

DFI member organisation survey of families experience of children services within Community Healthcare West

Response from 195 families across Galway , Mayo and Roscommon gathered between end

December 2022 - Mid February 2023

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Survey responses from families living across Galway, Mayo and Roscommon:

% By CDNT region:

CDNT 1 - North Mayo 16 %

CDNT 2 - South Mayo 20 %

CDNT 3 - West Mayo 11 %

CDNT 4 - West Galway 12 %

CDNT 5 - Galway City West 12 %

CDNT 6 - Central Galway and Galway City East 14 %

CDNT 7 - North Galway 17 %

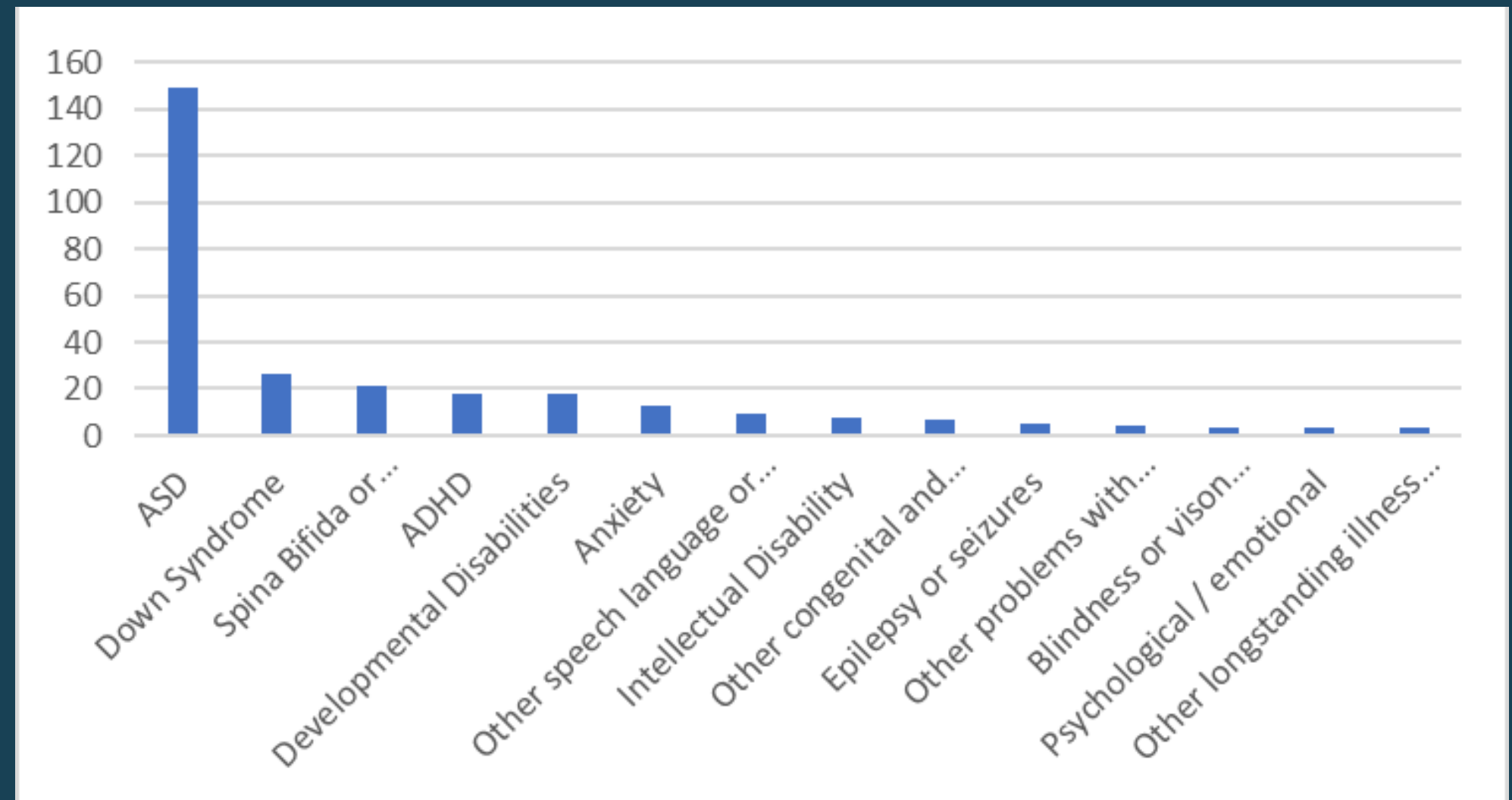
CDNT 8 - East Galway and South Roscommon 6 %

CDNT 9 - North Roscommon and North East Galway 11 %



Profile of disabilities:

- Autism Spectrum Disorder, ASD 149 / 76.4%
- Down syndrome 26 / 13.3%
- Spina Bifida or hydrocephalus 21 / 10.8%
- ADHD 18 / 9.2%
- Developmental Disabilities 18 / 9.2%
- Anxiety 13 / 6.7%
- Other speech language or hearing problems 9 / 4.6%
- Intellectual Disability 8 / 4.1%
- Other congenital and genetic disorders 7 / 3.6%
- Epilepsy or seizures 5 / 2.6%
- Other problems with tonsils or adenoids 4 / 2.1%
- Blindness or vision impairment 3 / 1.5%
- Psychological / emotional 3 / 1.5%
- Other longstanding illness or condition 3 / 1.5%
- Cerebral Palsy 2 / 1%
- Depression 2 / 1%
- Eczema or skin allergy 2 / 1%
- Kidney problems 2 / 1%
- Other eye problems 2 / 1%
- Severe behavioural problems 2 / 1%
- Deafness or a serious hearing impairment 1 / 0.5%
- Food and digestive allergy 1 / 0.5%
- Heart abnormalities 1 / 0.5%
- Hyperactivity or problems with attention 1 / 0.5%
- Oppositional Defiant Disorder, ODD 1 / 0.5%
- Problems using hands or fingers 1 / 0.5%

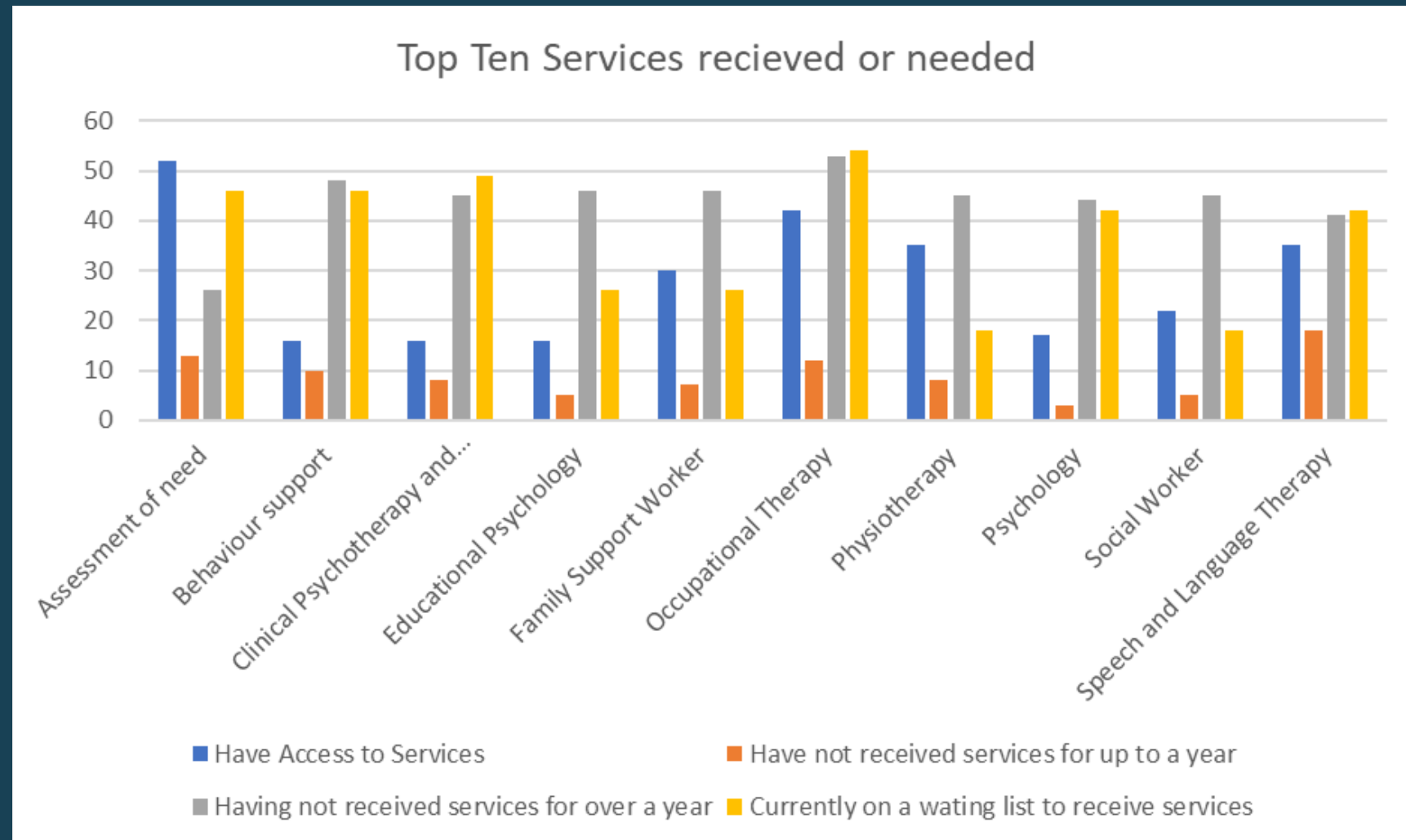


Prevalence of other conditions named in addition to those surveyed:

- Dyspraxia/DCD = 31 / 15%
- Learning Difficulties = 4 / 2.1%
- PDA = 4 / 2.1%
- Dyslexia = 7 / 3.6%



Service Deficit and delayed intervention:



Respondents who have not received services for 1 year +

Therapy

Occupational Therapy	53/27.2%
Behaviour Support	48/24.6%
Educational Psychology	46/23.6%
Family Support Worker	46/23.6%
Clinical Psychotherapy and psychological services	45/23.1%
Physiotherapy	45/23.1%
Social Worker	45/23.1%
Psychology	44/22.6%
Nutritionist	42/21.5%
Speech and Language Therapy	41/21%
Respite	34/17.4%

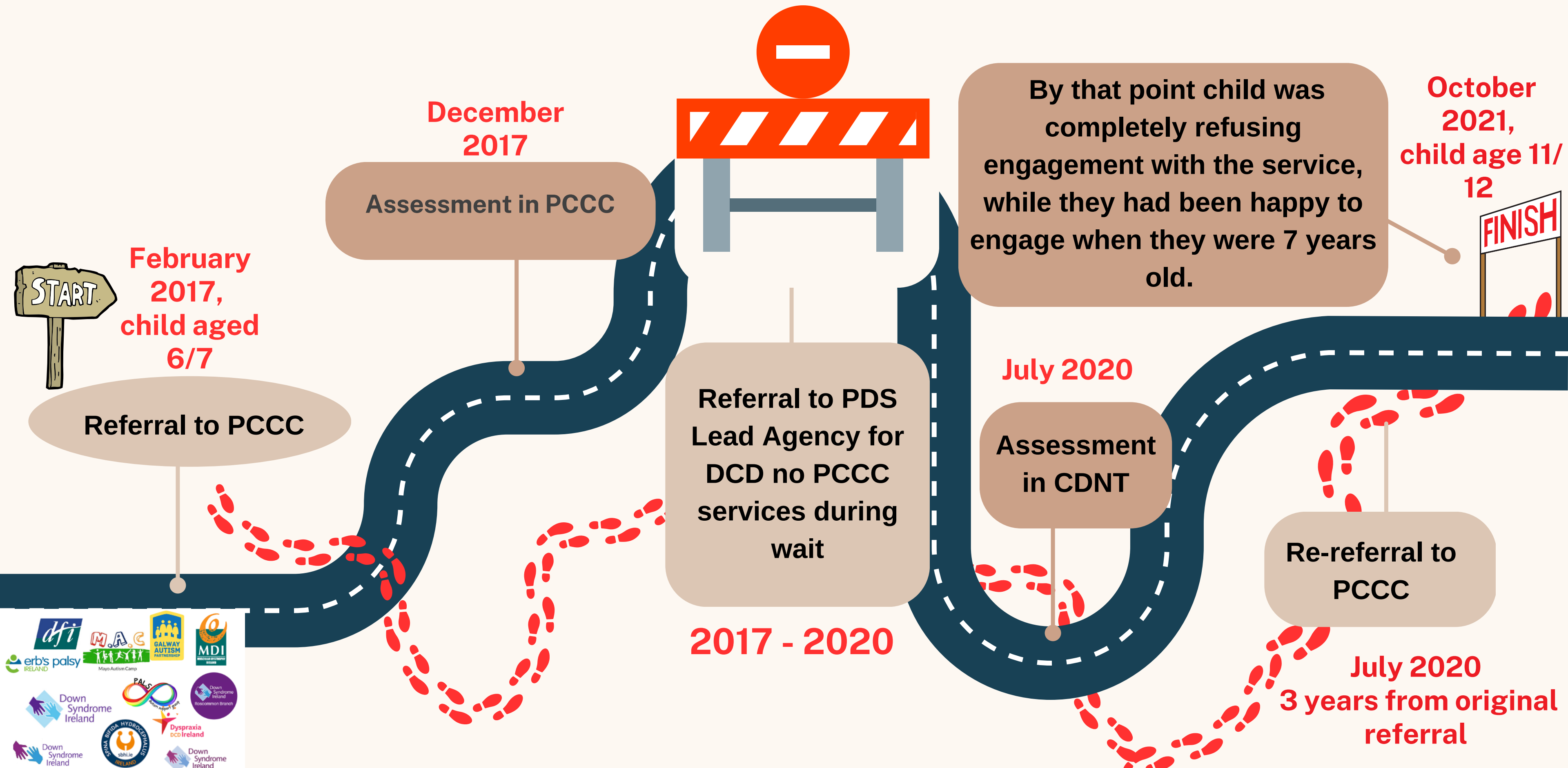
Number / % of respondents

Ophthalmology Service	33/16.9%
Counselling	32/16.4%
Psychiatry	30/15.4%
Consultant orthopedics	30/15.4%
Consultant neurologist	29/14.9%
Audiology Service	28/14.4%
Medication support	27/13.8%
Assessment of Need	26/13.3%
Consultant urology	21/10.8%
Surgery	21/10.8%

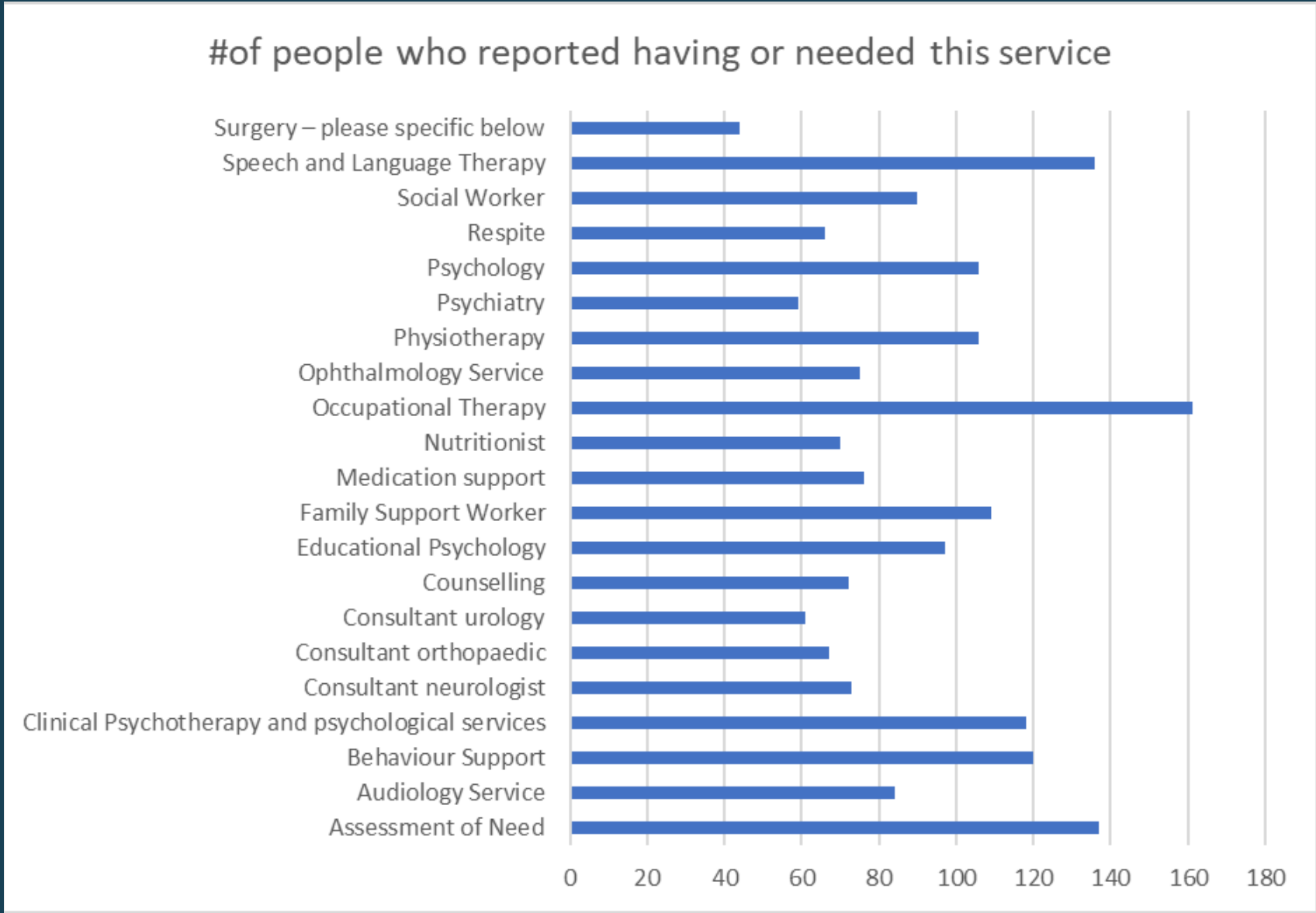
- " My son was referred to primary care OT October 2020 we still haven't been seen . We were told last week we have another 2 years to wait to be seen.... a referral to Camhs in November 2021 not even an acknowledgement of the referral"
- "Son 5.5 yrs, pre verbal, ASD diagnosed at 3yrs, has never seen anyone in public system. Have paid for private SLT twice a month"
- "We go to Dublin for cardiology. My son was moved onto a waiting list for physio 4 years ago (move from EI to school age) although I raised this as the CDNT family support meeting"
- "My daughter is 7 non verbal we are now currently waiting to see our 4th speech and language therapist in 4 years"



One family's 5 year journey referral for OT services:



Evidence of Need:



"We're waiting 3 years for OT through CDNT and have to seek private consultation."

"Our child is non verbal and in 2021 received 4 appointments with speech and language and in 2022 received 0 appointments with speech and language. Now in 2023 we have been appointed a new SLT who is now heavily burdened with work."

"Our OT has stopped now after 3 visits no review date set back on"

" I worry that this lack of services will mean he will end up with even more challenges, mental health etc. This would make him an even greater burden on the State. Where is the joined up thinking? We need Co-ordination of psychology, OT and behavioural supports."

"Despite a diagnosis of ASD more than 6 years ago my child has received no specific ASD supports apart from Galway Autism Partnership"

"My daughter who has spina bifida and hydrocephalus (wheelchair bound) has been in the system for some time. It is still slow enough getting appointments now. Can only email because telephoning you get put on hold"

"Keep being told my son is entitled to a support worker but have never had one... He was receiving speech support for a couple months - where they would go to school and work with rest of class. She is now on maternity leave - so we have nothing. Being nonverbal any help he gets is greatly appreciated. He has never received OT either."

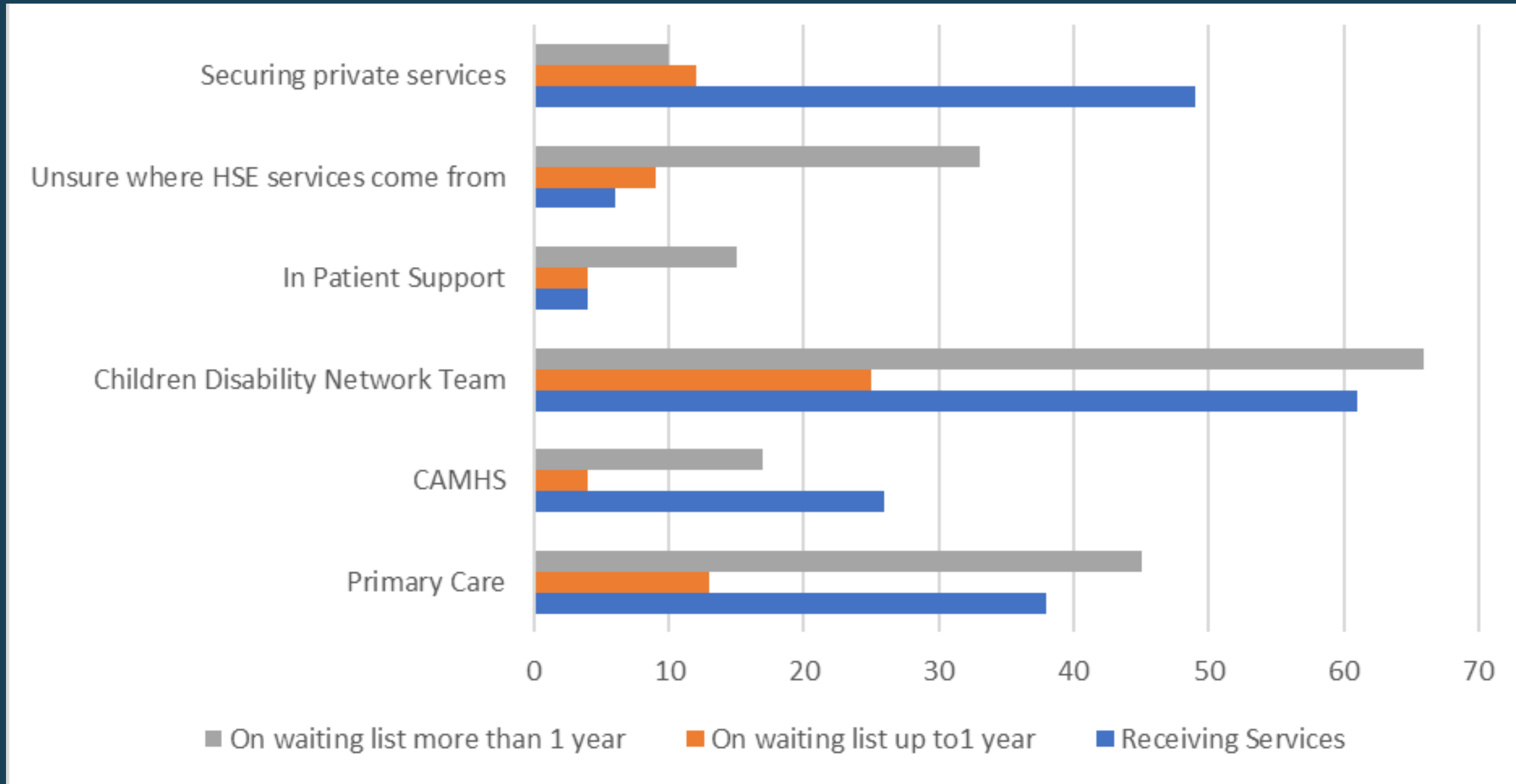
"Have had to privately source counselling, occupational therapy and educational psychology assessments, and have been on a waiting list for over 6 years for an autism assessment. Also on a waiting list for the same amount of time for therapeutic inputs."

"Waited a year for an urgent OT appointment. Waited close to a year for physio only to find there was no understanding of dyspraxia dcd. No coordinated approach. "

"I got a call very quickly to register my child as having a disability when he was 4 but have been refused any support either physical or financial since then. His 2 younger siblings suffer immensely as all of our additional income has to be used to fund every support privately."



Where are people accessing services from:



In total:

144/73.8% = CDNTs

92/47.2% = Primary Care

47/24.1% = CAMHS

70/35.9% = Private Services

23/11.8% = In Patient Support

48/24.6% = Unsure of where they receive services from

Many children experience coexisting conditions and therefore require multiple and distinct intervention of care.

"We were waiting for community psychology, CAMHS, OT and an ASD assessment referral pathway to become available, waited for ...5 years for several services to become available"



One child's journey on multiple roads of referral for assessment and intervention of support 2018 - 2022:

CAMHS: ADHD assessment

- Referrals and re-referrals to via PCCC Psychology, several GP, Pediatric Consultant,
- Referral refused or "lost" several times.
- Accepted in October 2022.

Received ADHD diagnosis in December 2022 but **no services yet.**

Community Psychology :

- Referrals and re-referrals through PCCC OT, GP and Enable Ireland
- Finally ready to be seen in December 2022, **BUT**
- At the same time we were accepted by CAMHS and therefore now **not eligible for PCCC Psychology anymore.**

Access to CDNT:

- Screened out by means of simple screening questionnaire sent from in 2021. Only one 30 minute online assessment with our child.
- The professionals who are seeing our child now are surprised they did not "make the cut" and advised to re-apply.
- Re-application for Children's Disability Network Dec 2022, **currently under review.**

Transgender Services: HSE Treatment Abroad Scheme:

- CAMHS would have been first step in referral pathway for transgender services, but refused referrals to see our child even just for onward referral to existing services through Tavistock.
- Family obtained private gender psychology services in August 2021 and have now been able to bypass CAMHS thanks to pediatric consultant and have accessed assessment abroad since December 2022 through the HSE Treatment Abroad Scheme.

ASD assessment:

- Due to no public referral pathway private ASD assessment in 2020.
- Not currently availing of any ASD-related services except through school and Galway Autism Partnership, GAP.

"We are just about beginning to receive services now, which should have been available 5 years ago, and we were bounced several times between various forms of primary care and specialist care with all of the services considering our child "not suitable for their services" and us therefore receiving no services or assessment."

"We felt completely disempowered and lost during the process."



Families experience of services - themes of general feedback:

Workforce planning crisis in recruitment, retention and ongoing training and support of staff.

- Staff shortages,
- Negative impact that constantly changing staff has an impact on children, who can't form a bond with their changing service providers,
- Lack of disability specific staff knowledge and expertise within teams,

"the new current OT has zero knowledge regarding wheelchair users and is of no benefit to my son who has complex seating issues"

"My daughter falls between the cracks, when it come to a dietitian"

"Our new services are bringing us across Galway city from Headford with travelling time over an hour to get therewe would have been able to keep our same fantastic OT if we were in the ... area. I had many reasons to appeal not just this one but they were having none of it. Feel like the new current OT has zero knowledge regarding wheelchair users and is of no benefit to my son who has complex seating issues. I have appealed this decision twice and both times told unless my child is terminal or has a sibling already in the services they will not accept us".

Lack of service support for transition into adult services, and lack of adult services:

- "No service after Camhs.....I begged for them to keep him until my son finished secondary school.....but he turned 18 in April 2022 and he sits his leaving cert exam in june 2023.....so he went from having support and being dropped at the most stressful time. A referral went to adult mental health services but was rejected. He gets NO services."
- "One of the children has just turned 18 his service provider was CAMHS he is autistic with multiple co morbidities. there is no service for autistic young people available so he will be discharged to the care of our GP as there is no adult service for him to go to "



Gaps in condition specific service provision and expertise:

- "My child was diagnosed with Hypermobile Ehlers-Danlos syndrome, hEDS in 2020 and there is no service for Ehlers Danlos Syndrome in Ireland"
- "I have an 8yr old with Developmental Language Disorder, DLD who was in a language unit for junior/senior infants and transferred to mainstream local school, he has barely received any speech therapy since. DLD is a disorder it doesn't magically disappear. He is also queried for DCD. My 12 Yr old is in 6th class has dcd ... I will have to take a loan to get him seen privately"
- "I have two nephews, one born two years ago with a limb difference and from the moment of his birth has been in receipt of regular OT, physiotherapy, prosthetic services and when he's older psychology. The other nephew is 14 years old and recently diagnosed with a very rare metabolic genetic disorder and was immediately assigned a team with an OT, physiotherapist and child psychologist outside of his medical team. His brother is autistic and has never had these services"
- "The information and advice around autism support is very general, a lot of which don't work on PDA profile, more awareness and training on PDA would be amazing - it impacts our progression with DCD related issues"
- "No operational pediatric transgender service in Ireland, contract with Tavistock expired"

"Where is the money going. Its unacceptable to get a check in call once in a blue moon and call it care"

Challenges for families navigating the system of PDS highlights a need for greater consistency of good communication and information to families:

- "...we don't understand how the OT that was working was taken away when it was a huge support and it was known that the ASD list was closed We were moved to CDNT and told in 2 letters since that no services available and none foreseen for future."
 - "There is no clear time line when we will receive support. Our child is preverbal and autistic with sensory needs..... You might then get a diagnosis but there is no signposting or support given to know how to get help, how to cope as a family or when anything will happen for our child."
 - "Promised recently that progress was being made but have had nothing offered to date. Most frustrating is that he had the services of an SLT and this has been removed.... now he has no services, which is less than he had before the CDNT format began."
- "Children are being failed and there is a huge impact on their lives and futures"



Lack of appropriate and timely access to mental health intervention

- "Our daughter is now 20 she spent years on waiting lists for assessment by psychology in Primary Care , she aged out without assessment for ASD. Her anxiety became so bad she self harmed... Because she hadn't actually attempted to kill herself and "just self harmed" she wasn't deemed "bad enough" for CAMHS services before she turned 18"
- "Was told it would be 2 yrs + for my almost 16yr old to receive psychology services...at that stage he will be 18 and will be discharged...and they are wondering why young men are jumping bridges?????"
- "She needs help it's years since she saw anyone for a diagnosis she is now 14 and needs so much help home life is unbearable at the minute and she struggles with everything she had no friends whatsoever it's so hard and sad as a parent to see this struggle everyday she has no life!!!"

Need for alternate therapeutic intervention, peer support for children, sibling support, parent counselling, respite and carer support were repeated named as needed by families:

- "Play therapy and art therapy mandatory to support child trauma and inherited family trauma"
- "More social groups with inclusive/integrated diverse groups"
- "My son needs socialisation. He has no ability to start a conversation or what to say if someone tries to talk to him. I'm despairing at this stage as it's becoming a major problem for him especially at school and he is becoming more and more anxious and upset about it"
- "Counseling and other supports should be offered to parents of children with disabilities to help them cope with their child's diagnosis"
- "The parent courses that are run in the mornings when most people are in work or caring for younger children are useless and I am sick and tired of requesting evening courses"

"We are people not numbers"

Waiting lists for clinical intervention and specialised aids and appliances:

- "Attending temple st. Waiting surgery for over 2 years"
- "Waiting for hip tendon release 2+ years"
- "Waiting for surgery on [my daughters] right knee going on 5years now and also waiting to get tonsils out.. got dates for both surgery's to get a letter in the post to say surgery was cancelled the week before, cause bed shortage.. she has spent a week in hospital, a week after her tonsils surgery was cancelled with severe tonsillitis & pneumonia"
- "My daughter is currently waiting to get a new wheelchair. What I don't understand is how an item such as this has to be approved for funding. Surely this item is a must have for my daughter"
- "Went Private to Orthopedic Consultant to get [my child] seen to in Cappagh. Previously had to source a private Urologist to get botox procedure - as no Urologist in Temple St.



The role of local voluntary disability organisations:

It was not the aim of this survey to capture reference to the role of voluntary disability organisations, however feedback repeated presented in open ended comments from families, recognising the support of local organisations in the absence of, and / in complement to statutory services:

- "My daughter has accessed some of the social supports from [Dyspraxia] / DCD Galway"
- "Down Syndrome Mayo are an amazing group we are lucky to be apart of the community"
- "Not availing of any ASD-related services except through school and [Galway Autism Partnership] GAP"
- "Despite a diagnosis of ASD more than 6 years ago my child has received no specific ASD supports apart from GAP"
- "Child now 15, [Dyspraxia] / DCD local support group was great in sharing information/ advise and organising activities for children locally, would welcome more support for teens to help set them up for adult years"
- "PALS - [Parents of Autistic people in Loughrea and Surrounds] is an excellent service"
- "...thank you to the local orgs and groups who are often volunteer advocates for doing what you do"
- "Child now 15, [Dyspraxia] Dcd local support group was great in sharing information/ advise and organising activities for children locally, would welcome more support for teens to help set them up for adult years"



Local voluntary disability organisations of support to disabled people and their families:

Down Syndrome Ireland

Nicola Hart

Nicola@downsyndrome.ie

<https://downsyndrome.ie/>

087 144 4382

Down Syndrome Ireland Mayo

Paula Dunne

mayotreasurer@downsyndrome.ie

<https://www.facebook.com/DownSyndromeMayo>

086 192 8622

Down Syndrome Galway

Deirdre Nugent

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086 871 9000

Down Syndrome Ireland, Roscommon Branch

Tom Mulry

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Facebook- search DownSyndromeRoscommon

087 228 3793

Erb's Palsy Ireland

Johann Verbruggan

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<https://www.erbspalsy.ie/>

087-7610098

Galway Autism Partnership

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091 588 899

Mayo Autism Camp

Elisha Sweeney and Colette Heaney

mayoautismcamp@gmail.com

<https://www.facebook.com/mayoautismcamp/>

087 7881864

Spina Bifida Hydrocephalus Ireland, SBHI

Áine Harrington

aharrington@sbhi.ie

<https://sbhi.ie/>

087 939 5371

Muscular Dystrophy Ireland, MDI

Una Sadler-Moran

fswwr@mdi.ie

086 3899286

P.A.L.S. Parents of people with Autism in

Loughrea and Surrounding Areas

Colleen Hawkins

palsgroup20@gmail.com

<https://www.facebook.com/groups/1404662353044374/about>

085 7290098

Dyspraxia / DCD Ireland

info@dyspraxia.ie

<https://www.dyspraxia.ie/>

01 874 7085



This survey was compiled on behalf of member organisations by the

Disability Federation of Ireland, DFI

www.disability-federation.ie

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