



# Understanding Common Experiences for Families of Individuals with Down Syndrome in British Columbia: Access to Services and Support

## *A Collaboration between Down Syndrome BC and Dr. Holden Chow, UBC*

**Purpose:** Little is known about the experiences of families caring for an individual with Down Syndrome in British Columbia. Anecdotal reports of lack of support and or poor quality of support across a variety of areas are common in mainstream media, social media and in offices of healthcare practitioners and support workers. Group advocacy is difficult for this population due to the lack of knowledge around the frequency of occurrence of these anecdotal reports in the Down Syndrome community across BC. The purpose of this research study is to define the current collective experience of caring for an individual with Down Syndrome with respect to access to support and services in British Columbia.

**Methods:** Research questions were formulated focusing on 7 main areas (accessing therapies, accessing childcare and preschool, funding for support, quality of therapies, quality of childcare and preschool, telehealth and advocacy), to be delivered in the form of an online survey. To participate in the study participants must have met the following criteria:

1. A primary caregiver of a child with Down syndrome between 0-18 years of age
2. Currently residing in British Columbia
3. Living in BC for a minimum of three years between January 2018 - survey response date

A primary caregiver was not eligible to participate if a different primary caregiver for the same child had already responded to the survey.

Study questions were reviewed, revised and approved by Dr. Holden Chow (Clinical Assistant Professor, Department of Family Practice, University of British Columbia). The survey was approved by the Down Syndrome BC Board of Directors prior to submission to the UBC Research Board of Ethics and the Fraser Health Board of Ethics. Research Ethics Board approval was granted by UBC (H21-01896) and a Letter of Authorization to Conduct Research was obtained from Fraser Health (2022161). The study was delivered using the web-based Qualtrics survey tool, hosted by UBC. Participant recruitment occurred via DSBC's social media accounts (Instagram, FaceBook); the DSBC email list, non-DSBC parent support groups (email lists and social media) and local organizations that serve the disability community (email lists and social media). The survey was active between March 31st 2022 and April 14th 2022.

All data was collected anonymously; no personal identifiers were collected or stored.



**Definitions:** The following definitions were provided to survey respondents throughout the survey and apply in this report.

<b>Public Service</b>	<p>Services in which an individual or family can self-refer (Child Development Centre or equivalent).</p> <p>Centres providing these services are directly funded or contracted by the government.</p>
<b>Individual Funding</b>	<p>Funding comes from the government and is attached to the child (At Home Program School-Aged Extended Therapies and/or Autism Funding Unit) for services of the families choosing</p>
<b>Familial Funding</b>	<p>Out-of-pocket, gift/loan from family member, and/or Private Insurance</p>
<b>Alternative Funding / Service</b>	<p>Funding or service from a charity or other non-government source ie. Variety Children’s Charity, Special Olympics etc.</p>
<b>Private Service or Support</b>	<p>Any family-directed service or support that is paid for with Individual, Parental/Familial, or Alternative Funding</p>
<b>&lt;5 years</b>	<p>Children who are not yet school-aged, and whose services can be provided under the umbrella of a Child Development Centre or equivalent</p>
<b>Children ≥5 years</b>	<p>Children who are old enough to attend Kindergarten and may be eligible for At Home Program School Aged-Extended Therapies</p> <p><i>Note:</i> In some cases/areas these Children may still be covered by Public Services</p>



## ***Survey Highlights and Key Takeaways***

75 caregivers of children with Down syndrome responded

More than half of caregivers accessed private therapy for their child aged 0-4

The At Home Program does not cover the cost of therapy services for 70% of respondents; this limited the amount of therapy those caregivers could access for their children in 50% of cases

More than one third of respondents have waited over three months to access speech therapy and the same number have waited over three months to access occupational therapy

76% do not feel that public services or individual funding adequately covers their child's speech therapy needs. 67% do not feel that public services or individual funding does not cover their child's occupational therapy needs. 67% do not feel that public services and individual funding do not cover their child's physiotherapy needs

The most common issue caregivers report with public services is that they are too infrequent. 83% of parents face this issue

79% of respondents have had a member of their family reduce their work hours in order to help their child access services.

41% of those attempting to enroll in childcare have been denied enrollment. A rationale of Down Syndrome or excess physical or developmental delay was the response given in over half (52%) of cases.

When public funding for a support person was not provided or not provided for all of the hours requested this resulted in the child not attending or leaving the program for 60% of children enrolled in those programs.

39% of caregivers reported needing to reduce their work hours or quit their job (personally, or another family member) because of lack of support for their child to attend daycare or preschool.

81% of respondents have used personal funds, or personal funds from family members/friends to pay for support.

If more government funding became available 84% of caregivers would immediately pursue additional services for their child.



22% of caregivers or their immediate family members have had to increase their work hours or gain new or additional employment for the sole purpose of funding private therapies for their child.

65% of caregivers of children aged 0-1 (in the past four years) rated the quality of public support and services available for families new to the Down syndrome community as poor

68% of caregivers of children aged 0-5 perceive therapists funded through Individual, Familial or Alternative funding sources as very knowledgeable. In contrast, 36% of these caregivers of children aged 0-5 find publicly funded therapists as very knowledgeable.

62% of caregivers rated public services for children aged 1-5 as **adequate or poor**. In contrast, 86% of caregivers rated private services as **excellent or very good**.

77% of caregivers of school-aged children rated public services as **adequate or poor**. In contrast, 67% of caregivers of school-aged children rated private services as **excellent or very good**.

Caregivers believe their children's physical, emotional and social needs are being mostly or completely met >70% of the time. They believe their children's intellectual needs are being mostly or completely met 59% of the time.

Over half of respondents rated their child's preschool or childcare support worker training as 'somewhat sufficient'.

60% of respondents have accessed online support in the past four years. 71% believe physiotherapy online is inferior to in person, 60% believe OT online is inferior to in person and 37% believe speech therapy online is inferior to in person. 47% of respondents believe some aspects of speech therapy online are superior to in person and some aspects are inferior to in person.

30 respondents have spent more than six hours in the last year advocating for public therapies for their child (either quantity or quality), and 16 spent more than six hours in the last year advocating for preschool or childcare services. The most common reason for advocating was lack of funding.

On average 27% of all respondents indicated their advocacy efforts were mostly or very successful.



## ***Noteworthy Quotes***

### ***Describe your experiences waiting for publicly funded therapy...***

We did not receive public funded therapies until almost aging out of early intervention because of lack of therapists and waitlists.

I've been in tears trying to get support for my child.

Our OT has left and has not been replaced for almost a year.

I don't use any public services because the waitlists are so long, there's also no consistency with a plan.

There has been a huge lack of services because of people leaving their position, and a new hire that went on maternity leave. These services were provided by Island Health but the service provider lives far away and covers a big part of Vancouver Island. There simply isn't enough services or time to see our children on the West Coast.

The support is not just offered and it is hard to know what to expect and how much. When asking for support, you have to be specific and forthright. Online therapy does not begin to compare to in person.

### ***Describe your experiences waiting for other publicly funded services...***

1:1 support necessary to attend inclusion based childcare at a local subsidized child care center. We finally received support, and it only covered 4 hours per day.

Supported child development so my son can attend daycare. We have been on the waitlist for 1.5 years.

We waited 6 months for an autism assessment at Sunnyhill (publicly funded assessment) and were ultimately denied the assessment.

### ***Describe your experience if you've had to travel more than 30 minutes for publicly funded therapies.***

All of our services are placed out of Port Alberni and during the pandemic these service providers have not traveled to the West Coast. The drive to Port Alberni on a good day is 1 hour and 45 minutes. With two kids it is really hard so my child with DS has barely received any of these services.

I live in a rural area and have to travel 45 minutes for most public services.



The CDC office is on the other side of Surrey from where we live. We get stuck in traffic and my son gets cranky or sleepy and by the time we get there for speech therapy he is over it and doesn't want to participate.

***Describe the reasons you were denied a childcare spot, if not listed...***

My daughter was tube feeding so no licensed childcare accepted her.

They would not take my child to school without an attendant.

Non-mainstream preschool (outdoor) was not allowed to have a publicly funded support worker.

They say he cannot attend without a support worker, and when trying to get a support worker it was not successful; they said 'No funding'. It is frustrating when the place to get a support worker says you have to have the daycare or preschool first before you get a support worker, but the daycare does not want to give you a spot without support in place. It has been a really frustrating experience and they always say, 'No funding, no funding'.

***Describe other barriers to enrolling your child in preschool or childcare...***

No additional support at the before school program, they weren't available until 9:00am

Waitlist. There is a big shortage of daycare spots in Tofino and there are no all inclusive daycares on the West Coast.

I had to attend preschool with my son until they found someone (months).

Lack of supervision and support in summer and spring break day camps.

The waitlist was too long and he 'aged out' at age 12. Then there are NO youth childcare options and he needs supervision. So I had to quit my job.

Boys and girls clubs are funded by the government and we were offered a spot 2 days a week for 7 hours. These hours don't sustain a family that works full time! Additionally the environment would not be our choice, we were forced to take it, then left as it wasn't a good fit. There are no flexible options for our children. Ideally I would have liked to enroll my child in a camp of my choice with his sibling and provided the support there. Having to split siblings up and piece together child care is stressful, segregative, and IS NOT family centered.

***If more funding became available, would you immediately pursue additional services for your child?***

Yes - My daughter would thrive with more hours at the daycare but we cannot put her in more hours as we do not have the funds for a support worker. I would also use the money for a support worker taking her to after school programs where drop off are available. We as parents have to stay with her and essentially be her support worker at every single activity she goes to. It is exhausting and not fair to my daughter either.



Yes - we would look into private therapy.

Yes - if I didn't have to worry about funding levels we would book more.

Yes - we would like weekly SLP and OT and more reading/math.

No - he's turning 19, so he's dropping into a black hole now.

Unsure - there are a lack of services for teens

Unsure- if it was available in our region

Unsure - if the funding allowed me to access services closer to home, yes. At the end of the day, I already cannot fit in all the services due to work.

Unsure - if the services could be applied to private therapies we are happy with and use currently, we would apply. If it couldn't be used for private therapies, we would not apply.

***If you or another family member have had to increase your work hours to gain new or additional employment for the sole purpose of funding private therapies, please describe...***

My husband works ALL THE TIME to fund these services.

My husband pursued part-time self-employment in addition to his full-time job.

I work extra shifts if my child needs additional support.

***General Comments on Access to Services and Supports...***

Very limited services in our region once our kids outgrow the CDC.

The CDC offers lovely people and services, but not specific to Down syndrome. I feel like I'm initiating what comes next based on what I read or see online.

There is not enough funding. Period. That I have to fight for my daughter to have a support worker so she can be included in her daycare is so sad. Furthermore, they have decided to take the funding away from her come September because she is school age. She is not going to school as we are holding her back and they can fund a support person if a child has a medical condition but they are choosing not to. This is beyond frustrating and if she cannot go to daycare then I will have to quit my job to have her home, which we cannot afford. Furthermore, she is being excluded from social interactions with her peers and great learning opportunities. How is this okay?

Rural areas lack ANY public services.





Would love to have more funding/support especially as we get closer to aging out of the Child Development Centre.

The worst thing regarding funding is you need to make things sound so terrible in order to get funding when all you'd like is to celebrate their victories. I have to go through my worst nightmare every time I apply for a funding grant.

The limit on hours of funding covered is extremely frustrating. It's not helpful to most people who work out of the home to only have part time care available if they work full time.

The lack of regular therapy for those not on extended medical is pitiful. Early intervention is key and out of reach for many. Having experts in DS at the DSRF has been a game changer for us. But, they are too far away for access to more beneficial services like OT, reading, etc.

Kids with Trisomy 21 get shafted, especially if they do not have an Autism diagnosis. The first 4 years of my daughters like we had NO FUNDING for anything. We spent our savings, thousands of our own money.

It shouldn't be such a battle to access services. Services should be available to all children regardless of diagnosis.

I am personally exhausted, defeated and angered by the lack of response to years of advocacy for my son, lack of personal funding options for him and our family that have caused personal and family stress, and worry. Finding adequate childcare services has been such a struggle and caused unnecessary distress for our family. Every summer I worry about how I will work when my child needs care (he is now 13 and that doesn't change the need). Not having respite ever. Not having any freedom to choose the therapies, environments, programs my child enrolls in, it is all dictated by the government in a terribly sparse "menu" of services- "you get choice A, or B for your child." What if A and B doesn't work for us or isn't enough? Well then we suffer- the child, the parents, the siblings and the community as a whole. I just want choice and adequate support for my son. We have a long way to go around inclusion and it needs to be the norm that children can enroll in any program they choose with support.

COVID-19 was a significant barrier to public support for us. We were generally happy with our public support until the pandemic, at which point services were drastically reduced and still have not returned. During the pandemic, we added private speech therapy because our daughter was clearly in a window of speech growth and the public services weren't keeping up with her. We are lucky to have flexible employer paid benefits that allow us to access private speech therapy weekly, as this is a significant expense (\$70/wk). We have been very happy with the outcomes for our daughter since starting private speech.

It can be very time consuming figuring out what services are available, how to access them. I have often given up trying as it's faster to pay for services myself.





Waitlists for childcare funding discriminate against those who move from out of province. And there is NO youth funding at all for before and after school care. I met with our MLA about this to no avail.

We are so grateful for the DSRF virtual services and would like government funding to bring the DSRF in person all over BC. Excellent services.

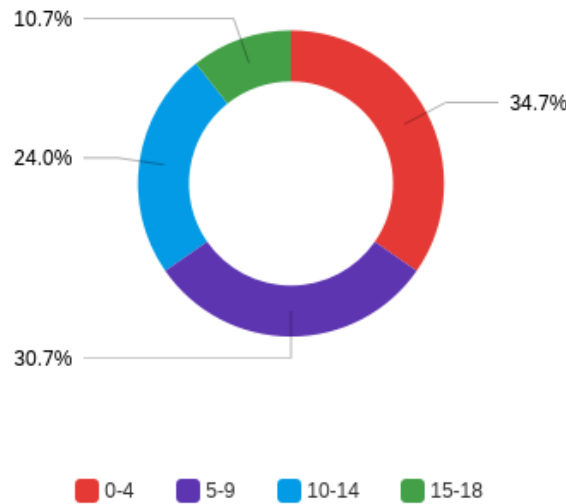
We live rurally and do not know of any services available to our daughter. We appreciate the funding provided by the At Home program, we could use respite support but are afraid to ask for more

**Results:**

**Demographics**

75 primary caregivers of children with Down syndrome completed and submitted the survey. 35% of these caregivers care for children aged 0-4, 31% care for children aged 5-9, 24% care for children aged 10-14 and 11% care for children aged 15-18.

Age of Respondents



**Figure 1.** Age of children with Down syndrome that respondents are the primary caregiver to

Caregivers were predominantly from the Lower Mainland (67% identified as being from Metro Vancouver and 23% from the Fraser Valley). The number of respondents by region is provided in Table 1. Respondents receiving services from Provincial services included 3 with Sunnyhill Healthcare Centre for Children and 3 with BC Family Hearing Resource Society. No respondents were receiving services through the Aboriginal Infant Development Centre Program.

**Table 1.** Geographical location of respondents accessing services in the four years prior to the survey response date

Region	Number of Respondents
Alberni-Clayoquot	1
Capital	6
Cariboo	2



Central Kootenay	6
Central Okanagan	8
Comox Valley	1
East Kootenay	1
Fraser Valley	13
Fraser-Fort George	4
Metro Vancouver	50
Nanaimo	2
Okanagan-Similkameen	2
Thompson Nicola	3
<b><i>Provincial Services</i></b>	
BC Family Hearing Resource Society	3
Sunnyhill Healthcare Centre for Children	3

55% of respondents reported having a child with no additional diagnoses in addition to Down syndrome, while 15% have a child with an additional diagnosis of Autism, and 13% identify as having a child with complex medical needs. All respondents with a child diagnosed with Autism receive Autism funding. Two of 11 children with hearing loss receive support through BC Family Hearing Resource Society or Deaf Children’s Society of BC. This equates to 100% of eligible respondents as 2/11 respondents were 0-4, and these societies only cover children until they are school aged.

49 respondents are aged five years or older. Of these respondents 49% received At-Home school-aged extended therapy funding and 51% do not.

***Accessing Services and Supports: Therapies***

Respondents asked about the breakdown of public and private services they received, according to age group. Of 49 possible respondents in the 0-4 age group (in the four years prior to the survey date), 48 accessed public speech therapy and 23 accessed private speech therapy; 47 accessed public occupational therapy and 9 accessed private occupational therapy; 47 accessed public physiotherapy and 21 accessed private physiotherapy.

In the 5-18 year age group, respondents children predominantly access speech therapy (public (n=18), private (n=26)) and occupational therapy (public (n=19), private (n=16)).

**Table 2.** Public and private therapies received by children aged 0-4.

Type of Service	Frequency of Service (Number of sessions/year)							Total
	Screening only	1-6	7-12	13-18	19-24	25-52	>52	
<b>PUBLIC</b>								
Speech Therapy	6	22	10	4	4	1	1	<b>48</b>
Occupational Therapy	4	24	11	2	4	1	1	<b>47</b>
Physiotherapy	0	21	14	6	3	2	1	<b>47</b>
<b>PRIVATE</b>								
Speech Therapy	0	4	3	3	8	5	0	<b>23</b>
Occupational Therapy	1	2	1	2	1	1	1	<b>9</b>
Physiotherapy	1	5	0	8	5	2	0	<b>21</b>

**Table 3.** Public and private therapies received by children aged 5-18.

Type of Service	Frequency of Service (Number of sessions/year)							Total
	Screening only	1-6	7-12	13-18	19-24	25-52	>52	
<b>PUBLIC</b>								
Speech Therapy	2	3	3	2	3	4	1	<b>18</b>
Occupational Therapy	3	4	4	3	3	1	1	<b>19</b>
Physiotherapy	0	2	0	1	1	2	1	<b>7</b>
<b>PRIVATE</b>								
Speech Therapy	0	1	1	3	5	16	0	<b>26</b>
Occupational Therapy	0	1	1	1	5	7	1	<b>16</b>
Physiotherapy	0	1	1	1	4	4	0	<b>11</b>



Of the 24 respondents that received At Home program support, 23 responded to the question pertaining to top-up fees for therapy sessions. 70% of respondents were required to pay a top-up fee to supplement At Home Program School Aged Extended therapy funding to cover the cost of private therapy with their chosen provider. Of these respondents, half reported that having to pay a top-up fee limited the amount of therapy they are able to access for their child. Top up fees for therapy sessions ranged from less than \$20/session (n=6), \$20-\$40/session (n=6), and greater than \$60/session (n=4).

Respondents that were not required to pay a top-up fee for therapy sessions answered a question related to hypothetically being required to pay such a fee. Two reported that if they were required to pay a top-up fee they would still access the same services, two reported they would be forced to cut services by up to 50%, one reported they would be forced to reduce services by 50-75% and two reported they would be forced to withdraw from services entirely.

When asked if they had ever had to wait more than three months to receive a public service, wait times of this time frame were reported for speech therapy by 37% of participants, occupational therapy by 37% of participants, and physiotherapy by 9% of respondents. 27 respondents had never waited more than three months for a public service, while 11 could not recall.

Respondents reported, *“I’ve been in tears trying to get support for my child”; “We did not receive public funded therapies until almost aging out of early intervention due to lack of therapists and wait lists”; “There has been a huge lack of services because of people leaving their position, a new hire that went on mat leave. These services were provided by Island Health but the service provider lives far away and covers a big part of Vancouver Island. There simply isn’t enough services or time to see our children on the West Coast”; “our OT left and has not been replaced for almost a year”, “We have never received any therapy or help for [child’s name redacted] without paying out of our pocket and being grateful to be able to do that. He has been on waitlists for YEARS”.*

In the past four years 13 respondents reported having to travel more than 30 minutes to access publicly funded speech therapy, 15 had to travel more than 30 minutes to access publicly funded occupational therapy and 9 had to travel more than 30 minutes to access publicly funded physiotherapy. 48 respondents have never had to travel more than 30 minutes to access publicly funded therapy. Respondents described these experiences: *“All our services are out of Port Alberni and during the pandemic these service providers have not travelled to the West Coast. The drive to Port Alberni is one hour and 45 minutes on a good day. With two kids it is really hard so my child with Down syndrome has barely received any of these services”; “I live in a rural area and have to travel 45 minutes for most public services”.*

Participants were asked whether they felt they had access to all the service their child needed entirely through public services or individual funding (Child development centre or equivalent, At Home Program funding, Autism funding or other public funding source). With respect to speech therapy, 76% do not feel that public services or individual funding entirely covers their child's



needs, 67% do not feel that public services or individual funding does not cover their child's occupational therapy needs and 67% do not feel that public services and individual funding do not cover their child's physiotherapy needs.

The most commonly reported barrier to accessing public services was available support is too infrequent (n=44), followed by finding support providers with appropriate skills and training (n=38), waitlists for supports are too long (n=37), hours of operation of therapy centre/support service don't work for our family (n=26), and commute distance (n=12). One respondent reported that finding a provider who speaks our family's language was a barrier to accessing support. Figure 2 shows all responses to this question.

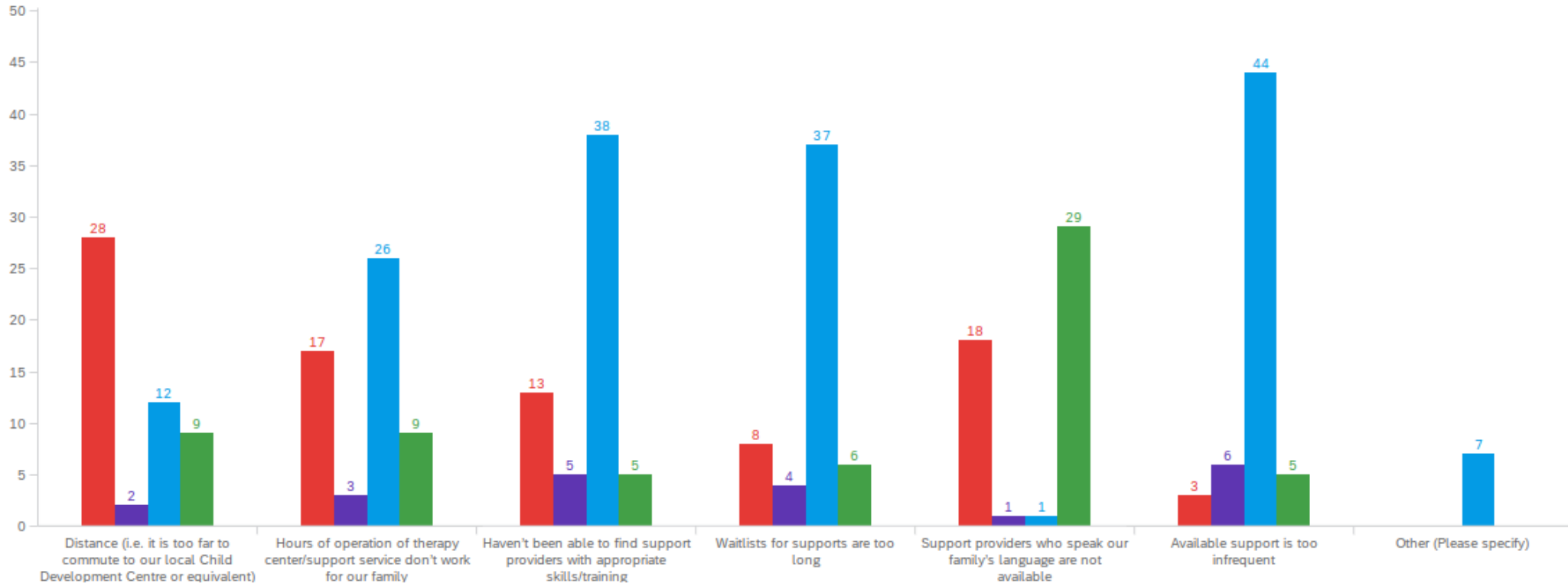
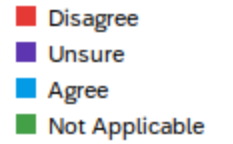
The most commonly reported barrier in accessing private services is cost (supports are too expensive and sufficient funding is not available, n=52), this was followed by not being able to find support providers with appropriate skills or training (n=29), waitlists for private supports are too long (n=23), hours of operation not working for our family (n=20) and distance (too far to commute to private services, n=20). Figure 3 shows all responses to this question.

Respondents were asked to describe the most significant barrier they've encountered in attempting to access public support for their child. Responses described issues accessing support, *"They are not available"*; *"Caseload of the therapists is too many, they will consult but not provide any program that can be applied"*, *"There are not OT's available, like none!!!"*, *"Waitlists"*. *"Support is too infrequent to make a meaningful difference and many of the few sessions we do receive are spent completing assessments rather than therapy"*. Issues with therapists skills and experience was reported, *"The last time our CDC worked with someone with Down Syndrome before us was 15 years"*, *"Unqualified personnel"*.

Caregivers that are or were accessing private therapy when their child was 0-5 years old, reported 'More frequent services' as the most common reason for accessing these supports (83%). This was followed by "superior training of staff in working with children with Down syndrome (73%), better quality of services (68%), no/minimal waitlist (58%) and no public services in my area (23%).

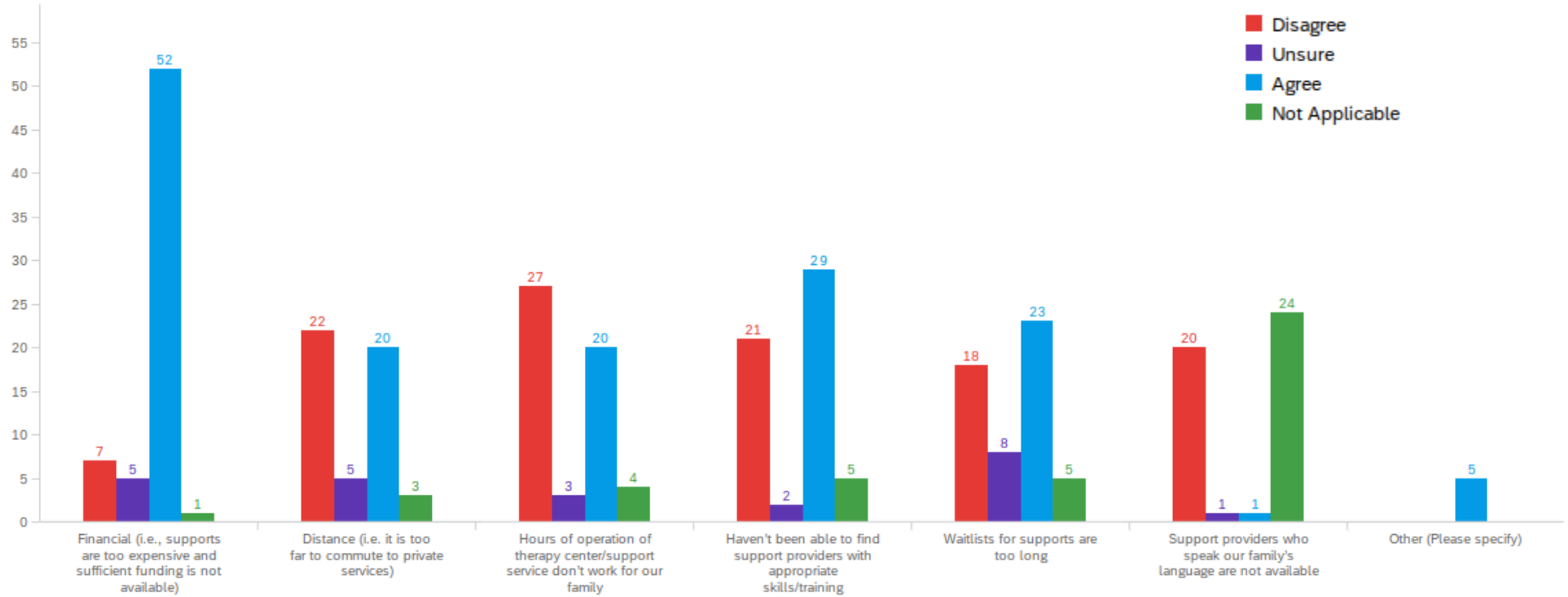
When asked whether they would be interested in Applied Behavioral Analysis (ABA) support, 40% indicated they were interested, 24% were not interested, 28% were unsure and 8% already had a child receiving ABA support.

79% of respondents reported having to reduce their working hours in order to help their child access support and services.



**Figure 2.** Reported barriers to accessing public services





**Figure 3.** Reported barriers to accessing private services

**Accessing Services and Supports: Childcare and Preschool**

When asked about enrolling in daycare, 75% of those who attempted to enroll were successful, whereas 54% of those who attempted to enroll in before and after school care were successful. Full results of this question are found in Table 4.

**Table 4.** Enrollment in Childcare and Preschool

	Successfully Enrolled	Attempted to Enroll
Daycare	21	7
Preschool	25	6
Before and after school care	14	12

41% of those attempting to enroll in childcare have been denied enrollment [n=23 of 56]. A rationale of Down Syndrome or excess physical or developmental delay was the response given in 12 cases. 15 respondents were told there was no funding for a support worker. Other reasons for denying enrollment included feeding related needs (including tube feeding), and only funding a support worker in a childcare environment that the family deemed inappropriate (not allowing a support worker at the childcare centre of the family's choosing).

When a support worker was provided for preschool, it was provided

**Table 5.** Reported experiences in accessing support workers

	All Hours Requested per week	Part of Hours Requested per week	None of the hours requested
Every year requested	15	8	1
Not every year requested	2	3	

11 respondents reported 'Other' as their response

When public funding was provided through a public agency 20 respondents reported a support worker was hired prior to their child starting preschool or childcare for all enrollment periods in which funding was provided, 3 respondents reported a support person was hired after the child started the childcare or preschool program in at least one enrollment period, and 4 respondents reported that a support person was never hired in at least one enrollment period in which funding was provided. No respondents reported not proceeding with childcare or preschool because the hours requested were not fully granted.

When public funding for a support person was not provided or not provided for all of the hours requested this resulted in the child not attending or leaving the program in 60% of cases [n=19].

When public funding was provided, but a support person was never hired this resulted in the child not attending the childcare or preschool program in 1 out of 4 cases in which this occurred.

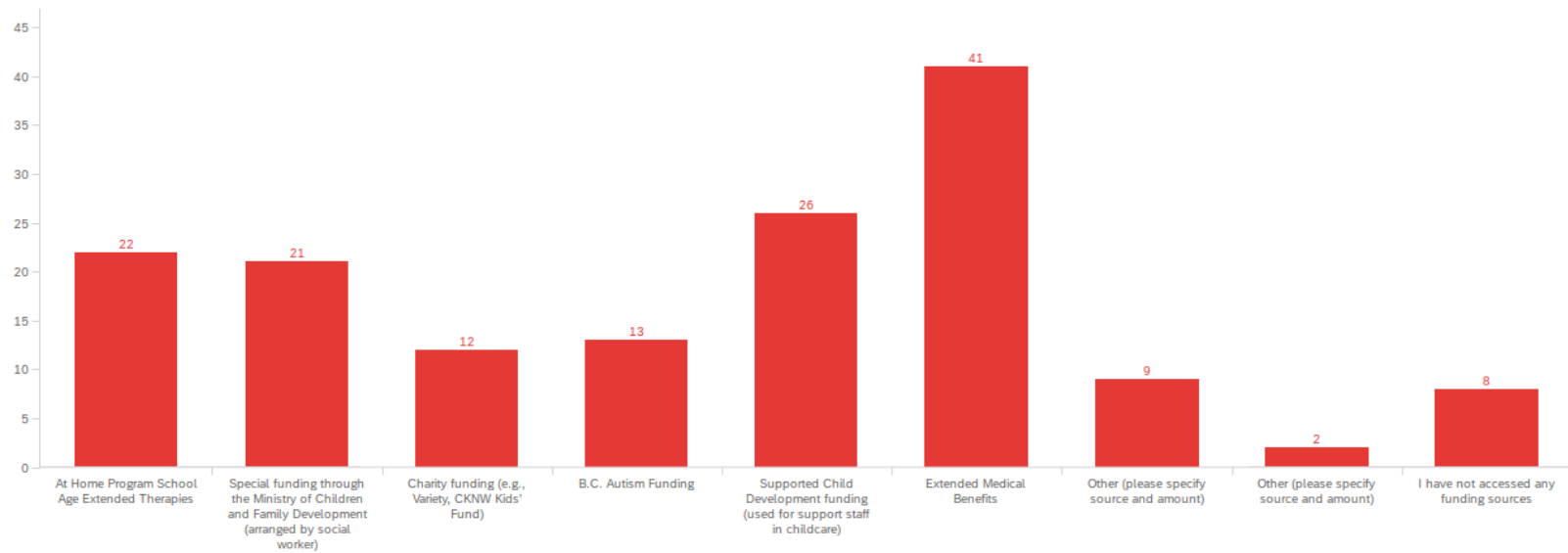
40% of respondents attempting to access childcare or preschool programs encountered other barriers to enrollment. In free form responses, caregivers report these barriers to include, “Waitlists”, “There are NO childcare options after age 12 and he needs supervision. So I had to quit my job.”, “They ignored her”, “We were on a waitlist since age three until she aged out”. “Having to piece together childcare is stressful, segregative, and IS NOT family centered”.

21 caregivers did not attempt to access childcare or preschool programs. 43% did not want or need the service, 19% did not apply because they did not believe their child would be accepted, 14% did not apply because the childcare or preschool type they desired does not exist in their community, and 24% did not apply for other reasons. These reasons included, “COVID - I wanted my child to live and not suffer”, “No available service workers to assist him”, “I wasn’t confident my child would be safe in daycare”, “Medically compromised infant and do not unnecessarily expose her to viruses/illnesses. Every child with Ds whom I know who attended daycare/preschool fell ill with RSV, Covid and/or other viruses”.

29 respondents (39%) reported needing to reduce their work hours or quit their job (personally, or another family member) because of lack of support for their child to attend daycare or preschool in the past four years.

### **Funding for Support and Services**

Caregivers use a variety of funding sources to access supports and services, as shown in Figure 4. Dollar values for these sources are shown in Table 6. Those reporting ‘Other’ as a source of funding, most commonly reported DSRF bursaries as the source of funding.



**Figure 4.** Sources of funding accessed to help pay for support and services



**Table 6.** Monetary value provided by funding sources

Funding Source	Range
At Home Program	\$3,800 - \$10,000
Special Funding through MCFD	\$260 - \$3,072
Charity Funding	\$120 - \$2,000
Autism Funding	\$6,000 - \$20,000
Extended Medical Benefits	\$500 - \$4,000

61 of 75 respondents have used personal funds, or personal funds from family members/friends to pay for support. 33% have used <\$1,000, 49% have used \$1,000 - \$5,000, 11% have used \$5,000 - \$10,000 and 7% have used >\$10,000 of personal funds.

Services paid for in full using familial funding (out-of-pocket, gift/loan, private insurance) or alternative sources of funding were physiotherapy [n=17], occupational therapy [n=13], speech therapy [n=25], support worker for preschool/daycare/before/after school care [n=16], equine therapy [n=2], specialized reading program [n=8], specialized math program [n=3], and others. Services topped up with familial funding (out-of-pocket, gift/loan from family, private insurance) or alternative sources of funding included physiotherapy [n=19], occupational therapy [n=21], speech therapy [n=23], support worker [n=13], and other [n=5].

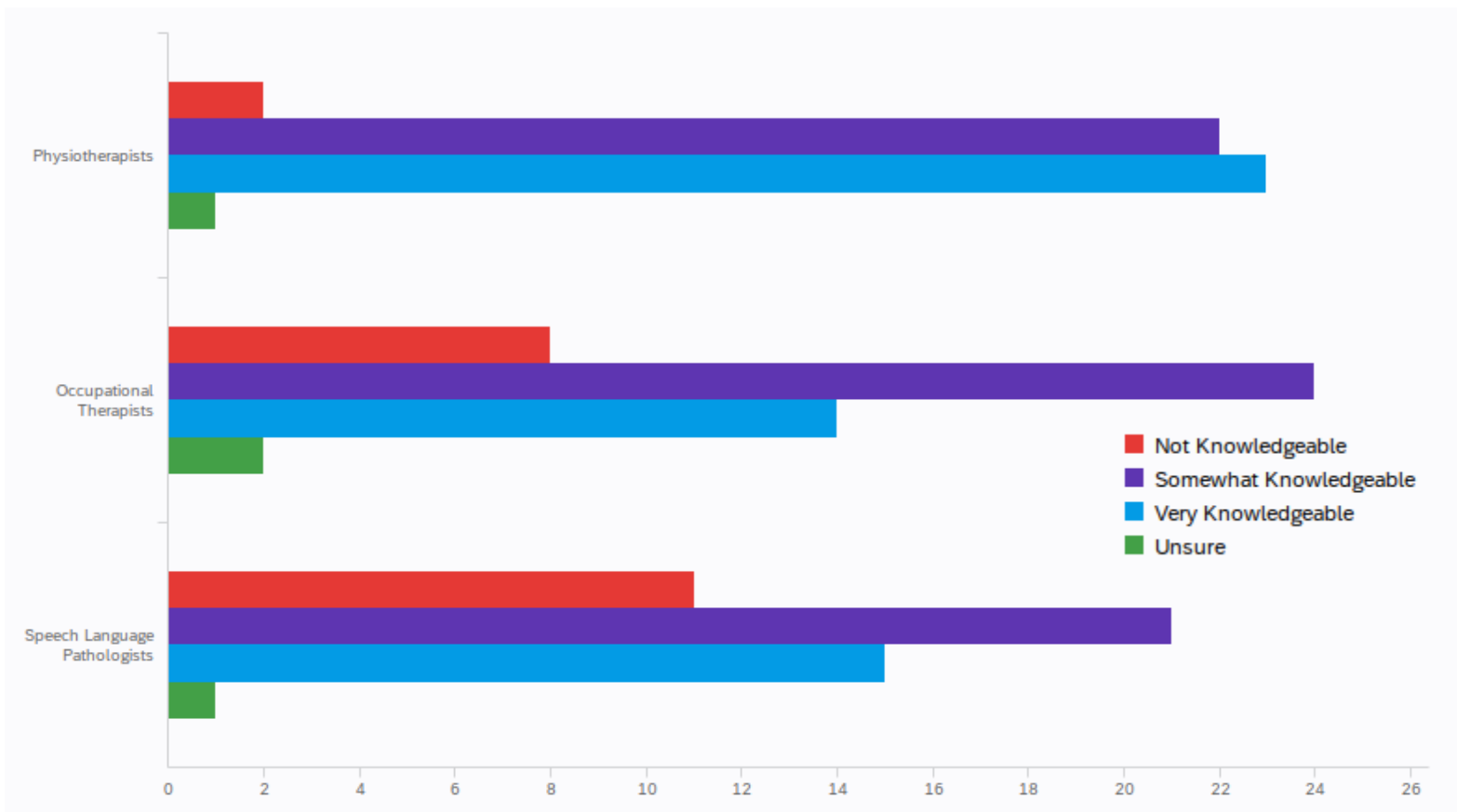
If more government funding became available 84% of caregivers would immediately pursue additional services for their child. 4% would not pursue additional services and 12% were unsure.

22% of caregivers or their immediate family members have had to increase their work hours or gain new or additional employment for the sole purpose of funding private therapies for their child. Caregivers reported the following, *“My husband has had to increase his work in order to make more money, since I had to go down in hours as we cannot get the support we need for our daughter. But we still need more money to fund therapies and top up on the support worker.”*, *“My husband works ALL THE TIME to fund these services.”*, and *“My husband has pursued part-time self employment in addition to his full-time job.”*

Those caregivers and family members who have not increased their work hours to fund therapy reported, *“If I worked more I’d be less available to attend therapy sessions”*, *“I can’t work more than part time because I need to bring my son to therapies and can’t access after school care”*, *“Only because additional work was not available”*, and *“We did not have to increase our hours but have had to make sacrifices in order to financially support our child’s therapy services”*.

### Quality of Support: Therapies

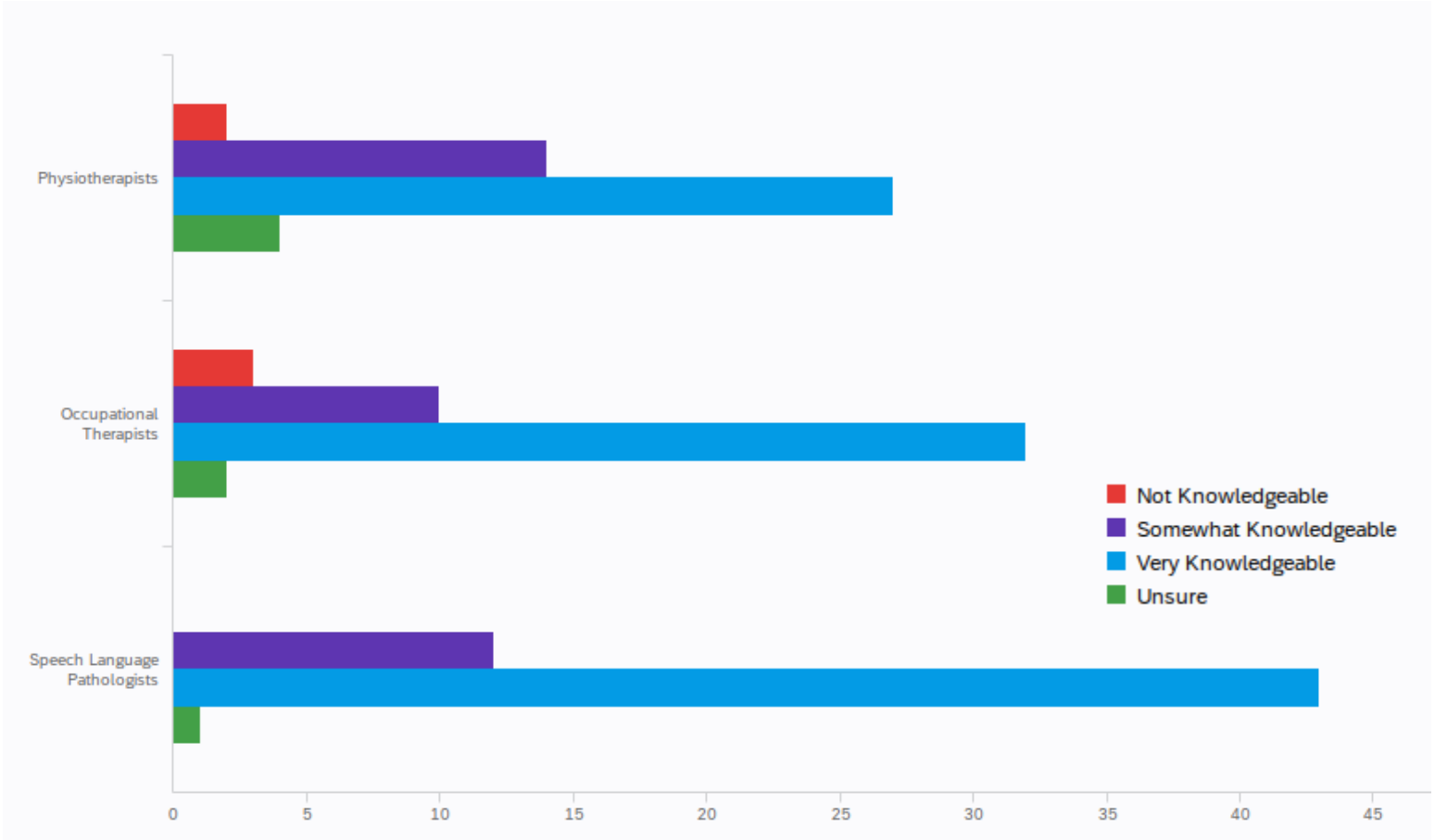
When asked about perceived training of specialized service providers (Speech Language Pathologists, Occupational Therapists etc.) and the understanding those professionals have of their child's needs, publicly funded therapists working with children aged 0-5 through a Child Development Centre or equivalent were rated as very knowledgeable by 36% of caregivers, somewhat knowledgeable by 46% of caregivers, not knowledgeable by 15% of caregivers and 3% of caregivers were unsure. A breakdown of these rankings by profession for SLP's, OT's and Physiotherapists are shown in Figure 5.



**Figure 5.** Caregivers' perception of the quality of public therapists training and understanding of their child's needs for children aged 0-5.

When the same question as in the previous question was posed to caregivers, but with respect to services accessed with Individual, Familial or Alternative funding sources, 68% felt these therapists were very knowledgeable, 23% felt they were somewhat knowledgeable, 4% felt they were not knowledgeable, and 4% were unsure. A breakdown of these rankings by profession is shown in Figure 6. Table 7 shows rankings by profession for both public and private services. 48

caregivers responded with respect to public physiotherapy, occupational therapy and speech therapy. 47, 47 and 56 caregivers responded with respect to physiotherapy, occupational therapy and speech therapy respectively, accessed with Individual, Familial or Alternative funding sources.



**Figure 6.** Caregivers' perception of the quality of therapists training and understanding of their child's needs, for therapists funded through Individual, Familial or Alternative funding sources for children aged 0-5.

**Table 7.** Caregivers’ perception of the quality of Physiotherapists, Occupational Therapists and Speech-Language Pathologists training and understanding of child’s needs by funding type for children aged 0-5

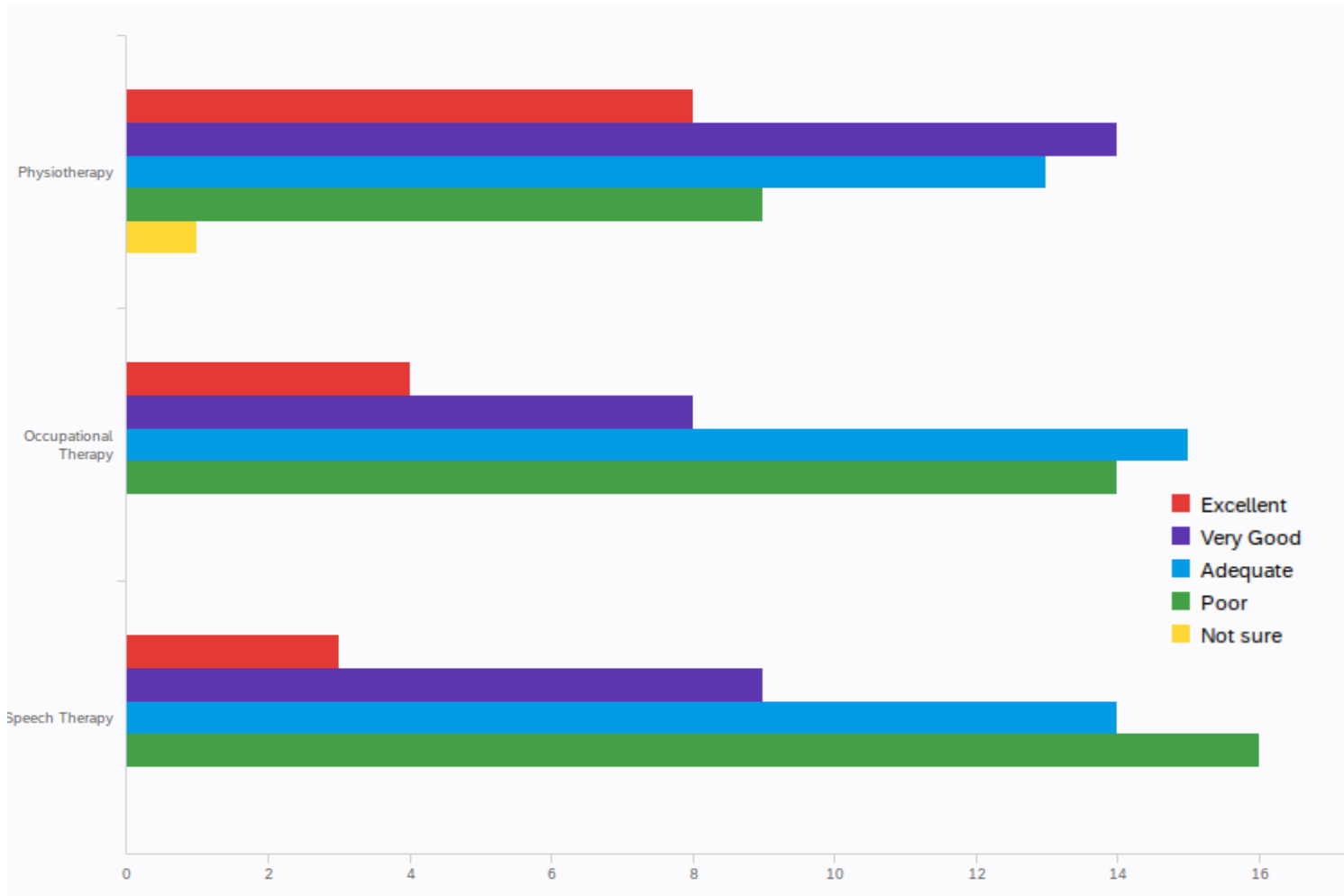
<b>Perceived quality of therapists training and understanding of child’s needs</b>	<b>Publicly funded therapist through Child Development Centre or equivalent</b>	<b>Therapist funded through Individual, Familial or Alternative funding sources</b>
<b><i>Physiotherapists</i></b>		
Very Knowledgeable	48%	57%
Somewhat Knowledgeable	46%	30%
Not Knowledgeable	4%	4%
Unsure	2%	9%
<b><i>Occupational Therapists</i></b>		
Very Knowledgeable	29%	68%
Somewhat Knowledgeable	50%	21%
Not Knowledgeable	17%	6%
Unsure	4%	4%
<b><i>Speech-language Therapists</i></b>		
Very Knowledgeable	31%	77%
Somewhat Knowledgeable	44%	21%
Not Knowledgeable	23%	0
Unsure	2%	2%

26 caregivers had a child aged 0-1 in the past four years. When their child was first born, 81% of caregivers report being connected with their Infant Development Consultant within the first 3 months, 15% report being connected when their child was 3-6 months and 4% report being connected when their child was 6-9 months of age. Half of caregivers (50%) report that their Infant Development Consultant provided a clear outline of the services available, how to access them, and how to reach out for support. 23% did not feel that their Infant Development Consultant provided this information, and 27% could not recall. Over the course of the first year, 85% report that their Infant Development Consultant kept in regular contact with them to ensure they felt well supported, while 15% reported there was no regular contact with their Infant Development Consultant to follow up on the level of support provided.

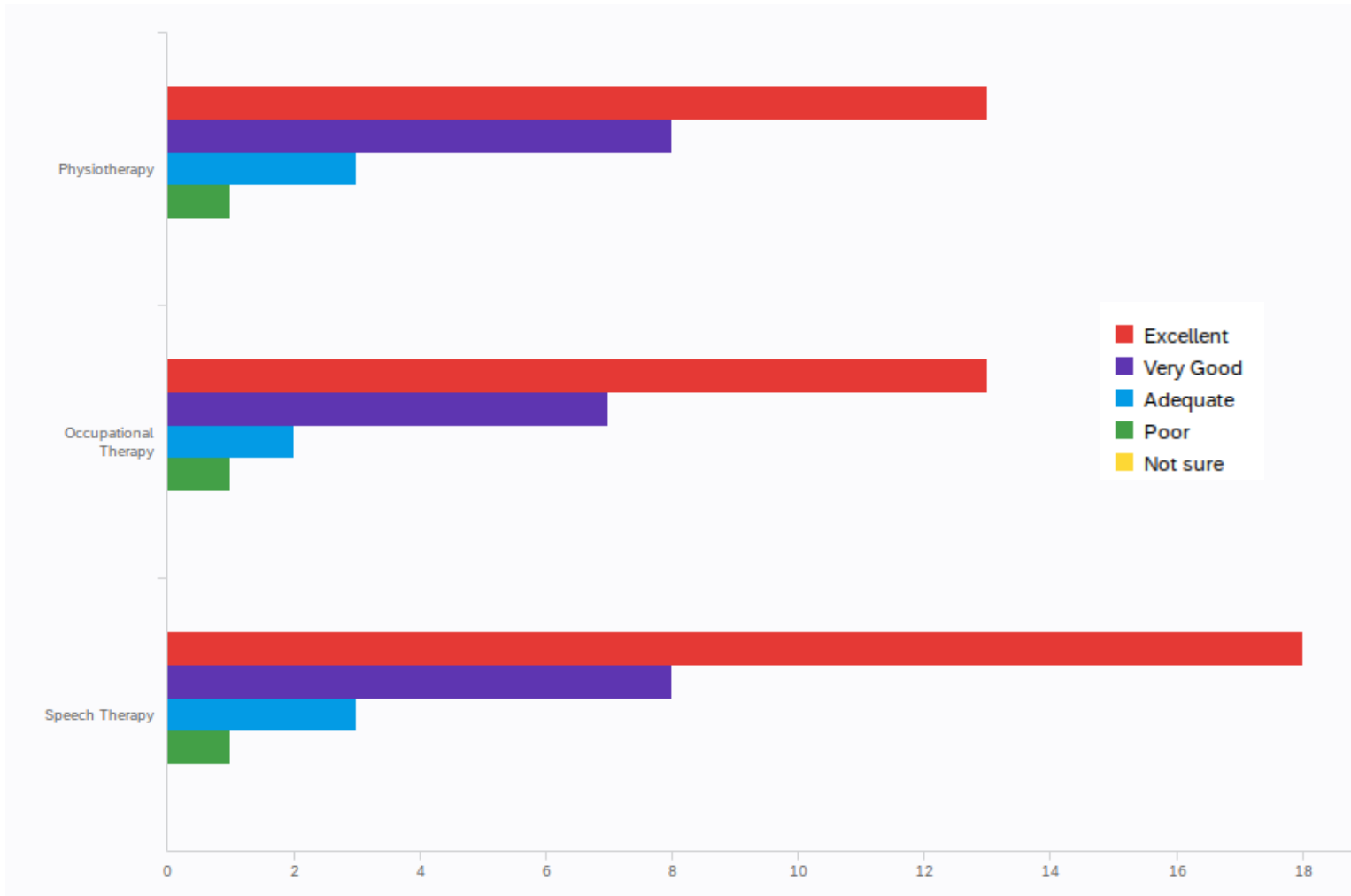


Caregivers of children aged 0-1 (in the past four years) most commonly rated the quality of public support and services available for families new to the Down syndrome community as poor (65%), followed by adequate (19%), very good (12%) and excellent (3%).

Caregivers of children aged 1-5 (in the past four years) were asked to rate the quality of public and private services. The number of caregivers accessing public services for their child ranged from 41-45 depending on the support for the three main support types; this range was 23-30 for private services. Across services, public services were rated excellent or very good by 37% of respondents whereas private services were rated excellent or very good by 86% of respondents. Public services were rated adequate or poor by 62% of respondents whereas private services were rated adequate or poor by 14% of respondents. 1% of respondents were unsure about the quality of public services. Figures 7 and 8 show these results broken down by support type for public and private services respectively. Table 8 shows ratings by support type comparing public and private services.



**Figure 7.** Caregivers' perception of the quality of public services for children aged 1-5



**Figure 8.** Caregivers' perception of the quality of private services for children aged 1-5

**Table 8.** Caregivers' perception of the quality of service by service type for children aged 1-5

<b>Rating of quality of services</b>	<b>Public Services</b>	<b>Private Services</b>
<b><i>Physiotherapists</i></b>		
Excellent	18%	52%
Very Good	31%	32%
Adequate	29%	12%
Poor	20%	4%
Unsure	2%	0
<b><i>Occupational Therapists</i></b>		
Excellent	10%	57%
Very Good	20%	30%
Adequate	36%	9%
Poor	34%	4%
Unsure	0	0
<b><i>Speech-language Therapists</i></b>		
Excellent	7%	60%
Very Good	21%	27%
Adequate	33%	10%
Poor	38%	3%
Unsure	0	0

Caregivers of school-aged children (aged 6-18) were asked about the quality of public services and support received through a Child Development Centre or equivalent (not including school board funded services or services funded with Individual funding). 16 respondents accessed physiotherapy, 17 accessed occupational therapy and 16 accessed speech therapy. Overall, 17% of the time these services were rated excellent or very good, whereas 77% of the time these services were rated as adequate or poor; 6% of respondents were not sure of the quality of services provided. A breakdown by service is shown in Table 9.

The same group of respondents were asked about the quality of private services and support received, if any. 21 respondents accessed physiotherapy, 28 accessed occupational therapy and 36 accessed speech therapy services. Overall, 67% of the time these services were rated as excellent or very good, whereas 26% of the time they were rated as adequate or poor; 6% of respondents were not sure of the quality of services provided. A breakdown by service is shown in Table 9.

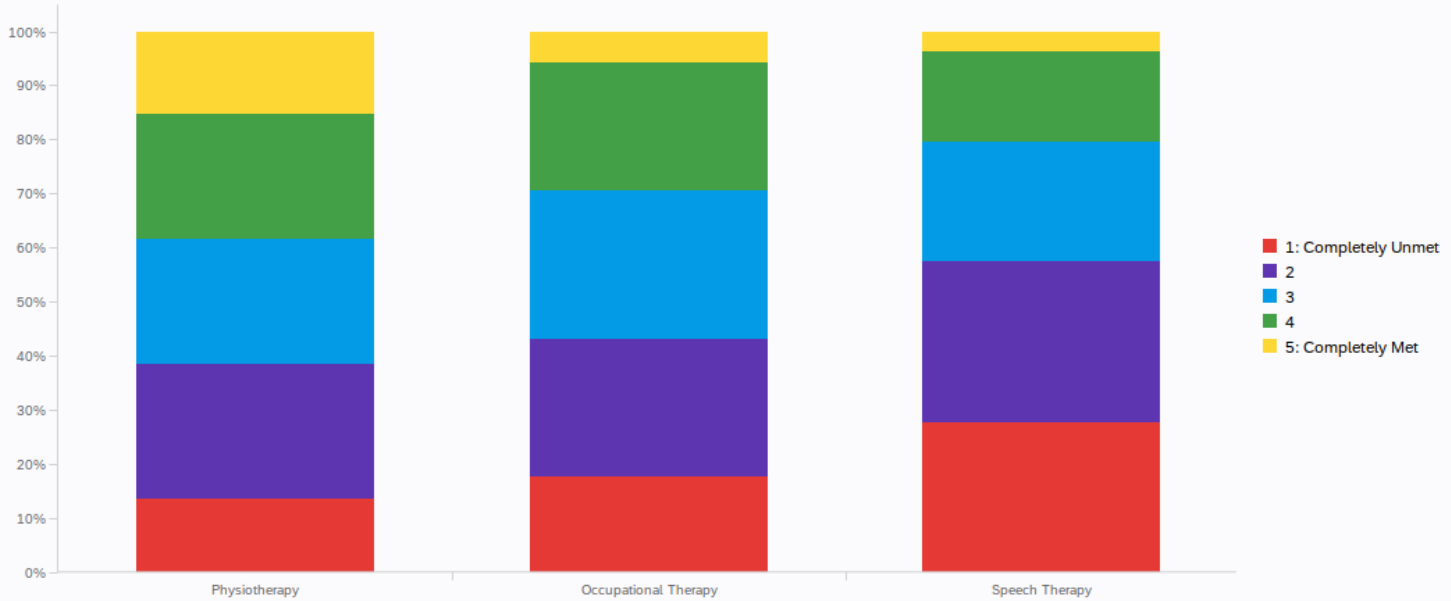
**Table 9.** Caregivers’ perception of the quality of service by service type for children aged 6-18

Rating of quality of services	Public Services	Private Services
<b><i>Physiotherapists</i></b>		
Excellent	13%	38%
Very Good	6%	10%
Adequate	0	33%
Poor	75%	5%
Unsure	6%	14%
<b><i>Occupational Therapists</i></b>		
Excellent	6%	43%
Very Good	6%	21%
Adequate	24%	25%
Poor	59%	7%
Unsure	6%	4%
<b><i>Speech-language Therapists</i></b>		
Excellent	6%	58%
Very Good	6%	19%
Adequate	25%	19%
Poor	63%	0
Unsure	0	3%

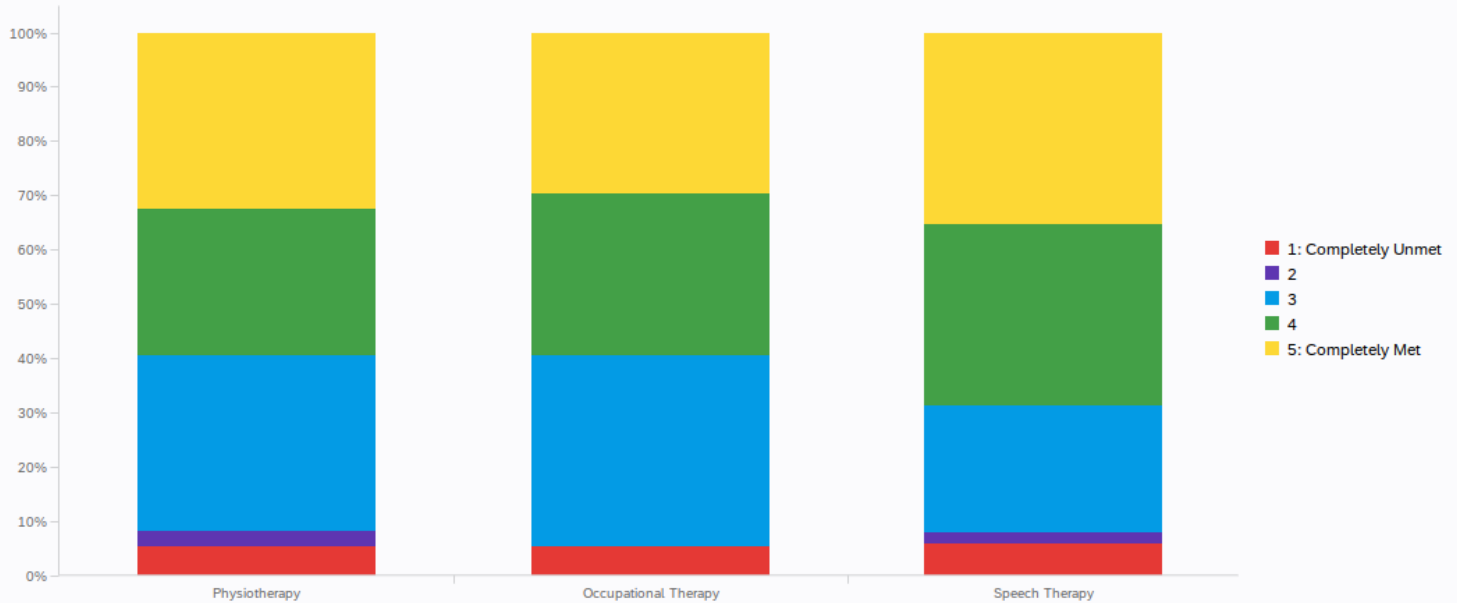
Respondents with children across all age groups were asked if they felt the public therapy their child received from their Child Development Centre, or equivalent, was meeting their child's needs. The same question was posed to these respondents with respect to private therapy

services. Responses were rated on a scale of one to five, where one indicated their child's needs were completely unmet and five indicated their child's needs were completely met. 52, 51 and 54 responses were received with respect to public physiotherapy, occupational therapy and speech therapy respectively; 37, 37 and 51 responses were received with respect to private physiotherapy, occupational therapy and speech therapy respectively. Results are shown in Figure 9.

### Public Therapy



### Private Therapy



**Figure 9.** Caregivers' responses to their perceptions of public and private therapy services ability to meet their child's needs.

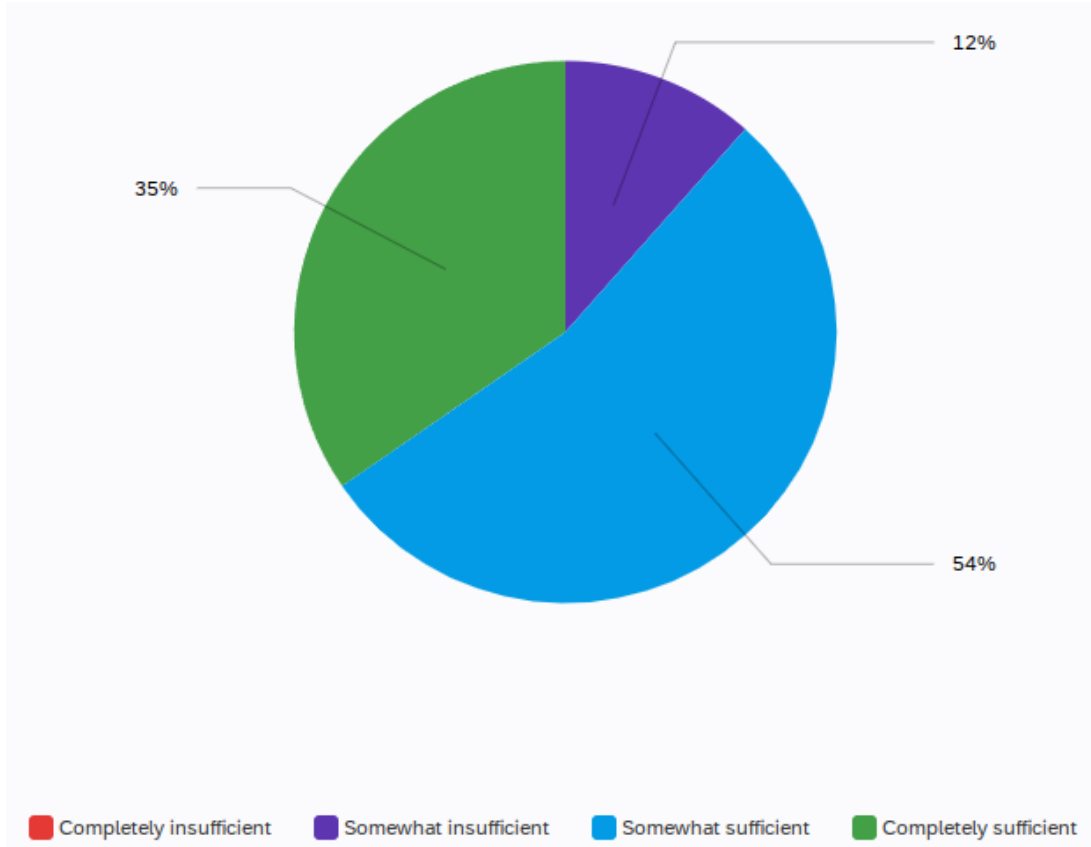
**Quality of Support: Childcare and Preschool**

Participants were asked whether they perceived their children’s physical, emotional, social and intellectual needs were met in their preschool or childcare program. If a child had attended multiple preschool and or childcare programs the participant could reflect on up to four of these programs. Results from these questions are found in Table 10.

**Table 10.** Caregivers’ perception of whether preschool and/or childcare program met child’s needs. 1 = Completely unmet, 5 = Completely met.

Rating Scale	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)
<b>Physical needs</b> feeding, toileting, movement, physical safety	2	8	18	23	49
<b>Emotional needs</b> child was cared for, appreciated, loved	1	6	21	22	49
<b>Social needs</b> child’s support worker interacted with them in a positive manner, their peers were encouraged and taught to interact with them	0	10	18	22	49
<b>Intellectual needs</b> child was intellectually stimulated, educational activities modified appropriately so child could participate, questions answered thoughtfully	0	14	27	20	39

Caregivers were asked whether they felt their child's support worker in preschool and/or childcare had sufficient training. Caregivers were able to submit a response for each childcare and/or preschool program that their child attended. Results of this question are shown in Figure 10.



**Figure 10.** Caregivers perception of level of training of child’s support worker in preschool and/or childcare.

Respondents that whose child was not provided with a support worker full time or for all of the hours requested, or the support worker was not hired by the time their child started in the childcare program, 2 reported feeling very unsafe leaving their child in the childcare setting, 4 reported feeling somewhat unsafe, 3 reported feeling somewhat safe and 4 reported feeling very safe.

Two thirds of respondents perceive their child’s preschool or childcare program to be very inclusive and approximately one third perceive the program(s) to be somewhat inclusive. 4% of respondents felt their child’s preschool or childcare program was not at all inclusive. Participants were able to submit a response to this question for each preschool and/or childcare program their child attended.

### **Telehealth**

60% of those surveyed have accessed online (i.e. telehealth, web-based) support services in the past four years to support their child. 20% of respondents did not access these supports because they were not interested in online service for their child, and 20% did not access these supports because they were not offered. Of those respondents that were not accessing support because it was not offered, 33% would try it if it were available, and 67% were unsure whether





they would try it; none of the participants not offered online support responded as not interested if it were offered.

Of those respondents that were or are accessing online support services for their child, 17 are accessing physiotherapy, 20 are accessing occupational therapy, 38 are accessing speech therapy, and 13 are accessing at least one other type of service. Other virtual services respondents were accessing include one-on-one reading, behavioural therapy, math and numeracy programs, mental wellness, sign language lessons and sexual health.

Participants were asked the reasons why they access online support services. Multiple answers were permitted for this question. The primary reason for accessing online support services was due to COVID-19 (54%), followed by out of necessity due to geographical location (21%), out of necessity to connect with the most knowledgeable support person for my child (17%), and it is my preferred service format (4%). Other reasons provided in free form responses included 'time management and transportation costs' and 'extra information and strategies'.

When asked about the quality of online support services as compared to in person support services, physiotherapy and occupational therapy were most commonly reported as inferior to in person (71% and 60% respectively), whereas speech therapy was most commonly reported as having some aspects superior and some aspects inferior to in person (47%). A full breakdown of responses is provided in Table 11.

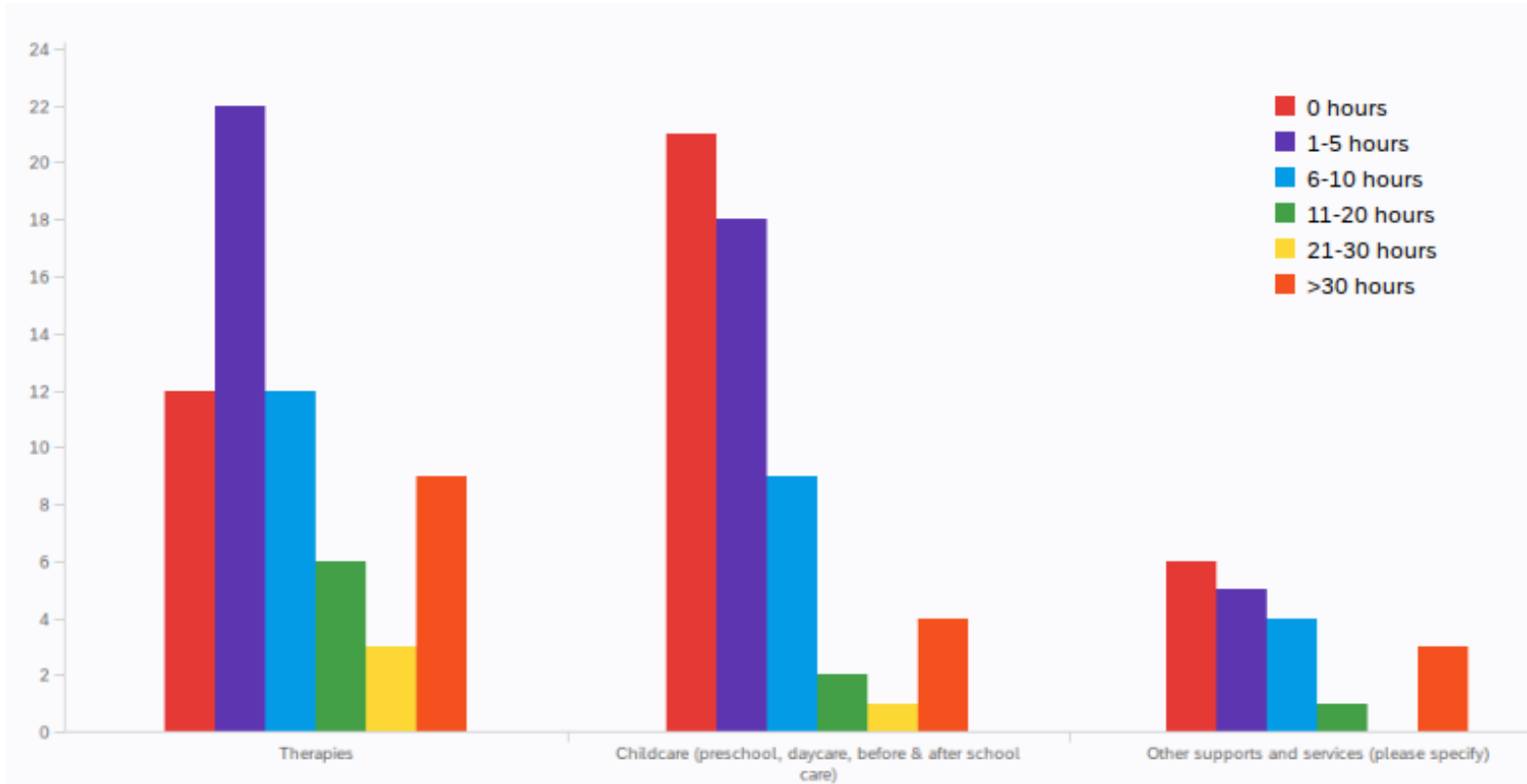
**Table 11.** Perceived quality of online support services as compared to in person.

<b>Rating</b>	<b>Inferior to in person</b>	<b>Equivalent to in person</b>	<b>Superior to in person</b>	<b>Some aspects superior, some aspects inferior</b>
<b>Physiotherapy</b>	71%	5%	5%	19%
<b>Occupational Therapy</b>	60%	4%	0	36%
<b>Speech Therapy</b>	37%	16%	0	47%
<b>Other</b>	30%	0	0	70%

**Advocacy**

Participants were asked to estimate the number of hours they spent in the last year advocating for public services or individualized funding that they believe should be provided directly to their child. Participants were instructed that this type of advocacy might include meetings, calls, letters, emails or other methods of voicing their concerns. It might include communication to the

entity where public funds will be used, or to their MLA or other government official. This type of advocacy was defined as being specific to their child’s experience or needs and not a larger group of individuals with Down syndrome or other disability. 30 respondents spent more than six hours advocating more therapies, 16 respondents spent more than six hours advocating for childcare and 8 respondents spent more than six hours advocating for other services. Results are shown in Figure 11. When asked about the same type of advocacy prior to COVID, 22 respondents spent more than 6 hours advocating for therapies, 21 respondents spent more than six hours advocating for childcare, and 4 respondents spent more than six hour advocating for other services.



**Figure 11.** Hours spent advocating for public services or individual funding in the past year.

41 respondents spent time advocating for increased service hours (28%), 52 respondents spent time advocating for increased funding for services (36%), 32 respondents spent time advocating for higher quality services (22%), and 10% spent time advocating for other reasons. 4% of respondents have not wanted to or needed to advocate in the past four years.

Participants were asked on a scale of 1-5 how successful they felt their advocacy efforts were, with 1 being not at all successful and 5 being very successful. This question was posed to participants with respect to advocacy both prior to the pandemic and in the past year. Results are shown in Table 12.

**Table 12.** Perceived success of advocacy efforts in the past year and prior to COVID.

Rating	In the past year	In the two years prior to COVID
<b>Therapies</b>		
1 - not at all successful	25%	25%
2 - mostly unsuccessful	25%	7%
3 - neither successful or unsuccessful	25%	43%
4 - mostly successful	19%	14%
5 - very successful	6%	11%
<b>Childcare</b>		
1 - not at all successful	21%	23%
2 - mostly unsuccessful	28%	18%
3 - neither successful or unsuccessful	10%	23%
4 - mostly successful	24%	27%
5 - very successful	17%	9%
<b>Other</b>		
1 - not at all successful	29%	100%
2 - mostly unsuccessful	43%	0
3 - neither successful or unsuccessful	14%	0
4 - mostly successful	14%	0
5 - very successful	0	0

Participants were asked what supports they have not received despite their advocacy efforts. Responses included; “Lack of funding for a support worker”, “Lack of training specific to Down syndrome”, “We have been without a physiotherapist for the last couple of years”, “Full Supported Child Development hours”, “SLP, OT, PT, ABA...”, “Access to supports who are trained in ASL”.