessed health professionals say to a mother I am working with that they should have seen the child/put in a referral months ago but are overloaded and then proceeded to offload about their work stress. This is uncalled for especially when told to a parent who is already at breaking point.

Comments and suggestions from Family Start workers

Our tamariki are still falling through the gaps, which is putting a huge strain on educators who don't know what to do with our children. For example, teenage children are being assessed with mental health issues because when they were young, the teacher thought that the child was misbehaving. But the child couldn't hear or see properly because this was not fully checked.

There is a lot of help, but it needs to be advertised more. Myself, I am not very family with Agency who can help the family. I may know few, but I am sure there is more. The agency should be connected and send their services to Community social agency

More trained teachers and funding for our Tamariki to get the right support at Early Childhood Education and school.

Children with disabilities are often the most vulnerable they need timely support and on-going support to reduce risk and to ensure that they have the best chance to fulfil their potential

I think that the health/medical professionals (Plunket, LMC, Nurses, GP's etc) should be able to identify and pick up signs of disabilities during the early stages of the child's life, some experiences, the child hearing impairment was not identified until they had started primary, if it had been identified earlier by a health professional, the support could have been sourced earlier.

Schools – Early Childhood Education are not set up well to have access to an early intervention teacher for a whole day/week, and other teachers do not take responsibility for these children.

There are inappropriate resources for these children in all centres, no specific safe space where they can be away from others if needed.

Hope child with a disability can join the daycare when parents are ready.

No waiting for extra longer compares to other children.

Funding and wait times are barriers for families.

Our whānau are serviced well, sometimes it's about them using the services and turning up to appointments.

Early inventions like Family Start are awesome we have been able to support and see families involved in domestic violence and drug and alcohol make changes just because we have been able to get them help with their children which have reduced stress.

Support with Holiday programmes.

I think that it is too narrow to simply look at disability alone. I would like to see a broader approach. When you look at the population of young children, there are always sizeable minority that are different from their peers in a number of ways. Some of these will present with obvious disabilities and others will have complex and challenging temperament traits. Furthermore, there tends to be quite a significant overlap between these two groups. A Dunedin longitudinal study identified two groups of children, on the outer edges of the trait continuums, that are likely to run into difficulties in the adult lives. These children account for 20% of the population but they account for 80% of the country's expenditure in prisons courts hospital admissions mental health services and welfare dependency. These children can be identified at 3 years old. What I am suggesting is that identifying children who are different in terms of disability and emotionality, at an early age could make early intervention and remediation possible. At the moment, both children with disabilities and those with challenging temperaments, often do not get detected early enough. And, even when they do, the early interventions are slow and inadequate.

Also, there are other vulnerable groups that are coming on stream such as transgender children. I would also include these children in the group showing difference and diversity. Ideally, I think there should be a service that kicks in around the age of 2 to identify children who presented differently as identified by teachers and parents. People working in this area would have to have a good understanding of child development, mental health, and disabilities, so that they could help parents get diagnoses when necessary but also do interventions to improve parents understanding of challenging temperaments so that goodness of fit can be created, both at home and at school. And this way we could disrupt a negative trajectory in the early stages of development.

Families raising children with disabilities are feeling the strain of not getting access to services, funding, or assessment processes that leave them on waiting lists for long periods of time leaving them stressed, isolated and exhausted.

Communications between the different services could be improved to help whānau.

That it is a privilege to walk alongside these families who are so brave yet so frightened about the future for their child/children. It important to remember that every child has a right to an education and a good quality of life and that we must as a community provide that the best we can and give them the opportunities to learn and grow to meet their full potential in whatever form that will be. We need to be the voice for their families and their children and be seen to be doing what is right for them.

In the years I have been working with Family Start I have supported a number of families/whānau with children who have had a variety of disabilities. A number of the parents have struggled to get the appropriate supports for their child.

When the system works, it works well however this is not the norm.

Some services unavailable to clients, it would be nice if clients can get Childcare Subsidy and Early Learning Payment or Oscar but often can only get Early Learning Payment.

If the system moves away from the clipboard and the focus is spent more on seeing the person/whānau we would have a more relational way of being. Positive outcomes/change happens when the whānau feels heard and supported.

If whānau are equipped with all resources, the child will thrive

I have noticed when some whānau have history with Oranga Tamariki, there is not much follow up or support when other organisations are/become involved. Those whānau end up repeating the cycle and being referred back to Orangs Tamariki. More could be done by all involved in regard to on-going/follow up support.

Schools should not put children with learning behaviours and disabilities in the too hard basket.

Some caseworkers at Work and Income should not judge families who have children with disabilities and make out that they are specialist in Health. (Who are applying for disability allowances).

Families need more additional supports.

Staff require more training to understand the wider implications of working with a family who are supporting a child with a disability.

I have one parent who has recently had a diagnosis of ADHD, and it is taking her time to understand what this means for her as a parent and as a woman.

This questionnaire is focused on children with disabilities but doesn't take into account a parent with a disability raising a child without a disability.

I would like to see the families be able to access services faster.

Parents have a lack of understand who to go too, where to go too and cost. For our Maori parents, they share the interactions with organizations, clinicians and doctors are poor. That whānau are not being heard. If it weren't for having Family Start, they wouldn't get anything. I think this is sad.

No enough services in the home.

When I support my families at WINZ appointments, they receive everything they are entitled to but when they go on their own, they do not. This is extra stress put on families.

I'd like you to look at how you support parents with disabilities.

It is evident in the families who have been affected by a loved one with a disability the amount of stress, sleeplessness nights; their need for respite; and the effects it has on them. For example, a father who works full time while moc cares for her two children in the home, the other three children attending school; then foc comes home after a long day to care for his children and during the night has to attend to his disabled daughter. This causes lots of stress in the home and at times violence.

Waiting lists need to be short so that a parent has at least got contact with someone if they need help or support.

Rural residents have very limited services for the children and youth of their communities, this is frustrating because the lack of services impact on outcomes for the people that we work alongside.

There are services available if the people are able to pay for them.

If the disabled person is arrested, they can access services through probation because they have the funding; this is unfair on the whānau that we work with because it leaves them with a criminal record.

It may be appropriate to collect separate information around types of disability as big variation in supports required.

Parents with disability. – Lots more in-home support required than can access at times.

Big waitlists for services leave no supports in place even after diagnosis and needs assessments sometimes.

It is too hard for families to find their own support people for Carer Support.

Parents with Carer Support cannot use this for respite if they have no-one else to look after their children.

I think feedback from frontline, social, health and Early Childhood Education services needs to be taken into consideration, more seriously when children with disabilities are assessed as often those carrying out assessments don't see what those who spend the most time with children do.

It's unlikely that the children on my current caseload do not have a disability, more than they are too young for diagnosis or there is a suspected disability/impairment, however for a number of reasons this has not been thoroughly assessed.

We need access to more services, which can accurately diagnose children/babies living with fetal alcohol spectrum disorder and other addictions, which cause issues – language, behavioural, etc. It's quite hard to get a referral done, would be good if these services were offered with Well Child/Tamariki Ora checks

Resources for agencies supporting children with disabilities are running on the smell of an oily rag. There appears to be an expectation of volunteers doing this most difficult work, and this is not okay.

There needs to be more access made available for parents to information, not the expectation that parents will go and look for it.

I find that another disability to consider is the support of the parent who has a disability.

More funding required!

The expectations of family/whānau [Family Start] workers and the workload involved has increased tremendously over the last few years. The complexity and needs of families have also increased tremendously. Medical establishments like CAFS or Speech Therapy have huge waiting lists and look to be becoming almost a late intervention as a result. Waiting lists for assistance and medical intervention on all levels needs to be reduced so that families are being seen in the early stages of deterioration of health, milestone development or emotional well-being. All agencies, government departments appear to be overworked with huge caseloads and waiting lists, which does not lend to a good outcome for families and leads to a too little too late intervention.

Maybe have a specialised team within Family Start across the Nation, so if you do happen to work with a whānau with disabilities, you can connect with them. The more information around what is available for whānau who deal with disabilities the better. This could be camps around the country that no one knows about, it allows or gives the opportunity for other whānau to get together as well and share their stories.

Sharing positive stories that whānau have is always a bonus as then they will not feel so alone in their journey.

Children with disabilities living rurally are being disadvantaged, as they do not have the ease of access to services that children living in urban areas have.

These parents need to be given the time they need to be heard and respected, as parents they have an inbuilt insight and that needs to be taken seriously.

I think there is great scope for community development approaches to address local need. Starting with input from the families themselves, as they know best what they need and how they would like it done. Action Research models can provide good participant involvement, eg, the development of the Otago Family Network back in the 90s, Also the Robbie White Charitable Trust in Dunedin which is a family driven language development group catering to the needs of the families and children involved.

There needs to be greater follow up for children who are at risk for fetal alcohol syndrome, testing throughout childhood to ensure that they get the support they need even if no formal diagnosis has made.

More disability, child, and adult mental health intervention services are needed.

Disability services are pathetic and treat families really badly most people do not understand the process it needs to be simplified and staff need to be exposed to empathetic mindfulness to the families

The Gateway Assessment is often the first time we learn about disabilities, so it is really helpful, and they are able to complete the appropriate referrals to address the concerns raised during the assessment

I would like to suggest specialised social work support for families with children with disabilities so that they can navigate the system and get the support they need. I say specialised because I have witnessed a family being told that they were entitled to allowances and supports months later than they were entitled with the professionals mumbling 'someone should have sorted this'. There doesn't seem to be a 'someone' who is doing this with the knowledge of the system.

ORANGA
TAMARIKI
Ministry for Children

EVIDENCE CENTRE
TE POKAPŪ TAUNAKITANGA