



In a recent survey of our members, 65% of respondents received zero Speech and Language therapy sessions last year.

Approximately 1 in every 444 babies are born every year with Down syndrome, usually between 120 and 150 babies. These children are almost always identified either prenatally or as neonates, and all will require ongoing therapies to support their development. This is a known, predictable need which the state has a responsibility to plan for, to ensure that the right services are available at the right time to maximise their impact on the child and their family.

Unfortunately, this is not happening.

**65% of respondents received zero Speech and Language therapy sessions last year.**

There is nowhere in the country where children are getting ready access to all of the therapies they need to support them to reach their potential. Our survey indicated that almost half of children aged 0-18 had no therapy of any kind in the last year. While the situation varies between one CHO area and another, there is nowhere where the system is functioning well for children with Down syndrome and their families.

Lack of services in the last year	All CHOs	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
No therapy of any kind	44%	35%	32%	44%	64%	37%	59%	56%	37%	44%
No SLT	65%	38%	55%	88%	82%	56%	66%	80%	58%	67%
No OT	87%	78%	83%	88%	89%	91%	93%	83%	86%	93%
No Physiotherapy	70%	81%	68%	76%	82%	70%	72%	65%	69%	63%
No Psychology	95%	88%	94%	92%	98%	98%	100%	95%	95%	95%

Down Syndrome Ireland has consistently advocated for improved access to therapies, particularly Speech and Language Therapy, which is of particular importance for people with Down syndrome. Essential therapy should not rely on charity and fundraising, however due to the absence of frequent consistent therapy provided through the public health service,

Down Syndrome Ireland's branches have provided subsidised SLT for more than 20 years. This has only been possible through parents and branches continuously and tirelessly fundraising and paying for this service.

We are aware of the added pressures on the health service due to the pandemic, but the lack of access to appropriate levels of publicly funded therapies for people with Down syndrome is a long-standing failure of the Irish health service.

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Over the last three years, we have regularly engaged with our members following indications that services were getting worse rather than better. In a previous survey of our membership about 2019 pre-pandemic services, only 44% of respondents were offered public SLT.

The average waiting time was 1–2 years and the average number of sessions across the age groups was 5 per year. Best practice for people with Down syndrome would involve multiple sessions each week, and research shows little or no benefit at the current dosage level\*.

## Findings from our 2021 Survey

In late 2021, due to increased engagement from our members on the lack of access to therapy, we conducted a survey of our membership to get a sense of the scale of the issue currently. 433 members completed the survey, representing almost 30% of our members with a child aged 0-18 from every CHO in Ireland. Many people also took the time to provide additional details about their particular situation, and some of their comments are included below. This large and representative response allows comparison geographically and across different stages of childhood.

This survey took place in the context of many services moving to the 'Progressing Disabilities' model, which is intended to streamline pathways and improve access to services, however, there is little public confidence that the intended outcome will be achieved.

**There is little public confidence that the intended outcome of Progressing Disabilities will be achieved.**

Only 2% of people who responded anticipated that their therapy services would improve following the current reconfiguration process, while 34% reported that they did not really have any services to improve.

**“We have yet to receive any services. It’s been almost three years.”**

(Parent of child aged 6-12, CHO6)

**“The whole process around PDS has been extremely stressful & the fears I highlighted have become a reality and my child is left without supports at an age when there is so much potential to support her if right supports are given.”**

(Parent of a child aged 6-12, CHO3)



**“We have and are receiving no service and I do not expect this to change. They are just rearranging the deck chairs on the Titanic again...nothing ever improves. I think families have completely lost faith in the ability of the services to offer any services.”**

(Parent of a child aged 13-18, CHO2)

Given that the survey was targeted at families of children with Down syndrome aged 0-18, more than one third of the respondents having no services at all is appalling. Children and teenagers with Down syndrome have cognitive and developmental delays, motor difficulties and developmental speech and language disorders.

**40% of respondents told us that they have had no communication from the HSE in the last 12 months.**

Supports such as SLT, OT, physiotherapy and psychology are vital to ensure that they are given the best chance to reach their potential. 40% of respondents told us that they have had no communication from the HSE in the last 12 months, while 44% have had no therapy appointments in the last year, not even an assessment or advice session.

**“I haven’t been approached with services, even though I have contacted multiple times, haven’t even received the “new way of getting services letter!”**

(Parent of a child aged 6-12, CHO4)

## Early Years (0-5):

This picture is slightly better in early years, with only 23% of respondents saying they had no services, which is likely to be driven by the relatively high access to early physiotherapy.

However, when you factor in the well-evidenced importance of early intervention in ensuring children reach their potential and live more independent lives, which reduces the supports needed throughout life, the fact that almost a quarter of children had received no therapy services at all is extremely worrying and will likely lead to the need for more input from health and social services throughout life.

**Almost a quarter of children aged 0-5 had received no therapy services at all which is extremely worrying**

For young children who are receiving therapy (77%), physiotherapy is most common, with 65% reporting seeing a physiotherapist at least once in the last year. Only 49% of children had seen an SLT, while just 22% had seen an OT.

**“There are not enough therapists to deal with the increased numbers. There was already a major shortage, now their client loads will be completely unmanageable.”**

**“I have been complaining to TDs for years about progressing disabilities for years and the official answer was always that it would ensure more equal access for all to therapies. So far it is equal in the sense of no one is getting anything.”**

(Parent of a child aged 3-5, CHO9)

Even where children are accessing therapies, parents describe a service stretched to breaking point.

**“My son was sick at the start of the year and we had to cancel our sessions. When I rang up to try and organise sessions for him. I realised that they had nearly forgotten him and he was being put to the back of the list. I needed help with feeding. The OT advised to buy a new high chair-haven’t heard from her since.”**

**“SLT hasn’t time to do, SLT she is only seeing him for feeding. He is seeing the Physio but we get no exercises or a written plan of any sort. Was given a Walker that we think is too small for him. He is 2 and not walking or talking yet.”**

(Parent of a child aged 2, CHO3)

**“Needs-based (therapy) is in conflict with ‘being the best version of themselves’.**

**There is no time reserved for my child - she just needs to be most in need....”**

**“The lack of intervention now is delaying a crisis down the line. Children with Down syndrome need a minimum amount of intervention - not left as they are because they are not the worst child. Expertise is being lost by the clinicians being made generalist - we still need Down syndrome experts. I am most concerned for the EI years, we are past them but the new babies I really worry for.”**

**(Parent of a child aged 3-5, CHO9)**

**“My area already operated as a Network Disability Team so that’s why I’m not sure if my service will change. We are also moving to the school age team soon so I’m sure there will be changes due to that. I am not happy with the way the NDT operates.”**



**“The buzz word is “family-centred” therapies but they seem to ignore the child and only focus on parent education. Parent education is great but the whole thing should start with the team getting to know the child.”**

**“I firmly believe not one therapist could pick my son out of a line-up and even if they could they’d struggle to tell me anything about his strengths, interests and challenges. The service needs a drastic re-focus on the child. It needs to be child-centred first and family-centred second.”**

**“The NDT/CDNT is not fit for purpose and needs to be dismantled and the focus needs to be put firmly on the therapists getting to know the children. The issue of retention of therapists also needs to be addressed.”**

**(Parent of a child aged 3-5, CHO7)**

## **School age (6-18):**

The situation worsens once children enter school, with more than half (54%) not receiving any therapies in the last year and 39% saying they have no therapy service at all.

**“Disheartening, disrespectful & disgraceful lack of service from the HSE. A violation of our children’s right to access necessary & vital services.”**

**(Parent of a 6-12 year old, CHO5)**





**“When my son was born over 9 years ago I cried for almost 6 weeks worried that my son would not receive the interventions he required to meet his own potential. I knew this as I had seen many children slip through the net. Almost 10 years on things are just the same.”**

**“Those working in the service do their best with the time they have available but they are stretched to the limit.”**

**“I was told when we moved house we would be lucky to be seen by one therapist in the next year so to choose what is our priority over everything else. The therapist who took my interview (without my son I might add) said there were children who were suicidal so they would get preference.”**

**“It made me feel like I shouldn’t ask for anything. Our family have to pay privately for what we can afford which isn’t enough.”**

(Parent of a 6-12 year old, CHO3)

The most common therapy support at this stage is SLT, with 28% of people reporting that they have had at least one SLT session in the last year. For a cohort of children with significant speech and language disorders attempting to access education, this is shamefully low.

Access to other therapies is even more limited: 15% of people have seen a physiotherapist, while just 9% have seen an occupational therapist in the previous 12 months.

## **Rights based approach**

The responsibility for providing therapy lies with the HSE. Ireland has signed the United Nations Convention for the Rights of Persons with a Disability (UNCRPD).

Article 25 of the UNCRPD (health) states: *‘The state shall provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities’*. Therapies for children with Down syndrome clearly come under this.

However, as we can see from the figures and comments above, the current system is not able to provide this support. Improving systems and recruiting more therapists is a good plan, but it underestimates the scale of the problem. Speech and Language Therapists working with children with complex needs, for example, need to be working with manageable caseloads of around 30-50 children in order to provide a meaningful, sustained level of service\*.

This would require not just a few more therapists, but more than doubling numbers of face-to-face therapists and ensuring that any long-term absences are covered.

We need a rights-based approach. It should be no more acceptable to tell a family that there will be a two year wait for therapy than it would be to tell them there will be a two year wait for education.

The level of recruitment and additional infrastructure needed to get to this point means that it's unlikely to happen overnight, so we also asked members what might be helpful in the meantime.

## Interim supports

73% of respondents would like financial support to allow them to source therapy themselves.

Smaller numbers of people would like additional online resources, once-off assessment and advice sessions, etc, but it was clear from the comments that these are no substitute for targeted, individualised, consistent therapy, and diverting scarce resources into providing these is of questionable value.

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**“At my daughters young age of nearly 4, the only thing that will help us is face to face regular meetings with our therapists. Video is no good. If the services can’t be provided then funding should to allow us to get the help we need.”**  
(Parent of 4-year-old, CHO2)

**“Phone Consultations don’t work, they don’t follow through and all it’s doing is ticking boxes.”** (Parent of 6-12 year old, CHO7)

**“SLT is so important. For us we had 6 sessions with SMH before we had to go to the back of the list and apply again. Our son was just starting to make progress. The private therapy is really helping, it needs to be more accessible for all.”**

(Parent of 6-12 year old, CHO9)

**“Access to personal budgets for children. Give over service delivery to those who can manage to care for children WHEN therapies are needed.”**

(Parent of 12-18 year old, CHO8)

**“Let’s face it. Parents and the charity is picking up the tab when it comes to therapies, services and supports for our children. The charity is doing such a good job that when kids get assessed by the HSE they are told their speech is good and they don’t need ongoing therapy. It’s an absolute joke. The system is beyond repair.”** (Parent of 3-5 year old, CHO3)

The evidence presented here highlights that while this is a longstanding issue, the situation has been worsened by the pandemic. For children with Down syndrome, missing out on the early and consistent benefits of necessary therapies has lifelong negative consequences but it also has consequences for our health service in terms of increased need for health and social care services across the lifespan.

Ireland cannot continue to fail to deliver vital health therapies in violation of the UNCRPD. A short-term solution is needed while longer term policy and implementation issues are being worked out, particularly in light of the delays caused by the pandemic.

We have real concerns about the effectiveness of the Progressing Disabilities policy in meeting the needs of children with Down syndrome and the current lack of access to appropriate levels of therapy.

