EVIDENCE CENTRE
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Understanding children with disabilities in the Family Start programme

September 2019

ORANGA TAMARIKI
Ministry for Children

EVIDENCE CENTRE
TE POKAPŪ TAUNAKITANGA

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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.
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CONTENTS

CONTENTS **1**

LIST OF FIGURES **1**

LIST OF TABLES **1**

EXECUTIVE SUMMARY **1**

Background 1
Key findings of the research 2

INTRODUCTION **5**

Research rationale 5
Report structure 6

PART 1: BACKGROUND **7**

Children with disabilities in New Zealand 7
International statistics on disability in young children 8
Research context 9

PART 2: THE FAMILY START DISABILITY SURVEY **10**

Purpose 10
Objectives 10
Method 10
Limitations/Caveats 11

PART 3: SURVEY RESULTS **12**

Family Start workers' caseloads 12
Family Start workers working with children with disabilities 13
Prevalence and nature of disabilities among children enrolled in the Family Start programme 13
Supporting children with disabilities and their families 20

LIST OF FIGURES

Figure 1: Children with disabilities by gender and disability type 15
Figure 2: Boys and Girls with disabilities by type of disabilities 15
Figure 3: Services/supports to which families with children with disabilities have access and/or have been referred 26
Figure 4: Childcare Assistance services that families with children with disabilities access and/or have been referred to 27
Figure 5: Early Intervention Services that families with children with disabilities access and/or have been referred to 27
Figure 6: Disability Support Services to which families with children with disabilities have access and/or have been referred 28
Figure 7: The top five most helpful services and supports for families with children with disabilities by rank 30

LIST OF TABLES

Table 1: Rate of children with disabilities by ethnicity and sex 8
Table 2: Disability type by gender for young children with disabilities aged 0-4 8
Table 3: Families and children by Family Start region 12
Table 4: Family Start workers, families and children by Family Start region.................. 13
Table 5: Children with disabilities as a proportion of Family Start workers' children caseloads 14
Table 6: Types of disability in Family Start children 14
Table 7: Children with disabilities by gender and disability type..................................... 15
Table 8: Types of families that are part of Family Start workers' caseloads 16
Table 9: Family Start workers by children's disability type 18
Table 10: Family Start workers by disability type and number of children 18
Table 11: Family Start workers by number of disability types 19
Table 12: Family Start workers by type and number of disabilities 19
Table 13: Caseload of Family Start workers by disability type and number of children they work with 20
Table 14: Top five most helpful services and supports for families with children with disabilities 29

EXECUTIVE SUMMARY

Background

The report *Understanding children with disabilities in the Family Start programme* presents the results of a survey about families with children with disabilities who participate in the Family Start programme. The survey aimed to extend our knowledge and understanding of young children with disabilities receiving early intervention[1], and contribute to a better understanding of the needs, prevalence and disabilities of young children in vulnerable families.

Family Start is a home-visiting programme that supports families with young children aged 0-5 years. While not specifically designed to support children with disabilities, the programme supports vulnerable children and their families, including those with disabilities. It is estimated that Family Start sites around the country have about 5200 children enrolled at any given time, and about 8000 enrolments each year.

The survey was commissioned because we do not have consistent data collected on the rates of disability among children who are showing early signs of need, and who may be at risk of needing care or protection. However, we had one way to identify children with disabilities – they are a subgroup of the Family Start population.

We will use the survey findings to improve our understanding of how best to support and help parents/caregivers to care for children with disabilities at home, and in doing so reduce the risk that some of these children may require statutory intervention. While disability may not be part of the reason for a child coming to our attention, we know from international research that:

- children with disabilities are more vulnerable to abuse, neglect and exposure to family violence
- children with disabilities who live in out-of-home care are also vulnerable
- without the right supports and services, children with disabilities are particularly vulnerable to poor outcomes.

For example, the Fetal Alcohol Syndrome Disorder (FASD) Working Group estimates that about 50% of children in statutory care are affected by fetal alcohol spectrum disorder.[2][3] While this figure might not apply to all children in the families enrolled in the Family Start programme, it indicates the extent of the problem and the need to provide support to vulnerable families whose young children are showing early signs of developmental issues.

The survey was conducted online, and the questionnaire used definitions and classifications used by Statistics New Zealand and international conventions.[4] All Family Start providers were invited to participate, and as a result, 33 sites (including 283 Family Start workers) agreed to take part. A total of 159 Family Start workers responded to questions about children they supported during 2018.

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[1] Early intervention refers to the coordinate support and services for children and whānau showing early signs of need.

[2] FASD Working Group (2016) *Taking Action on Fetal Alcohol Spectrum Disorder: 2016–2019: An action plan* Wellington: Ministry of Health. Page 2. Available at www.health.govt.nz/system/files/documents/publications/taking-action-on-fetal-alcohol-spectrum-disorder-2016-to-2019.pdf.

[3] The damage alcohol does to the developing body and brain is permanent. Based on international evidence, fetal alcohol spectrum disorder is likely to be New Zealand's leading preventable cause of non-genetic intellectual disability. It is the cause of poor outcomes for children and young people, including increased mortality, abuse and neglect, poor educational achievement, engagement with the criminal justice system, benefit dependency, and mental health and alcohol and drug issues, ibid (page 7).

[4] For more details on the definitions used in this research, please refer to *Disability Survey: 2013 Definitions*, available at www.archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013/Definitions.aspx, *Defining Impairment and Disability*, issued by The Centre for Disability Studies, University of Leeds at www.disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Northern-Officers-Group-defining-impairment-and-disability.pdf and *Disabilities That Qualify Infants, Toddlers, Children, and Youth for Services under IDEA 2004* issued by the United States Department of Education, Office of Special Education Programs and available at www.ldonline.org/article/12399.

Key findings of the research

The prevalence and nature of disabilities among children enrolled in the Family Start programme

- Three-quarters (121) of the Family Start workers who responded to the survey reported that their caseloads included families who had children with one or more disabilities.
- The Family Start workers reported a total caseload of 1664 families and 2471 children aged 0-5. Of the children, (22%) had one or more disabilities. The 2013 Census reported a five per cent disability rate in children aged 0-4 years in the general population; this indicates a higher prevalence of disabilities among young children in vulnerable families.
- Children can have multiple disabilities. The most prevalent were developmental (37%), speech and language (37%), intellectual (33%), and hearing (24%).
- Boys were found to be 1.5 times more likely to have a disability than girls. The higher prevalence in boys is consistent with local and international statistics.
- Of those with disabilities, boys were twice more likely than girls to have speech and language disabilities, and 1.7 times more likely to have developmental and intellectual disabilities.
- Only 56% of the children reported by Family Start workers as having disabilities had been diagnosed as such by a medical professional.
- Fifty-two per cent of the Family Start workers reported working with families whom they considered to have children with disabilities that had not yet been diagnosed by a medical professional.
- Fifteen per cent of children with disabilities live in families with two or more children with disabilities.
- Twelve per cent of the children with disabilities have at least one parent or caregiver with a disability.
- The 121 Family Start workers whose caseloads include families with children with disabilities often work with families that have two or more children with disabilities, or families where at least one child and one parent or caregiver have disabilities. Most of them work with children with speech and language, developmental, intellectual and hearing disabilities.
- Of the Family Start workers whose caseloads include children with developmental disabilities, 96% also support children with other disabilities. Forty-nine per cent of them work with children with five or more disabilities. This figure shows that while developmental disabilities are the most prevalent, Family Start workers are likely to work with a broad range of disabilities.
- Family Start workers whose caseloads include children with intellectual disabilities also support children with a diverse range of disabilities. Fifty-eight per cent work with children with five or more disabilities and 99% support children with other disabilities in addition to those with intellectual disabilities.
- Family Start workers whose caseloads include all seven disabilities (developmental, intellectual, speech and language, hearing, agility, vision and mobility) have on average the highest rates of children with developmental, intellectual and speech and language disabilities. This finding might indicate the need for research into potential patterns of coexistence involving specific types of disability, such as developmental and speech and language disabilities.

Families with children with disabilities face multiple issues

Family Start workers reported that families with children with disabilities have issues with:

- subjective wellbeing
    - Emotional stress, including a sense of grief and loss
    - Parental stress due to the demands associated with caring for children with disabilities
    - Insufficient or unavailable home support and respite

- social connections
  - Social isolation, discrimination, stigma, negative judgement and marginalisation
  - Lack of understanding
  - Not being treated with the consideration and care that are needed/deserved
  - Not being listened to
- knowledge and skills
  - Lack of knowledge on how to deal with the care needs of children with disabilities
  - Lack of information about the services and supports they can access
  - Lack of skills to cope with the disparate issues associated with disabilities
  - Inadequate training and knowledge of professionals supporting families
- income and resources
  - Financial stress and poverty
  - Insufficient or inadequate access to services and supports for families in rural areas
- health
  - Families' issues of drug use, addiction and/or mental and behavioural problems (associated with both parents'/caregivers' and children's disabilities)
  - Families' complex needs when parents/caregivers with disabilities care for children with disabilities
  - Long waiting lists and delays in accessing adequate treatment
- transport
  - Lack of public transport
  - Cost and time associated with travel frequency and distance to appointments and treatment
  - Lack of adequate transport for children with disabilities
- housing
  - Inadequate housing
  - Lack of affordable and accessible housing.

Services and supports most commonly used by families with children with disabilities

- According to Family Start workers, the services and supports that families with children with disabilities most commonly access or are referred to are:
  - Childcare Assistance (87%) from Work and Income, including in the majority of cases Early Childhood Education (62%), the Early Learning Payment (56%) and the Childcare Subsidy (54%). As many young children have not yet been diagnosed by a medical professional, families are likely to access and be referred primarily to services and supports that are not specific to children with disabilities (such as those listed above). These services can also be of benefit to children who do not have or are not suspected of having disabilities
  - Early Intervention Services (75%) funded by the Ministry of Education, most commonly by referrals to Speech-language Therapists (76%). Referrals to Psychologists and Early Intervention Teachers are also relatively common
  - Child Disability Allowance (74%) and Community Services Card (73%) from Work and Income
  - Disability Support Services (72%) funded by the Ministry of Health. Referrals are most often to Child Development Services (79%) or, less often, Behaviour Support Services (49%). Thirty-six per cent of Family Star workers reported referrals to Autism Spectrum Disorder Support.
- Family Start workers reported that the five most helpful services and supports for families with children with disabilities are the Child Disability Allowance (62%), the Early Learning Payment (40%), Speech-language Therapists (36%), Early Childhood Education (33%) and Child Development Services (31%).
- Direct monetary transfers (such as the allowances above) were seen as especially helpful for families because many face poverty and deprivation. They help with additional costs related to their

children's disabilities and sometimes the parents'/caregivers' disabilities. Many parents/caregivers are full-time carers of children with complex disabilities and need multiple sources of financial help.

Ways to better support families with children with disabilities

Family Start workers provided the following suggestions to better support families with children with disabilities:

- Develop a tailored approach to support the specific needs of children with disabilities and the general needs of vulnerable families that have children with disabilities and, in some cases, adult members with disabilities.
- Improve the way families are supported by taking an integrated and coordinated approach to respond to children's and families' needs.
- Provide more funding and financial support to families and the services that support them.
- Increase the availability of, access to and hours of home support and respite to parents/caregivers caring for children with disabilities.
- Address the disparity of availability and access to services experienced by families with children with disabilities.
- Provide specialised education and training to Family Start workers who work with children with disabilities but might lack the experience and knowledge to support them effectively.
- Provide specialised education and training for professionals who provide disability-related support services for children with disabilities but might lack the experience and knowledge to support them effectively.

Policy implications

- There is a lot of evidence that confirms the developmental and behavioural benefits of early intervention for these conditions, and the need for agencies to support families to cope with the challenges of raising children with disabilities.
- This research highlights the importance of ensuring that mainstream services that support vulnerable families with young children are responsive to and meet the needs of families with children with disabilities.
- The Family Start workers' most reported disabilities (developmental, intellectual and speech and language disabilities) indicate that targeted and specialised services supporting these disabilities should be timely, available and well resourced.
- The finding that families are often not receiving the support and services they need is an issue that we are seeking to address through our cross-agency work on early intervention. In a child's first three years of life, the experiences and relationships they have heavily influence their brain development. We know that intervening early in life with the right specialised support and services that focus on making the most of a child's strengths and abilities can promote development and learning of children with disabilities in pre-school years. This, in turn, can increase their potential to succeed at school and help them to live the fullest life they can later on in life.
- Part of our early intervention work involves gaining a stronger understanding of what are the early needs of children and families, what services are currently available to meet those needs and where there are areas for improvement. Services include those offered by Oranga Tamariki as well as services funded by other government agencies.
- The survey findings reinforce one of the problems that our work on early intervention seeks to address – to improve the coordination between different services for families who may be facing multiple challenges caring for children with additional needs.

INTRODUCTION

This document presents the results from the Family Start disability survey, an exploratory analysis of families participating in the Family Start programme, with a focus on children with disabilities.

Family Start is a child-centred (pre-birth to five years), intensive home-visiting programme that focuses on improving:

- children's health, learning and relationships
- family circumstances
- the family environment and safety.

The programme supports families who struggle with challenges or problems that put their children's health, education and social outcomes at risk – including children with disabilities and in need of special care. Families' participation in the programme is voluntary.

The research was commissioned by the Policy team of Oranga Tamariki—Ministry for Children and conducted by the Research and Evaluation team within the Oranga Tamariki Evidence Centre. The information it provides will contribute to the development of a new Oranga Tamariki operating model, which is inclusive of children and young people with disabilities.

Research rationale

There are gaps in our knowledge of children with disabilities in care. Most of what we know about the experiences of children and young people with disabilities is based on our information about those who come into care. This information includes children's and young people's disability levels and complex needs, including behavioural problems.[5]

To address the data gap about child disability, we collected information from Family Start workers via a short online survey. The survey was designed to help us better understand the prevalence of disability among vulnerable children and young people and identify ways to intervene early.

International research shows that children and young people with disabilities are more likely than vulnerable children and young people without disabilities to have high and complex needs that require early intervention. They are also more at risk of abuse, neglect and poorer life outcomes. For example, a study in the United Kingdom showed that:

- youth offenders in custody have much higher rates of neurological disability than the general population
- almost a quarter of youth offenders in custody have learning difficulties
- the rate of traumatic brain injury among youth offenders in custody is three times higher than that of the general population.[6]

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[5] CYRAS, the Oranga Tamariki case management system, has only limited information on the prevalence of disabilities among children and young people for whom we have received notifications and who are in, or at risk of entering statutory care. There are several reasons for this gap in our knowledge. Social workers are not explicitly required to record a child's or young person's disability in CYRAS, and they are often reluctant to record it without a formal clinical diagnosis from a health professional. Because of this, there are children and young people who come to the attention or are in the care of Oranga Tamariki whom social workers consider may have disabilities, but there is are records of them in CYRAS. Therefore, information collected in CYRAS about the disabilities of children and young people in care can be unreliable and inconsistent.

[6] See, for example, Williams, W. H., Chitsabesan, P., Fazel, S., McMillan, T., Hughes, N., Parsonage, M., & Tonks, J. (2018). Traumatic brain injury: a potential cause of violent crime?. *The Lancet Psychiatry*, *5*(10), 836-844.

Report structure

The report *Understanding children with disabilities in the Family Start programme* has three parts:

- Part 1 provides details about children with disabilities in New Zealand and internationally, the research context of this study, and changes to legislation that are affecting the support we need to provide to children with disabilities.
- Part 2 explains the survey's purpose, objective and methodology.
- Part 3 provides a summary of the survey results.

Five appendixes provide supplementary information:

- Appendix 1 has details of the Family Start Programme.
- Appendix 2 has additional information on the survey methodology.
- Appendix 3 has full details of the survey questionnaire.
- Appendix 4 has details of the supports and services available for children with disabilities and their families.
- Appendix 5 features the survey participants' responses to the open-ended questions in the survey.

PART 1: BACKGROUND

Children with disabilities in New Zealand

In New Zealand, disability is defined as an impairment that has a long-term, limiting effect on a person's ability to carry out day-to-day activities. 'Long-term' is defined as six months or longer. 'Limiting effect' means a restriction on or lack of ability to perform. A person is not considered to have a disability if an assistive device (such as glasses or crutches) eliminates their disability.[7] However, it is important that people with disabilities have access to these devices.

'Disability' covers functions such as:

- hearing
- vision
- mobility
- agility
- intellectual
- psychiatric/psychological
- speech
- learning
- memory.

Statistics New Zealand's report on the 2013 Disability Survey[8] has the most up-to-date figures. According to the report:

- 13,000 children aged 0-4 (5% of that age group) had disabilities. Figures for the 0-14 age group showed 60,000 boys and 35,000 girls with disabilities
- the prevalence of disability was higher among boys (13%) than among girls (8%)[9]
- among children, disabilities were most commonly caused by conditions existing since birth (49%), followed by diseases and illnesses (25%)
- the percentage of children with disabilities is likely to increase with age, as many conditions will develop as the children do. Accidents, illnesses and life experiences also contribute to this increase
- disability is more prevalent in Māori children (15%) than it is among children from other ethnic groups. Children identified as Asian had the lowest prevalence, at 4% (see Table 1).

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[7] See www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013/Definitions.aspx

[8] See Disability Survey: 2013, www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013/Tables.aspx.

[9] Gender differences in reported disabilities have been noted internationally. See, for example, *Disability in Canada: A 2006 Profile* at www.canada.ca/content/dam/esdc-edsc/migration/documents/eng/disability/arc/disability_2006.pdf and *CO1.9: Child Disability* – OECD Family database www.oecd.org/els/family/CO1%209%20Child%20disability%20FINAL.pdf.

Table 1: Rate of children with disabilities by ethnicity and sex[10]

Ethnicity	Male	Female	All
European	13%	8%	11%
Māori	19%	10%	15%
Pacific peoples	11%	8%	9%
Asian	5%	3%	4%
Other (MELAA(1) and other)			8%
Total	13%	8%	11%

(1)Middle East, Latin America, Africa

- children and young people with disabilities can have one or multiple disabilities (51% and 49% respectively). There are significant gender differences: 51% of boys have multiple disabilities compared with 42% of girls.

International statistics on disability in young children

Internationally, the prevalence of disabilities in the general population is highly variable, partially due to differences in definitions and data collection.

Disabilities in preschool children (0-5 years) are likely to be underreported, as professionals can find them difficult to diagnose or identify because the children develop at different paces. The number of disabilities increases with age. For example:

- it might not be until children are at school that learning disabilities are recognised and children with special educational needs are identified[11]
- as time passes, people are more exposed to illnesses or accidents that can lead to disabilities.

Despite the above limitations, statistics on disabilities in young children are available for some countries. For example:

- in Australia, the 2009 Survey of Disability, Ageing and Carers, conducted by the Australian Bureau of Statistics, reported that 3.9% of males and 2.9% of females aged 0-4 years had disabilities
- in Canada, the 2006 Participation and Activity Limitation Survey reported that 1.7% of children under five had disabilities. Table 2 shows the prevalence of disability type by gender in Canada for young children with disabilities aged 0-4.

Table 2: Disability type by gender for young children with disabilities aged 0-4, Canada, 2006[12]

Disability type	Boys	Girls
Chronic condition	1.4%%	0.9%
Developmental delay	1.3%	0.9%
Hearing	0.2%	0.2%
Seeing	0.2%	0.2%

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[10] See Disability Survey: 2013, Table 2.02 www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013/Tables.aspx. Note that when a child reported more than one ethnic group, they were counted in each applicable group.

[11] *CO1.9: Child Disability* – OECD Family database www.oecd.org/els/family/CO1%209%20Child%20disability%20FINAL.pdf, page 4.

[12] See Participation and Activity Limitation Survey, 2006, Statistics Canada, www.canada.ca/en/employment-social-development/programs/disability/arc/disability-2006.html#s3.

Developmental delays and chronic conditions are more prevalent than hearing and seeing disabilities, as these are likely to become more evident at a later developmental stage. Chronic conditions and developmental delays are also more common among boys than in girls.

Research context

Oranga Tamariki is expected to respond to the specific needs of children and young people with disabilities in the care system. This work is supported by the 2017 changes specified in the provisions of the Children, Young Persons, and Their Families (Oranga Tamariki) Legislation Bill (the Bill).[13]

The legislation changes removed the pathway of parents to place their child in out-of-home care voluntarily it they were no longer able to provide care at home (sections 141 and 142 of the Act),[14] and set out provisions to be included in the Act to ensure children and young people with disabilities have a voice and have the same rights as non-disabled children and young people in care.

Oranga Tamariki is now designing services for children and young people with disabilities in its care. This process includes improving our understanding of the support that parents/caregivers need to care of their children with disabilities at home.

Family Start workers work with vulnerable young children and their parents/caregivers, and often have to use their professional judgement to make crucial decisions about the children's safety and wellbeing. Family Start's success depends on the workers' ability to establish effective working relationships – with families and with the government agencies and community organisations that refer families to the programme and with which they have mutual clients.[15] Therefore, we considered that surveying Family Start workers about the families with which they worked would be the most effective way to estimate the number of children with disabilities and the services and supports they access.

Given the Oranga Tamariki focus on early intervention, we must have a better understanding of vulnerable young children who have been identified early as having disabilities (that is, before a statutory care response is needed). The results from the Family Start Disability Survey will help to provide such an understanding.

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[13] The Bill went before Parliament to repeal sections 141 and 142 of the Oranga Tamariki Act (the Act), and to amend the conditions and protections of children and young people with disabilities to reflect the non-disabled children and young people, which flowed on to impact the new operating model of the Ministry for Children, Oranga Tamariki.

[14] Section 141 refers to the Agreements for extended care of severely disabled children and young persons and Section 142 refers to the Agreements with persons providing residential disability care. For more details see www.legislation.govt.nz/act/public/2017/0031/latest/DLM7064646.html

[15] See the *Family Start Programme Manual*, issued in 2016 by the Ministry of Social Development at www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/service-guidelines/family-start-programme-manual-2016.pdf, page 7.

PART 2: THE FAMILY START DISABILITY SURVEY

We designed the Family Start disability survey to extend our understanding and knowledge of young children with disabilities receiving early intervention.

While not specifically designed for children with disabilities, the Family Start programme supports vulnerable children and their families, including those with disabilities. It is estimated that Family Start sites around the country have about 5200 children enrolled at any given time, and about 8000 each year. This puts Family Start workers in a good position to:

- understand early childhood disability in vulnerable families
- have information on the prevalence and types of disability among young children and their families in the Family Start programme
- identify families' and young children's needs and any gaps in service delivery.

This information is not currently completely captured or available in the Family Start FS-Net.

It is important to note that only the youngest child aged under five years in a family can be enrolled in Family Start. However, Family Start workers support all children aged under five years, including those with disabilities.

Purpose

The purpose of the survey was to address the gaps in knowledge at Oranga Tamariki about the experiences, and levels and types of need among young children (0-5 years) with disabilities and their families. The knowledge gathered from the survey will increase our understanding of the prevalence of disability among the vulnerable population of young children and contribute to identifying ways to intervene early and effectively to meet their needs.

Objectives

The objectives of the survey were to better understand:

- the population of children with disabilities on the Family Start programme who have (or may have) disabilities
- the disability-related challenges that they and their families face
- the types of supports and services they receive or would benefit from receiving
- the issues associated with families with children with disabilities (eg, the presence of family violence, financial stress, and inadequate housing).

Method

The Family Start Disability Survey was conducted via SurveyMonkey between October and December 2018. The survey participants comprised Family Start workers from all of the programme's regions.

Participants were recruited in two phases:

1. All Family Start providers were contacted via email about the survey and its purpose and asked to support their staff to take part. From the 44 providers contacted, 33 agreed to enable their staff to participate in the survey. They provided email addresses for a total of 283 Family Start workers.

2. Via SurveyMonkey, we sent invitations to all 283 Family Start workers to take part in the survey. One hundred and fifty-nine of them provided responses and 121 reported caseloads that included families with children with disabilities.

The results and analysis included in this report are based on the responses from the Family Start workers working with these families.

Limitations/Caveats

As the Family Start workers' participation was voluntary, the survey was based on a non-probabilistic sample of Family Start workers from sites that had agreed to participate in the survey. This means that the survey results do not claim to be representative or otherwise of all Family Start workers, and are subject to caveats and limitations on accuracy in terms of the wider population.

Where responses are analysed by demographic variables (eg, disability types), indicative results are presented. However, these should be interpreted with particular caution as the sample size may be in single figures.

It is also important to recognise that:

- the Family Start workers who took part in the survey do not have: perfect knowledge of the young children and their families; diagnostic information; or information on the extent to which services are available in their regions (including services provided in other sectors). This may affect the accuracy of their responses
- the survey questions were formulated to facilitate Family Start workers' responses
- the information collected was aggregated and relied on Family Start workers' views of the families they were supporting at the time of the survey.

PART 3: SURVEY RESULTS

The survey had two parts:

1. The first part asked questions about:
    - the prevalence of disability among children and parents/caregivers
    - the prevalence of different disabilities according to children's genders
    - family members with disabilities.
2. The second part asked questions about:
    - the services and supports to which families had been referred or to which they have access
    - the helpfulness of these services and supports for families
    - the main issues facing families with children with disabilities, and how to better support these families.

    These questions were mostly qualitative, with the participants providing their own accounts of their experiences and their own recommendations.

We analysed the data from the first part in two sections:

1. Responses from all the Family Start workers. This provided general information on the Family Start workers' caseloads, and looked at the number of families and children per Family Start worker and the regional distribution of participants and caseloads.
2. Responses from the Family Start workers whose caseloads included children with disabilities. These provided detailed accounts of children with disabilities and their families, and information on the Family Start workers' caseloads.

Family Start workers' caseloads

Caseload: The average caseload for Family Start workers was 13 families and 20 children.[16]

The surveyed Family Start workers provided information about 2075 families and 3021 children. Table 3 shows the distribution of families and children by Family Start regions. Central, Midland and Southern regions had the highest levels of Family Start worker participation.

Table 3: Families and children by Family Start region (N=159)

Family Start region	Families		Children	
	Count	Percentage	Count	Percentage
Northern	183	9%	271	9%
Auckland	187	9%	251	8%
Central	517	25%	783	26%
Midland	586	28%	851	28%
Southern	602	29%	865	29%
Total	2,075	100%	3,021	100%

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[16] This figure includes all children aged 0-5 years in the family.

On average, there are 1.5 children in every family. Families in Auckland are slightly smaller than those in the other areas (1.3 children per family). Ten Family Start workers reported caseloads with more families than children. This could be due to families enrolling during pregnancy.

Family Start workers working with children with disabilities

Of the 159 Family Start workers who responded to the questionnaire, 121 (ie, 76% of the workers taking part in the study) reported that at least one family in their caseloads had a child with disabilities.

These 121 Family Start workers reported a total caseload of 1664 families and 2471 children. Table 4 shows the distribution of the Family Start workers, families and children by Family Start region.

Table 4: Family Start workers, families and children by Family Start region

Family Start region	Family Start worker[17]	Total number of families per Family Start worker	Total number of children per Family Start	Average number of families per Family Start worker	Average number of children per Family Start worker
Northern	9	112	177	12	20
Auckland	11	187	251	17	23
Central	27	363	570	13	21
Midland	33	491	727	15	22
Southern	41	511	746	12	18
Total	121	1,664	2,471	14	20

Prevalence and nature of disabilities among children enrolled in the Family Start programme

Children with disabilities

Family Start workers reported that 541 children had one or more disabilities, which corresponds to 22% of the children they work with.

When asked how they identified children with disabilities, Family Start workers reported that only 56% (301) of the children with one or more disabilities had been diagnosed by a medical or health professional. This means that four in nine children that Family Start workers believe have one or more disabilities have not had a diagnosis. In addition, 52% (63) of the Family Start workers reported working with families that they consider have children with disabilities who have not yet been diagnosed by a medical professional.

Children with disabilities by region

The distribution of children with disabilities by Family Start region shows that the Northern and Midland areas have the highest proportions of children with disabilities relative to the total number of children. In contrast, lower proportions were observed in the Central and Southern regions.

The reported number of children with disabilities was highest in the Midland and Southern region and lowest in Northern and Auckland. Table 5 has more detail.

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[17] This corresponds to the Family Start workers who reported at least one family with children with impairments/disabilities in their caseload.

Table 5: Children with disabilities as a proportion of Family Start workers' children caseloads

Family Start region	All Children	Children with disabilities	Proportion of children with disabilities
Northern	177	51	29%
Auckland	251	63	25%
Central	570	96	17%
Midland	727	210	29%
Southern	746	121	16%
Total	2,471	541	22%

Children by type of disability

Family Start workers reported that the children they work with have developmental, speech and language, intellectual, hearing, agility, vision and mobility disabilities. Appendix 3 has details on each disability.

Table 6 shows the count of children with each of these disabilities. Note that children can have multiple disabilities, so the total count is higher than the reported number of children with disabilities.

Table 6: Types of disability in Family Start children (N=541)

Disability	Count	Percentage
Developmental	202	37%
Speech and language	198	37%
Intellectual	180	33%
Hearing	130	24%
Agility	56	10%
Vision	44	8%
Mobility	42	8%

Developmental, intellectual and speech and language disabilities were the disabilities most reported in children with one or more disabilities. Vision and mobility disabilities were the least reported; these disability types are likely to appear or be diagnosed later in the life of a child.

Children with disabilities by gender

It has been noted both at national level[18] and internationally[19] that male children are more likely to have disabilities than female children. The survey results showed that, on average, boys are 1.5 times more likely to have disabilities than girls. Family Start workers reported 322 boys and 219 girls with disabilities, which means that 60% of all the children with disabilities were male.

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[18] See, for example, www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/disability

[19] See, for example, www.oecd.org/els/family/CO1%209%20Child%20disability%20FINAL.pdf, www.doe.k12.de.us/cms/lib/DE01922744/Centricity/Domain/78/20162017ChildCount35byDisabilitybySexbyELLStatus.pdf, www.unicef.org/pacificislands/Children_Women_and_Men_with_Disabilities_in_Vanuatu.pdf.

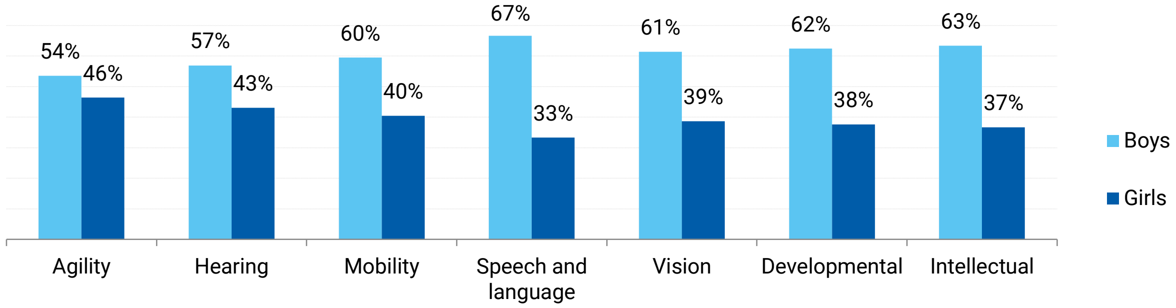
When looking at disabilities by gender, boys are twice more likely than girls to have speech and language disabilities. Similar differences have already been reported.[20] Table 7 has more detail.

Table 7: Children with disabilities by gender and disability type

Disability	Boys		Girls		Boys/Girls Ratio
	N	%	N	%	
Speech and language	132	67%	66	33%	2.0
Developmental	126	62%	76	38%	1.7
Intellectual	114	63%	66	37%	1.7
Hearing	74	57%	56	43%	1.3
Agility	30	54%	26	46%	1.2
Vision	27	61%	17	39%	1.6
Mobility	25	60%	17	40%	1.5

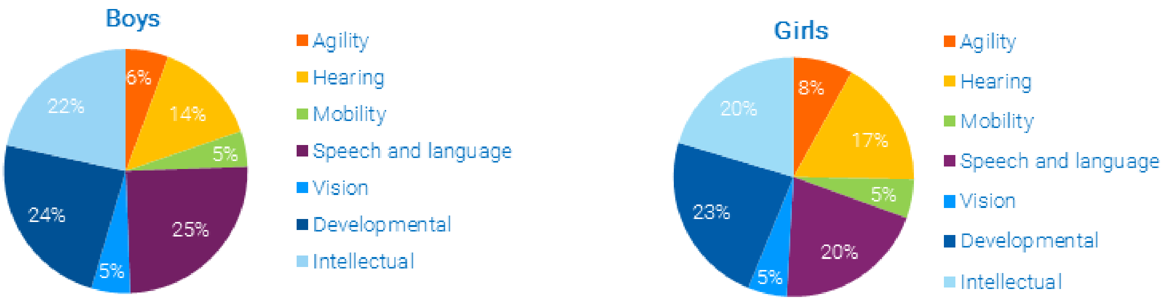
Boys outnumber girls in every disability type. Figure 1 has a graphic representation of the figures.

Figure 1: Children with disabilities by gender and disability type



However, the disability types' distribution among boys and girls is similar. Figure 2 has more detail.

Figure 2: Boys and Girls with disabilities by disability type



Please note that the percentages in the above pie charts do not add up 100% due to rounding.

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[20] See, for example, www.doe.k12.de.us/cms/lib/DE01922744/Centricity/Domain/78/20162017ChildCount35byDisabilitybySexbyELLStatus.pdf, www.unicef.org/pacificislands/Children_Women_and_Men_with_Disabilities_in_Vanuatu.pdf.

Children with disabilities and their families

It is important to understand the prevalence of disabilities in families because it tells us:

- how many children are affected by disabilities
- whether they live in families where other young children have disabilities
- whether their parents/caregivers have disabilities themselves.

The different types or forms of disability in families, affecting one or more children and parents/caregivers, provide indications of:

- the families' complexity
- the support they require
- the challenges family members might face.

In this survey, we asked for information on the types of family that are part of Family Start workers' caseloads, as shown in Table 8.

Table 8: Types of families that are part of Family Start workers' caseloads

Child/children with impairments/ disabilities per family			Families with at least one child with impairment s/disabilities and one parent or caregivers with impairment s/disabilities	Children cared by at least one parent or caregivers with a disability/impairment
One child with impairment/ disabilities	Two children with impairment/ disabilities	Three or more children with impairment/ disabilities		

From the 541 children with disabilities reported by Family Start workers, 85% are the only child with disabilities in the family. This means that 15% of the children (80) with one or more disabilities live in families that have one or more additional children with disabilities. This is one child in every seven children. Twelve per cent (64) of the children with disabilities have at least one parent or caregiver with a disability. This is one child in every eight children.

Family Start workers reported working with families that have two or more children with disabilities

- In total, 82 families have two or more children with disabilities.
- Fifty nine (72%) families have two children with disabilities.
- Twenty-tree (28%) families have three or more children with disabilities.

Family Start workers reported working with families that have both at least one parent or caregiver with a disability and at least one child with a disability

- In total, 60 families have at least one parent or caregiver with a disability.
- Eighteen (30%) families have at least one parent or caregiver with a disability and one child with a disability.
- Forty-two (70%) families have at least one parent or caregiver with a disability and two or more children with disabilities.

Family Start workers and the children and families they work with

It is important to understand how children with disabilities and their families are distributed among the Family Start workers because it provides an estimation of:

- how many Family Start workers have clients with disabilities
- the concentration or spread of Family Start workers among these clients

- the types of families with disabilities they support.

This information is helpful when we consider the types and intensity of supports that children with disabilities and their families need. It can also indicate Family Start workers' specialisation levels and the difficulty of their cases when a few might be working with families with disabilities that have complex needs.

Children with disabilities per family

Of the 121 Family Start workers working with families with children with disabilities:

- fifty-seven per cent (69) reported working with families that have **only one child with a disability**. This is four in seven Family Start workers
- thirty-two per cent (39) reported working with families that have **two children with disabilities**. This is almost one in three Family Start workers
- forty-two per cent (52) reported working with families that **have two or more children with disabilities**. This is almost five in 12 Family Start workers
- eleven per cent (13) reported working with families that **have three or more children with disabilities**. This is almost one in nine Family Start workers
- families that have **only one child** with a disability make up on average 27% of a Family Start worker's caseload
- families that have **two children** with disabilities make up on average 16% of a Family Start worker's caseload
- families that have **three or more children** with disabilities make up on average 13% of a Family Start worker's caseload
- both types of families (**two children** and **three or more children** with disabilities) make up on average 11% of a Family Start worker's caseload. This means that for every nine children, a Family Start worker supports, one child with a disability lives in a family that has one, two or more children with disabilities.

Families with at least one child with a disability and one parent or caregiver with a disability

Of the 121 Family Start workers working with families with children with disabilities:

- twenty-nice per cent (35) reported working with families with children with disabilities that have at least one parent or caregiver with a disability. This is two in seven Family Start workers
- twenty-one per cent (25) reported working with families with two or more children with disabilities that have at least one parent or caregiver with a disability. This is more than one in five Family Start workers
- families with children with disabilities that have at least one parent or caregiver with a disability make up on average 11% of a Family Start worker's caseload
- families with two or more children with disabilities that have at least one parent or caregiver with a disability make up on average 7% of a Family Start worker's caseload. This means that of every 14 families, this Family Start worker supports, one has two or more children with disabilities and one parent or caregiver with a disability.

Children cared for by at least one parent or caregiver with a disability

Of the 121 Family Start workers working with families with children with disabilities:

- thirty-three per cent (40) reported working with children with disabilities who have at least one parent or caregiver with a disability. This is one in three Family Start workers
- children with disabilities who have at least one parent or caregiver with a disability make up on average 22% of the children with disabilities whom a Family Start worker supports. This means that of every nine families whom a Family Start worker supports, two have a child with a disability cared for by at least one parent or caregiver with a disability.

Family Start workers and the children with disabilities they support

Most Family Start workers reported working with children with speech and language disabilities 73% (88), followed by developmental disabilities 66% (80), intellectual disabilities 57% (69) and hearing disabilities (51%, 62). Table 9 has more detail.

These figures indicate that the Family Start workers would need to be familiar with these disabilities and know how to connect families with the relevant services. Further research is needed on Family Start workers' specialisation in and knowledge of the disabilities they support, their knowledge gaps and opportunities for training.

Table 9: Family Start workers by children's disability type (N=121)

Disability	Count	Percentage
Speech and language	88	73%
Developmental	80	66%
Intellectual	69	57%
Hearing	62	51%
Agility	39	32%
Vision	32	26%
Mobility	29	24%

When looking at the average number of children with each disability (noting that some children have multiple disabilities), the highest number of children per Family Start worker are those with intellectual disabilities (see Table 10). On average, each Family Start worker whose caseload includes families with children with intellectual disabilities has 2.6 children with these conditions among their clients.

The same applies to Family Start workers with caseloads that include children with speech and language disabilities: they each have on average 2.5 children with these disabilities. Table 10 has more detail.

Table 10: Family Start workers by disability type and number of children

Disability	Family Start worker Count	Children Count	Ratio
Speech and language	88	202	2.5
Developmental	80	198	2.3
Intellectual	69	180	2.6
Hearing	62	130	2.0
Agility	39	56	1.4
Vision	32	44	1.4
Mobility	29	42	1.4

We were also interested in the variety of disabilities that Family Start workers support. Eighty-three per cent (101) of them reported working with children with two or more disability types. Notably, a third of Family Start workers work with five or more disability types at a given time. Table 11 has more detail.

Table 11: Family Start workers by number of disability types

Disability type	Count	Percentage
1	20	17%
2	20	17%
3	23	19%
4	17	14%
5	25	21%
6	7	6%
7	9	7%
All	121	100%

When looking at the variety and types of disabilities in children that Family Start workers most commonly support, the majority of the Family Start workers whose caseloads include children with developmental disabilities 96% (77) support children with other disability types too. Notably, 30% (24) of them work with children with five other disability types.

Family Start workers whose caseloads include children with intellectual disabilities also support children with a diverse range of other disabilities. Notably, 35% (24) work with children with five other disability types, and 99% (68) of them support children with other disability types in addition to those with intellectual disabilities. Table 12 has more detail.

Table 12: Family Start workers by type and number of disabilities

Family Start workers	Number of disabilities with which Family Start workers work															
	1		2		3		4		5		6		7		All	
	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage	Count	Percentage
Developmental	3	4%	9	11%	18	23%	11	14%	24	30%	6	8%	9	11%	80	100%
Speech and language	7	8%	11	13%	16	18%	13	15%	25	28%	7	8%	9	10%	88	100%
Intellectual	1	1%	3	4%	15	22%	10	14%	24	35%	7	10%	9	13%	69	100%
Hearing	7	11%	8	13%	6	10%	7	11%	19	31%	6	10%	9	15%	62	100%
Agility	2	5%	1	3%	5	13%	3	8%	14	36%	5	13%	9	23%	39	100%
Vision	0	0%	2	6%	0	0%	5	16%	11	34%	5	16%	9	28%	32	100%
Mobility	0	0%	0	0%	3	10%	3	10%	8	28%	6	21%	9	31%	29	100%

Table 13 shows the average number of children with each of the seven disabilities (noting that some children have multiple disabilities), and the disability types that Family Start workers work with.

Family Start workers whose caseloads include all seven disability types (9) have the highest rate of children with developmental, intellectual and speech and language disabilities. On average, each Family Start worker whose caseload includes families with children with developmental disabilities among the other six types has 4.1 children with these conditions among their clients. Equally, the Family Start worker can have 3.9 children with speech and language disabilities and 3.8 children with intellectual disabilities (noting that one child can have multiple disabilities).

Table 13: Caseload of Family Start workers by disability type and number of children they work with

Disability	Number of impairments /disabilities Family Start worker work with							
	1	2	3	4	5	6	7	All
Developmental	1.0	2.7	2.0	2.1	2.6	2.8	4.1	2.5
Speech and language	1.1	1.3	1.6	1.6	2.9	3.1	3.9	2.3
Intellectual	2.0	2.0	2.1	1.8	3.1	2.0	3.8	2.6
Hearing	2.0	1.5	1.5	1.4	2.7	1.8	2.1	2.0
Agility	1.0	1.0	1.0	1.0	1.6	1.0	2.0	1.4
Vision	0	1.0	0	1.6	1.2	1.8	1.3	1.4
Mobility	0	0	2.3	1.0	1.3	1.0	1.8	1.4

Supporting children with disabilities and their families

In this section, we explore:

- the issues and challenges faced by families with children with disabilities
- the services and supports to which these families have access or are referred
- how Family Start workers rate the helpfulness of these services and supports
- how Family Start workers believe families with children with disabilities could be better supported.

Main issues faced by families with children with disabilities

When asked about the main issues faced by families with children with disabilities, participants' comments fell into the areas of: subjective wellbeing[21], social connections[22], knowledge and skills, income and resources, health, transport and housing.

The following quotes by Family Start workers illustrate the challenges that many families face:

Subjective wellbeing

Most Family Start workers reported that families with children with disabilities face emotion and stress, including a sense of grief and loss. Parents feel overwhelmed with the stress of caring for disabled children. The issues associated with caring for a child with a disability include lack of sleep, parental stress and frustration.

> *Parents often struggle to look after other children when they have a child with disability and siblings.*
>
> *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.*

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[21] Subjective wellbeing refers to "how people experience the quality of their lives and includes both emotional reactions and cognitive judgments". For more details, see Diener, E. (1984). Subjective well-being. *Psychological Bulletin, 95*(3), 542-575.

[22] Social connection refers to the "experience of feeling close and connected to others. It involves feeling loved, cared for, and valued". For more details, see Eisenberger, N. I., & Cole, S. W. (2012). Social neuroscience and health: neurophysiological mechanisms linking social ties with physical health. *Nature Neuroscience*, 15(5), 669.

> *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.*
>
> *It is evident in the families who have been affected by a loved one with a disability the amount of stress, sleepless nights; their need for respite; and the effects it has on them. For example, a father who works full time while mother cares for her two children in the home, the other three children attending school; then father 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.*
>
> *Parents feel overwhelmed with the stress of caring for a disabled child. Parenting a child with disabilities can have its challenges, which may impact parenting capacity.*

One of the most salient issues mentioned by Family Start workers was the insufficient availability of home support and respite for families with children with disabilities.

> *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.*
>
> *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 on things because the whānau cannot afford it, or they have to go to support their child.*
>
> *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.*
>
> *Better response from respite care. 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.*

Social connections

Families with children with disabilities often face social isolation, discrimination, stigma, negative judgement and marginalisation.

> *Discrimination from schools and people in the community.*
>
> *Many of the whānau we work with live in isolation and are unable for whatever reason to access support.*
>
> *Isolation, judgements and ignorance from others.*
>
> *Often the added stress of having a child with a disability can lead to social isolation or worsen issues around maternal/paternal depression.*
>
> *Stigma and negative judgement from the wider community.*
>
> *Families struggle with judgement, marginalisation, telling their story again and again, working with people who have no idea of what it is like for them. Trying to pretend its 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.*
>
> *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.*

Family Start workers said there is a lack of understanding about what families with children with disabilities are going through. They are often not being heard or treated with the consideration and care they need/deserve.

> *They could be better supported if they feel they have been listened to and that their fears and anxiety are taken into consideration. Whānau feels 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.*
>
> *Lack of understanding, 'professionals' telling them what they 'need'.*
>
> *These parents need to be given time, they need to be heard and respected, as parents, they have an inbuilt insight, and that needs to be taken seriously.*

> *Sometimes clients feel like they are being kept out of the loop.*
>
> *There needs to be 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 day-care centre. They had no understanding whatsoever of autism, which is concerning.*
>
> *Disability services is 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.*
>
> *Parents have a lack of understanding whom to go to, where to go to and cost. For our Māori parents, they share the interactions with organisations, 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.*
>
> *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.*

Knowledge and skills

Family Start workers explained that often parents/caregivers lack knowledge on how to deal with the care needs of their children with disabilities, as they are not informed enough about their children's conditions. Families also do not have the necessary skills to cope with the disparate issues associated with disability and information about the services and supports they can access.

> *Lack of knowledge of support services in the community.*
>
> *They are not sure as to what supports they are entitled to.*
>
> *There needs to be more access made available for parents to get information, not the expectation that parents will go and look for it.*
>
> *More information about entitlement and access to appropriate services/resources for their needs.*
>
> *Services do not explain to families properly what their role is, and some do not follow through or follow up. GPs and nurses are not helpful to clients, and this means they need more appointments and waiting in waiting rooms to address the problem.*

Family Start workers mentioned that professionals supporting families sometimes lack adequate training and knowledge of disabilities. Some mentioned that Family Start workers themselves need to be better prepared to support families with children with disabilities effectively.

> *Our tamariki are still falling through the gaps. This 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.*
>
> *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.*
>
> *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.*
>
> *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.*

Income and resources

Most Family Start workers mentioned that families with children with disabilities face financial stress and poverty.

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

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

Families with children with disabilities that live in rural areas face insufficient or inadequate access to services and supports.

> *Rural residents have very limited services for the children and youth of their communities; this is frustrating because of the lack of services impacts on outcomes for the people that we work alongside. There are services available if 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.*

> *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.*

> *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.*

Health

Family Start workers mentioned that some families face issues of drug use, addiction and mental and behavioural problems (associated with their own disabilities and those of the children). Some families, where parents/caregivers with disabilities care for children with disabilities, have complex and high needs that are not properly supported.

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

> *Being able to include the parents in the support so they can learn how to take care of their child, while they are dealing with their own mental illness and/or disability.*

Most Family Start workers mentioned long waiting lists and delays in accessing adequate treatment as two of the main difficulties faced by families with children with disabilities.

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

> *The main issue is being able to access the most appropriate services, 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.*

> *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.*

> *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 a parent who is already at breaking point.*

> *Waiting lists need to be short so that a parent has at least got contact with someone if they need help or support.*
>
> *Long waiting times for appointments – 16 months max.*
>
> *Medical establishments like Child, Adolescence and Family Services (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 need to be reduced so that families are being seen in the early stages of deterioration of health, milestone development or emotional wellbeing. 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.*

Transport

Several Family Start workers mentioned that families with children with disabilities face difficulties associated with transport. Families frequently need to travel for treatment and appointments, which causes high transport costs. Some families live in remote areas or areas where there is no public transport available. Families might also lack adequate transport for children with disabilities, including suitable vehicles.

> *Families who have children with a disability often face additional costs, particularly with transport to appointments.*
>
> *Lack of money to access vehicles that are suitable for children with disabilities.*
>
> *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.*
>
> *The cost of travel for those who live on the boundary of being entitled to travel expenses means that a number of families miss out on essential services.*

Housing

Some Family Start workers mentioned that inadequate housing and a lack of affordable housing are issues faced by many families with children with disabilities.

> *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 and appliances and strong community support and access to a range of free fulltime childcare and holiday care and respite.*
>
> *Need housing to be free and good.*

Services and supports most commonly used by families with children with disabilities

The services and supports available for young children with disabilities and parents/caregivers caring for children with disabilities were collated from the websites of various government agencies, including the Ministry of Social Development, the Ministry of Health, the Ministry of Education and CCS Disability Action. Here are all the services and supports included in this study:

Work and Income – Ministry of Social Development

- Childcare Assistance (subsidy) CCS
- Early Learning Payment
- Early Childhood Education (20 hours of Childhood Education)
- OSCAR Subsidy (Out of School Care and Recreation)
- Guaranteed Childcare Assistance Payment (GCAP)
- Flexible Childcare Assistance

Disability Support Services – Ministry of Health

- Needs Assessment and Service Coordination Service (NASC)
- Autism Spectrum Disorder Support (ASD)

- Child Development Services
- Behaviour Support Services
- Supported Living
- Carer Support – Respite Services
- Equipment and Modifications Service (EMS)
- Community Residential Support Services
- Home and Community Support Services

Early Intervention Services (Ministry of Education-funded services – help for children with special needs)

- Early Intervention Services
- Advisor on Deaf Children (AODC)
- Early Intervention Teachers
- Kaitakawaenga or Māori Cultural Advisors
- Psychologists
- Speech-language Therapists (SLTs)

Ministry of Health (claims, provider payments and entitlements)

- Travel and national accommodation – national travel assistance

CCS Disability Action

- Mobility Parking Permit

The services and supports included in the survey are not exhaustive, but they provide a fair representation of what is available for families caring for children with disabilities. Family Start workers were invited to provide information on services and supports additional to those listed above. Appendix 3 has details.

It is important to note that the listed services and supports include a combination of mainstream services and supports and services and supports that are specific to children and adults with disabilities. The reason for this inclusion is two-fold:

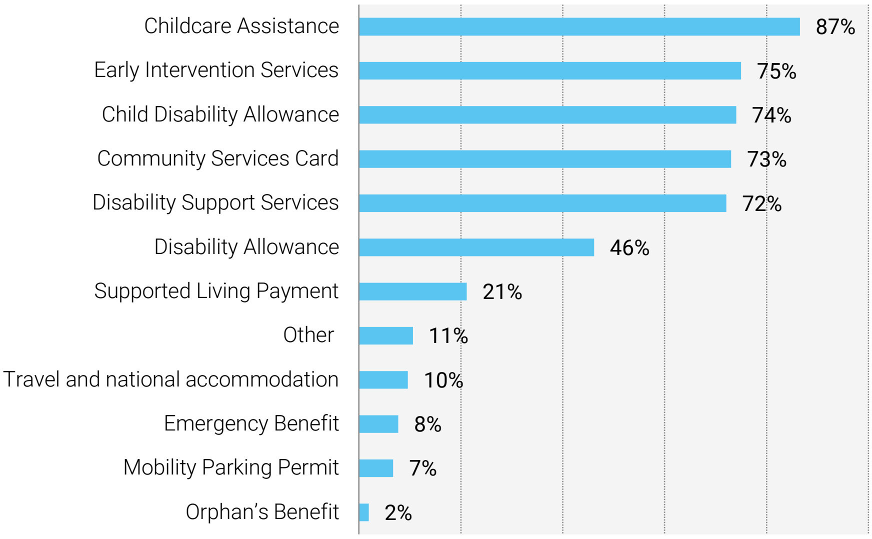
1. Families with children with disabilities tend to face greater challenges than families with children without disabilities. They, therefore, require both mainstream services and supports specific to their children's needs.
2. As the survey results show (see page 12), not all children with disabilities have been diagnosed by a medical professional, so in the absence of a formal diagnosis, children with disabilities would be only able to access to mainstream services and supports. The lack of diagnosis is likely to happen because the children are very young, and the extent of their disabilities is still unfolding, as is particularly the case for developmental and speech and language disabilities.

Of the 121 Family Start workers whose caseloads include children with disabilities, 105 commented on the services and supports to which families with children with disabilities have access or have been referred. Their responses are presented in this section.

Family Start workers were asked: *Thinking of the families with children with disabilities, from your knowledge and experience, which of the following services/supports do they access/have they been referred to?*

The top five services and supports that participants selected were Childcare Assistance 87% (90), Early Intervention Services 75% (78), Child Disability Allowance 74% (77), Community Services Card 73% (76) and Disability Support Services 72% (75). Figure 3 has more detail:

Figure 3: Services/supports thst families with children with disabilities have access and/or have been referred to (N=105)



In the category *Other*, participants mentioned impairment practitioner, counselling services, Physiotherapists, DHB paediatrics, Ministry of Education, Kupenga Support Net, home help, nanny, ACC, conductive education and Epilepsy New Zealand. Each was mentioned only once.

Figures 4 and 5 show the services and supports to which families with children with disabilities have access or have been referred within Childcare Assistance[23] and Early Intervention Services, respectively. Each group of services and supports includes a variety of specific and tailored services and supports to meet the needs of clients.

Within Childcare Assistance, the services and supports to which families commonly have access or have been referred are :

- Early Childhood Education 62% (67): 20 hours a week of free early childhood education for children aged three to five years
- Early Learning Payment 56% (61): a payment of $7.55 per hour for up to 20 hours per week for the early childhood education of a child aged 18-35 months
- Childcare Subsidy 54% (58): includes children age 0-5 years and consists of a payment towards the cost of childcare of $1.62-$5.22 per hour for up to 50 hours.

None of this financial assistance for childcare is specific to families with children with disabilities. Given that many families with children with disabilities have several children, a family might require Childcare Assistance for children without disabilities so that they can look after a child with a disability. It might also be the case that children with disabilities that have not been diagnosed yet to be entitled to financial assistance for children with disabilities.

In the case of Early Intervention Services, the services are targeted to preschool children with special needs. Consistent with the high number of speech and language disabilities reported in children, the services that families with children with disabilities access or are referred to are Speech-language Therapists 76% (59), followed by Psychologists 37% (29) and Early Intervention Teachers 36% (28).

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[23] It is important to note that Childcare Assistance is available to all preschool children. For more detail, see https://www.workandincome.govt.nz/providers/childcare-assistance/types-of-childcare-available.html

Figure 4: Childcare Assistance services that families with children with disabilities access and/or have been referred to (N=90)

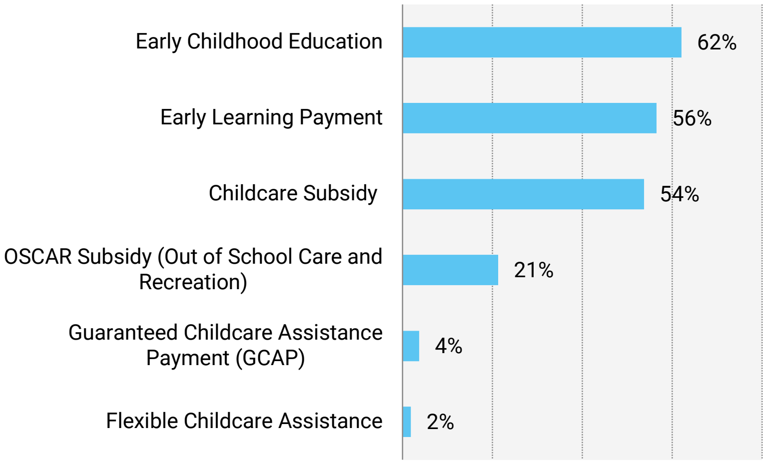
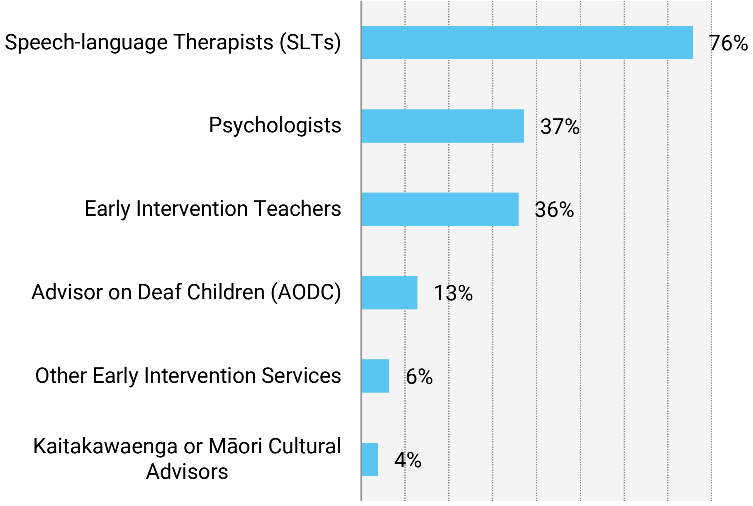


Figure 5: Early Intervention Services that families with children with disabilities access and/or have been referred to (N=78)



The Community Services Card is the fourth support to which families with children with disabilities most commonly have access or have been referred. Seventy-six Family Start workers selected this support, which gives people access to reduced-cost health services, including dentistry and travel and accommodation for treatment at public hospitals for people referred from outside the area. Community Services Cards are not specific to adults or young people with disabilities, but those on low incomes.[24]

The fifth support to which families with children with disabilities most commonly have access or have been referred to is Disability Support Services.[25] Seventy-five Family Start workers selected this support, which includes a suite of services and supports designed to identify and meet the needs of adults, children and young people with disabilities as defined by the Ministry of Health.[26] Figure 6 has detail on the supports to which families with children with disabilities most commonly have access or have been referred to within Disability Support Services.

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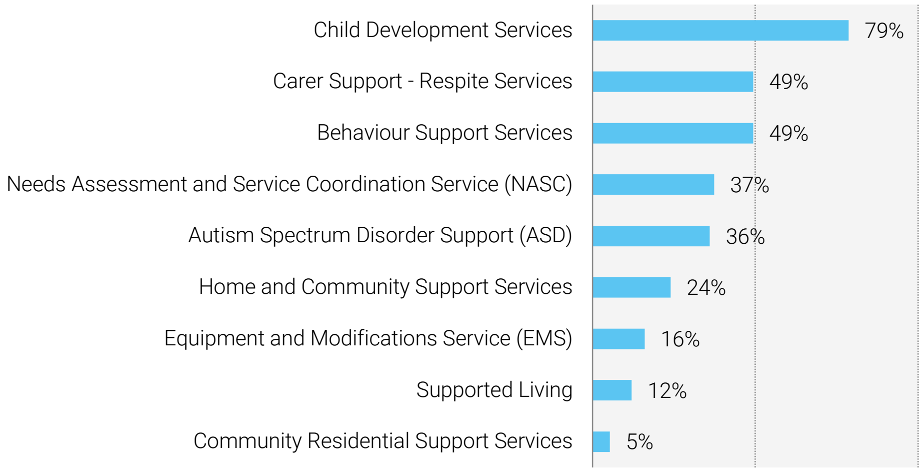
[24] For more details about the Community Services Card, see www.workandincome.govt.nz/products/a-z-benefits/community-services-card.html

[25] For more details about Disability Support Services, see www.health.govt.nz/your-health/services-and-support/disability-services.

[26] Currently, the Ministry of Health specifies that people with disabilities include "people with a physical, intellectual or sensory disability (or a combination of these) that is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required". For more detail, see www.health.govt.nz/system/files/documents/topic_sheets/disability-support-services-faq.pdf

The services to which families with children with disabilities most commonly have access or have been referred is Child Developmental Services 79% (59), which corresponds to the high number of children with intellectual and developmental disabilities. Child Developmental Services are followed by Care Support – Respite Services 49% (37) and Behavioural Support Services 49% (37%), which might indicate the presence of more severe disabilities within a family. It is important is note that 36% (27) of participants reported Autism Spectrum Disorder Support, which indicated at least an equal number of families with at least one child with an autism spectrum disorder. Appendix 4 has more details on these services and supports.

Figure 6: Disability Support Services to which families with children with disabilities have access and/or have been referred (N=75)



Most helpful services and supports for families with children with disabilities

The list of services and supports in the survey was not exhaustive, but it provided a representation of what is available for families caring for children with disabilities. Family Start workers were invited to provide information on services and supports additional to those above. Appendix 3 has details.

Of the 121 Family Start workers whose caseloads included children with disabilities, 108 commented on the services and supports to which families with children with disabilities have access or have been referred. Their responses are presented in this section.

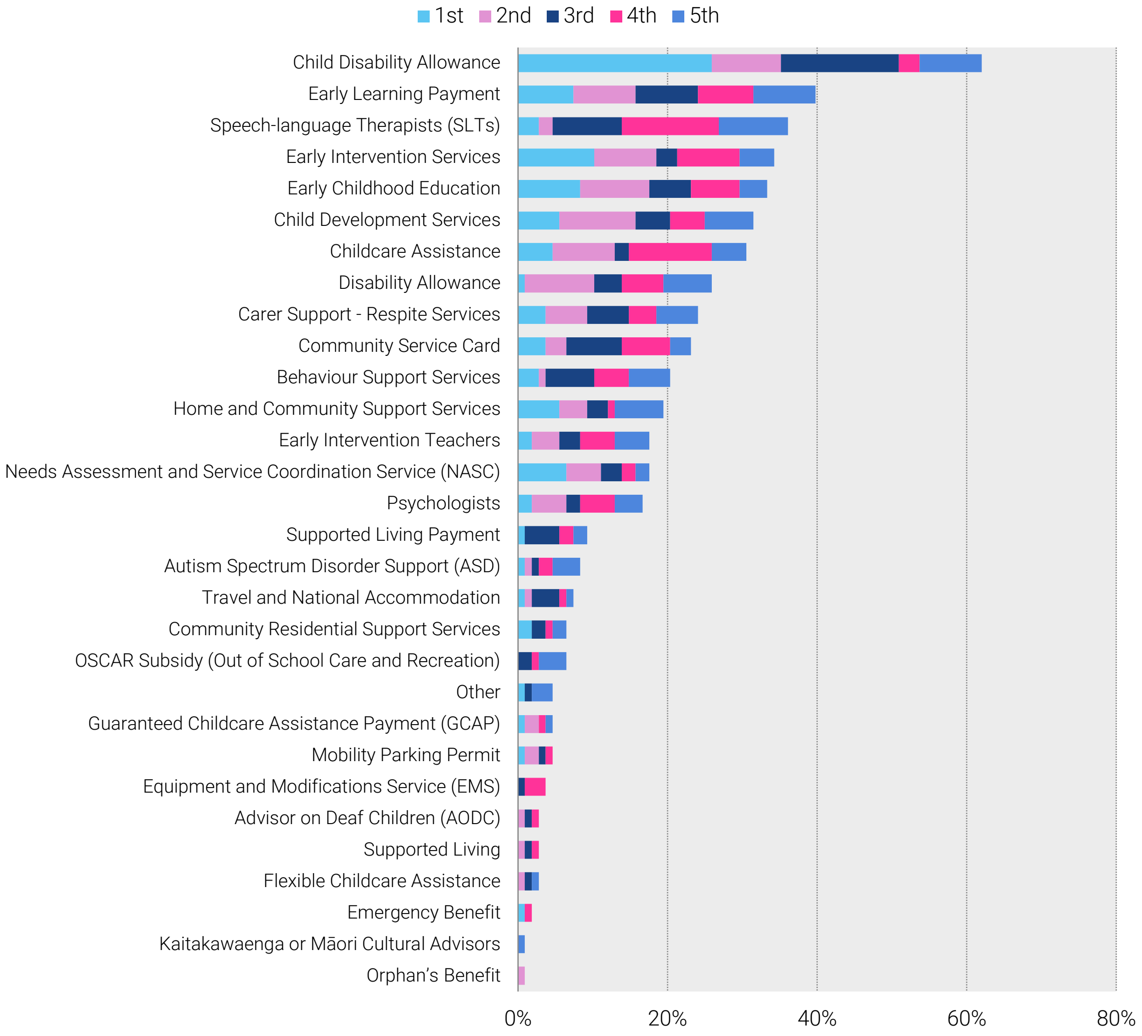
Family Start workers were asked to rank the top five most helpful services and supports for families. By far, they considered the Child Disability Allowance 62% (67) the most helpful, followed by the Early Learning Payment 40% (43). Both are direct cash transfers to families, with the Child Disability Allowance designed to meet the additional costs associated with caring for a child with a disability, and the Early Learning Payment subsidising the costs of early childhood education for children aged 18-35 months.

Speech-language Therapists was listed as the third most helpful assistance for families by 36% (39) Family Start workers. Table 14 has more details, and Figure 7 shows the top five most helpful services and supports ranked by Family Start workers.

Table 14: Top five most helpful services and supports for families with children with disabilities (N=108)

Services and Supports for families with children with disabilities	Responses	
Child Disability Allowance	67	62%
Early Learning Payment	43	40%
Speech-language Therapists (SLTs)	39	36%
Early Childhood Education	36	33%
Child Development Services	34	31%
Childcare Subsidy	33	31%
Disability Allowance	28	26%
Carer Support – Respite Services	26	24%
Community Services Card	25	23%
Behaviour Support Services	22	20%
Home and Community Support Services	21	19%
Needs Assessment and Service Coordination Service (NASC)	19	18%
Early Intervention Teachers	19	18%
Psychologists	18	17%
Supported Living Payment	10	9%
Autism Spectrum Disorder Support (ASD)	9	8%
Travel and national accommodation – national travel assistance	8	7%
OSCAR Subsidy (Out of School Care and Recreation)	7	6%
Community Residential Support Services	7	6%
Mobility Parking Permit	5	5%
Guaranteed Childcare Assistance Payment	5	5%
Other	5	5%
Equipment and Modifications Service	4	4%
Flexible Childcare Assistance	3	3%
Supported Living	3	3%
Advisor on Deaf Children	3	3%
Emergency Benefit	2	2%
Orphan’s Benefit	1	1%
Kaitakawaenga or Māori Cultural Advisors	1	1%

Figure 7: The top five most helpful services and supports for families with children with disabilities by rank (N=108)



Why services and supports for families with children with disabilities are especially helpful

Responses from Family Start workers about the reasons for services and supports for families with children with disabilities being especially helpful coincided, in that while this depends on the unique circumstances of families, financial and childcare supports are especially helpful.

The services and supports associated with early intervention and early childhood education were frequently mentioned for three main reasons:

- They provide a gateway to access more specialised services, such as Early Intervention Services.
- They help families to deal with their children's special needs.
- They provide time off/respite from care responsibilities.

Financial services and supports were mentioned often because families benefit greatly from direct cash transfers; many have low or single incomes and face poverty and deprivation. Financial assistance helps them to meet additional costs related to their children's disabilities and sometimes the parents'/caregiver's own disabilities. Families also experience income losses owing to their caring responsibilities – many parents and caregivers are full-time carers of children with disabilities. Some families care for more than one child with disabilities, and some have parents or caregivers with disabilities who also need care. For these families, multiple sources of financial support are especially helpful and necessary.

For example, Family Start workers explained why the Child Disability Allowance is especially helpful for families with children with disabilities. Their comments included:

> *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 expenses for such a large family.*
>
> *Child disability allowance. Families who cannot work because their children have high needs. They need this.*
>
> *Extra finances help my family's financial situation, as the father is no longer in the picture.*
>
> *Child Disability Allowance permits the parent/s to pay for additional services for their child to enhance their well-being.*
>
> *To increase ability of rural families to meet their costs.*
>
> *Child Disability allowance is helpful as it is providing additional financial resources, as normally for families of children with disability, there are always additional financial needs.*

Family Start workers also explained why the Early Learning Payment is especially helpful for families.

> *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.*
>
> *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.*

When commenting on why Early Intervention Services and Early Childhood Education are especially helpful for families with children with disabilities, Family Start workers said:

> *Early services can mean early identification of needs for both child and whānau; this includes support which can help reduce stress on the families both financially and emotionally and prevent abuse and neglect.*
>
> *Early professional intervention will help children to achieve more if they are supported from early stages.*
>
> *Families who struggle 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.*
>
> *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 the children have been taken care of during the day and they then take over in the afternoon and evenings.*
>
> *Early intervention to give children the best start in life whether that is a referral to family start, speech and language Therapists, psychologist etc.*

Ways to better support families with children with disabilities

Family Start workers' suggestions on how children with disabilities and their families could be better supported reflect the unique needs of individual families and the general needs of vulnerable families who have children and, in some cases, adult members with disabilities.

Family Start workers' suggestions also offer ideas for improving the way families are supported, often mentioning the need for an integrated and coordinated approach and response to child and family needs. At the core of the suggestions is a strong demand for more financial support for both families and the services that support them. The responses also show the disparity of experiences and access to services, suggesting that equity and quality are a problem.

Family Start workers provided other suggestions to better support families with children with disabilities. The following are in their own words.

Develop a tailored approach to support the specific needs of children with disabilities and the general needs of vulnerable families that have children with disabilities and, in some cases, adult members with disabilities

We need access to more services, which can accurately diagnose children/babies living with Fetal Alcohol Syndrome 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.

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.

Listen to the whānau and the people with disability to find out what they require.

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

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.

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

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

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.

Improve the way families are supported by taking an integrated and coordinated approach to responding to children's and families' needs

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

Automatic services and entitlements rather than having to make an appointment with WINZ. GP Medical needed only. It is our responsibility as 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 one meeting.

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

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.

There is a lot of help, but it needs to be advertised more. Myself, I am not very familiar 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.

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.

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.

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.

Provide more funding and financial support to both families and the services that support them

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.

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

Extra financial support that recognises the extra expenses.

> *Extra funding for one on one teachers for children with disabilities and behavioural problems and more training for teachers, health professionals and social workers.*

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

> *By removing the kilometre range from the service provider to a service that supports financially 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.*

Increase the availability of, access to and hours of home support and respite to parents/caregivers caring for children with disabilities

> *Having more respite or in-home support workers.*

> *More hours and availability for respite.*

> *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 on things because the whānau cannot afford it or they have to go to support their child.*

Address the disparity of availability and access to services experienced by families with children with disabilities

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

> *In the 15 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.*

Provide specialised education and training to Family Start workers who work with children with disabilities but might lack the experience and knowledge to support them effectively

> *Educate staff in Family Start about disabilities particularly if they have never had to deal with whānau with disabilities, and 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).*

> *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.*

Provide specialised education and training for professionals who provide disability-related support services for children with disabilities but might lack the experience and knowledge to support them effectively

> *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.*

> *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.*

Additional comments from Family Start workers on ways to better support families with children with disabilities covered:

- access and support for families in rural areas
- more support to face transport limitations

- support for families with issues of drug abuse, addiction and mental and behavioural problems
- support for transgender children

Appendix 5 has further details on Family Start workers' responses.

ORANGA TAMARIKI
Ministry for Children

EVIDENCE CENTRE
TE POKAPŪ TAUNAKITANGA