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University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Speech and Language Therapy services for people with Down syndrome - the disparity between research and practice.

Running Head: SLT in Down syndrome - research practice disparity

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Ethics: This research was approved by the Social Research Ethics Committee of University College Cork.

Abstract:

Background: The need for speech and language therapy (SLT), for people with Down syndrome (DS), is well documented. However, there is a significant disparity between research and practice. This study addresses two of the three pillars of evidence-based practice by 1) quantitatively profiling some key features of the 2019, public SLT service in Ireland, and referencing this against current best evidence; 2) asking parents, and adults with DS what supports they need in relation to an adequate SLT service.

Methods: Adults with DS (*n=33*) and parents of those with DS (*n= 557*), completed an anonymous survey online. The function of the survey was to collect information on: SLT service provision; levels of satisfaction with services; and SLT supports required.

Results: Based on parent responses, only 44% of participants (*n = 253*) were offered public SLT services, in 2019. The mode waiting time was 1-2 years and the average number of sessions across the age groups, was 5 per year. There was a strong association between age and number of sessions. Individual therapy was the most common model of service. 40% of parents reported a 0 level of satisfaction. Seven key themes emerged from the qualitative support data. None of the participating adults received public SLT services in 2019.

Conclusion: Our aspiration for evidence-based SLT practice is far from being realized. The average number of sessions reported, does not in any way approximate the intervention intensity specified in evidence-based interventions. Our limited service, at all ages, has detrimental implications for people with DS and our negligible adult service is in breach of human rights. Targeted, strategic investment is needed to allow practice to be aligned with best evidence; to support and treat people with DS effectively; to allow them to reach their maximum potential; and to exercise their right to communicate.

Key Words: Down syndrome, Intellectual Disability, Speech and Language therapy, Evidence Based Practice.

Introduction

The research-practice gap has received considerable attention from both practitioners and researchers, not only in medicine and education but also in the field of speech and language therapy (SLT) (Grol et al., 2013; Olswang & Prelock, 2015). The application of new knowledge to routine care is a complex process and several factors contribute to the implementation of evidence-based practice. In 2000, Sackett et al. updated his original definition of Evidence-based medicine (EBM) as "the integration of best available evidence, clinical expertise and patient preferences and values". In doing so, he gave equal weighting to the three core factors to be considered 1) the patient's /clients goals, needs and preferences, 2) the best available research evidence, and 3) the clinical expertise of the practitioner. With respect to the best available research evidence, one way to begin to bridge science and practice is to document the current service that is being provided to specific patient groups, and to highlight to policy makers, obvious discrepancies between what research has shown to be evidence based, and what is offered in practice. With respect to client needs, moving effective interventions from research to practice requires significant collaboration, not only between researchers and clinicians, but also between clients (or parents on behalf of their children) and clinicians to establish what is feasible, and what supports would be necessary to adhere to treatment programmes reliably. The current study addresses aspects of two of the three pillars of evidence based practice, with reference to people with Down syndrome (DS), by 1) asking adults with DS and parents of children with DS to retrospectively describe key quantitative features of their SLT service in the previous year, such as time waiting for services, and number and frequency of sessions (so that this information can be referenced against current best evidence)

and 2) asking adults with DS and parents of children with DS, what supports they believe are needed for themselves, or their children, with respect to their SLT service.

Although there is considerable individual variability in people with DS, in that IQ scores can span from severe to the average range (Roizen, 2007), the majority of people with DS have a moderate intellectual disability (Chapman & Hesketh, 2001). As a group they present with particular areas of difficulty in relation to their speech, language and communication skills and consequently they have a significant need for SLT services across their lifespan (Meyer et al., 2017). With respect to speech, their intelligibility is particularly impaired and studies indicate a profile of both delayed and disordered patterns (Kent & Vorperian, 2013; Cleland, Wood, Hardcastle, Wishart, & Timmins, 2010). The characteristic profile of their language abilities suggests that receptive language is usually better than their expressive language (Chapman et al., 2002; Laws & Bishop, 2003) and that their understanding and use of vocabulary is stronger than their syntactic abilities (Abbeduto et al., 2003; Berglund et al., 2001; Chapman et al., 1991). One key finding in relation to the need for speech and language therapy is that people with DS have been shown to have disproportionate difficulties with language, relative to their level of intellectual disability (Frizelle et al., 2018; Martin & McEltree, 2009; Loveall et al., 2016). The presence of these specific language difficulties distinguishes them from other individuals with intellectual disability of unknown aetiology, and negatively influences levels of inclusion in mainstream school.

Intervention duration and Dose Frequency in effective Interventions

Despite the broad range of speech, language and communication difficulties evinced by people with DS, the empirical research shows that interventions can be effective across their life span (Bauer & Jones, 2014; Fey et al., 2006; Hewitt et al., 2005; Karaaslan & Mahony, 2013;

Rvachew & Folden, 2018; Terband et al., 2017). While rarely systematically manipulated with this population, key features of effective interventions appear to be quantitative dosage components, such as dose frequency, and total intervention duration. Based on growth in vocabulary, Yoder and colleagues (2014) found that (while controlling for intellectual ability) young children with DS (mean age 22 months) who were exposed to five 1-hour individualized sessions per week had better outcomes than those exposed to one 1-hour session per week (over a 9 month intervention period). While holding dose frequency constant (at 1- 3 sessions per week) in an expressive language intervention, Neil and Jones (2019) manipulated other aspects of dosage such as session duration, dose and spacing of learning opportunities. Based on three children with DS, they found that high doses of one-to one intervention resulted in more efficient learning of communication targets.

Other interventions described as being effective, report varying degrees of dose frequency across a broad age range. In a Cochrane review of parent mediated interventions (n = 3) for young children with DS (O'Toole et al., 2018), one study had a treatment duration of 13 weeks, with nine group sessions and four individualized home-based sessions, 26.5 hours in total (Giralometto, et al., 1998); another study took place for 6 months, with 24 weekly individual clinic-based or home-based sessions each 1.5 to 2 hours long (48 hours) (Karaaslan, & Mahony, 2013); and the final study was 12 weeks in duration and included one 2 - 3- hour group session, twice-weekly individual clinic-based sessions (30 minutes), and once weekly 20 minute home based sessions (19 hours in total) (Kaiser & Roberts, 2013). Importantly in this context, the study that gave the largest amount of intervention was the only one in the review to report gains on composite measures of overall language ability.

In a recent systematic review, Smith al., (2020) reported on the positive language intervention effects for older children with DS (on average 5 to 10 years), with varying effect sizes. Again, dose frequency and session length varied across the 8 studies included, however, most studies

had multiple sessions per week and five out of the eight had daily sessions (5 days a week) (Baxter et al., 2018; Burgoyne et al., 2012; Goetz et al., 2008; MacDonald et al., 1974; Yoder et al., 2014). The mean length of interventions was 4.5 months, and notably the shortest intervention (2 months, Goetz et al., 2008) was one of the two interventions for which no effect was shown. With respect to older individuals with DS, Rvachew and Folden (2018) found gains in speech accuracy in an adolescent with DS following simultaneous receipt of three interventions, each one given once per week for six weeks (18 sessions in total). Hewitt et al., (2005) also reported positive gains in the use of targeted morphemes following an expressive grammar intervention with 3 adults with DS (29 to 52 years). Here the dose frequency was once weekly and for a period of 12 weeks.

Overall, there is considerable variation in dose frequency and total intervention duration reported in speech and language interventions described as being effective for people with DS. We note intensities ranging from as high as 5 1-hour sessions per week over a period of 9 months with very young children to a more modest once weekly for a period of 12 weeks, with adults. However, not all studies are carried out with the same level of scientific rigor or can be considered to show equal levels of evidence. In the context of this paper, it is noteworthy that the literature converges on the view that higher dose frequency and longer intervention durations yield better outcomes for people with DS.

The Irish Context

As a basic human right, the right to communicate is enshrined in Article 21 of the UNCRPD (Convention on the Rights of Persons with a Disability, United Nations, 2006), and it includes the responsibility of the state to ensure all appropriate supports, to develop communication skills, are put in place. In Ireland public service SLT is provided either directly or indirectly by the Health Service Executive (through a service level agreement with voluntary agencies). In

2004, the Irish government launched the National Disability Strategy as a framework for improving services for people with disabilities. Integral to this strategy were two key pieces of legislation, the EPSEN Act 2004 and the Disability Act 2005. While the former has never been fully enacted, the latter sets out the right to an assessment of need and service statement, which indicates when and what that service will be. The assessment of need should be initiated within 3 months of referral, and completed within the following 3 months, and a service statement should be completed within one month of the assessment report. The HSE has a legal obligation to provide the services named in the statement, however when service statements are prepared they are not based solely on assessed need, the act allows for the cost and availability of services to be taken into account as well as an estimated 'realistic' timescale as to when the services can be delivered. This means that in practice, there is no statutory right to services, as the needs of the child are described within the context of resources available.

Although government policy recognises the importance of SLT in early years (see National Early Years Access Initiative, (O'Dwyer & McCormack, 2014), there are insufficient SLT posts available to meet the needs of those with disabilities (Inclusion Ireland, 2014); recent figures from the Health Service Executive show that almost 45,000 children are currently on waiting lists for speech and language therapy (Bermingham, 2021) and despite an estimated 10% of therapists on leave at any one time (National Disability Authority, 2014) there is a policy of non-replacement of staff due to maternity; parental; or sickness leave (Inclusion Ireland, 2014). This has placed an exceptional burden on schools and public services to deliver optimal SLT interventions with fewer resources. Data relating specifically to people with DS is not collated, however, of the 6,596 people with disabilities referred for an assessment of need in 2019, only 9.8% of them were seen within 1 year (HSE Performance Report, 2019). This is

in contrast to the figures reported for Primary Care [1] and Disability combined where approximately 94% were seen for assessment within 1 year and less than 1% were waiting more than a year.

If speech and language intervention is not provided for people with DS, this can result in an accumulation of difficulties which can become chronic and can lead to reduced potential, poor social skills, behavioural problems, emotional difficulties, literacy disadvantage, and mental illness (Antonarakis & Epstein, 2006; Cardoso-Martins et al., 2009; Roizen & Patterson, 2003). While some families turn to private organizations for therapeutic intervention and support, there are large numbers of families who do not have the resources to pay for private treatment and therefore rely solely on public SLT services. However, there is limited research into whether current SLT public services align with either evidence based recommendations or parent preferences. In the current study we ask:

- What is the typical SLT public service offered to families, in which there is a person with DS, in Ireland?
- Is there a relationship between 1) the number of SLT sessions received and the age of the person with DS?
- What is the model of service delivery across each educational stage?
- How satisfied are parents with the current level of service?
- What supports do parents believe they need in relation to an adequate SLT service?

Method

Ethics

[1] Primary care SLT service includes children and adults who have developmental or acquired speech, language, voice and or eating, drinking and swallowing difficulties.

Ethical approval was granted from the Social Research Ethics Committee at University College (deleted for anonymity).

Survey

Both quantitative and qualitative data were collected through an online anonymous survey, developed in collaboration with DS Ireland (DSI). DSI is an organization which provides support and therapeutic services for families of people with DS in Ireland. The survey was developed to specifically address our research questions and was piloted with a smaller cohort of parents of adults/children with DS (n =105). There were two editions of the survey, one for parents of those with DS and the other an easy read version, specifically for adults with DS. Questions from the parent survey were adapted by the authors (2 of whom had significant experience working with people with DS) to facilitate the literacy and comprehension level of adults with DS. Both surveys are provided in the supporting information. The surveys were divided into 3 sections.

1) *Inclusion criteria*: Participants were asked to indicate whether they were a parent of a child/adult with DS, a parent of child/adult with another disability or if they were an adult with DS. Parents of children/adults with another disability were excluded. Adults with DS were provided with an easy read version of the survey.

2) *General Information*: This section asked for demographic information such as the age of the people with DS, their geographical location and their stage /type of education/employment.

3) *Speech and Language Therapy*:

Parent version: This section focused on speech and language therapy service provision, asking for information such as number and frequency of sessions received, waiting time for services and model of service delivery provided. While the exact number of sessions was asked for, session frequency information was requested according to pre-determined categories. An open

text box also allowed for further clarification. With respect to model of service delivery, participants were asked to choose from one of five options: one to one sessions for your son or daughter, group sessions with other service users, one to one sessions for parents, group sessions with other parents, and school visits. Participants were also asked to rate their level of satisfaction with SLT services, from 0 - 10, where 0 indicated not at all satisfied and 10 indicated extremely satisfied. Finally, participants were asked, in free text, to describe the kind of support they believe they require from Speech and Language Therapy.

Adult with DS version: The adult easy read version covered the same broad themes as those outlined above but the questions were phrased differently. For example, participants were asked how many times they went to speech therapy in 2019, without distinguishing between number and frequency of sessions. With respect to satisfaction, they were asked if they were happy with their speech therapist or if they would like more speech therapy, rather than using a rating scale.

Recruitment

The survey was published online using Microsoft forms and the link to the survey was disseminated through the DSI members list, private Facebook groups, and other social media networks. Most adults with DS recruited through DSI were recruited through a family member as unless they have joined independently, DSI does not have access to their contact details. The head of member services in DSI facilitated recruitment and acted as the contact person for any queries about the study. There were two information sheets outlining the purpose of the study, one for parents of those with DS (linked to the parent version of the survey) and an easy read version for the adult participants with DS (linked to the DS version). Consent to participate was recorded by a tick-box prior to proceeding to the respective survey versions. The survey remained ‘live’ for a total of two weeks.

Data Analysis: Quantitative data on demographics, SLT provision and satisfaction were analyzed descriptively. Spearman correlations were carried out to examine if there were relationships between age or levels of satisfaction and number of SLT sessions received. Qualitative data were analyzed using thematic analysis, with consideration of best practice guidelines described by Braun and Clarke (2021). Two researchers carried out the analysis, one psychology graduate and one SLT graduate, both of whom had experience completing qualitative analyses. Responses were transcribed by both researchers independently, to validate the data through cross verification. Each researcher then familiarized themselves with the data and began systematic data coding, followed by initial generation of themes and subthemes, while debriefing at each stage. Following the generation of initial themes, the researchers reviewed the themes a second time and refined them in the context of the overall dataset. In addition, they kept notes about how the hierarchy of themes developed, to ensure confirmability. Data credibility was enhanced by the fact that data were collected from more than one source (adults with DS as well as parents of those with DS).

Results

A total of 607 people participated in the survey. One parent completed the survey twice, therefore their duplicate response was excluded. In addition, 16 responses were from parents of children/adults with a different disability (not DS) and were therefore excluded. This resulted in a total of 590 responses, 557 of which were from parents of children or adults with DS and 33 from adults with DS. Our sample reflects 18% of the total DSI membership and approximately 10% of the overall DS population in Ireland[2] Demographic information, including the age, and stage of education or occupation of 1) the adults with DS who completed

[2] DSI membership is skewed towards younger people as parents usually join on behalf of their children. As parents age, membership is often not renewed. Therefore, a considerable portion of the cohort that did not respond are likely to be adults not receiving any SLT services.

the survey and 2) the children/adults whose parents completed the survey is summarized in Tables 1a and 1b. Responses were given from all but one of the 26 counties in the Republic of Ireland, with the highest responses from the counties that included the 3 major cities (Dublin, Cork and Galway) and two additional counties Mayo and Meath. Details of the response breakdown per county is given in Table 1 in the supporting information. Insert Tables 1a and 1b about here.

Table 1a: Information from parents describing their son/daughters age and stage of education / occupation **(N = 557)**

Age Range (Years)	***n* (%)**	**Stage of Education/ Employment**	***n***
0-2	44 (7.9)	Mainstream preschool	61
3-5	70 (12.6)	Special preschool	9
6-12	179 (32.1)	Mainstream primary school	143
13-17	84 (15.1)	Special school	71
18-25	109 (19.6)	Mainstream post primary school	34
25+	70 (12.6)	Adult day service	123
No response	1 (0.1)	Adult Education	38
		Work experience or voluntary work	23
		Paid employment	23
		At home	58
		Childcare	7
		Other	5
Note: education/occupation categories were not mutually exclusive			

Table 1b: Information from adults with DS describing their age and stage of education / occupation **(N = 33)**

Age Range (Years)	***n* (%)**	**Education/Occupation**	***n***
18-24	13 (39.4)	Paid work	9
25-30	15 (45.5)	Volunteer work	2

31-35	3 (9.1)	Work experience	8
36-40	2 (6.1)	Adult education/Third Level	17
		Secondary School	3
		Day Centre	18
		At home	9
		Other	6

Note: education/occupation categories were not mutually exclusive

Quantitative Data

Our first research question addressed what the public SLT service provision is for children through to adulthood, with DS in Ireland?

Responses from parents: Only 44% of participants (n = 253) were offered public SLT services in the year 2019. Of the 56% not offered services (n = 304), 26% (n = 83) reported being on a waiting list, 77% (n = 64) of whom specified the time they were waiting for services. The mode waiting time was 1 to 2 years, and the longest waiting time was reported to be 10 years. (see Table 2).

Table 2: Waiting time for SLT services

Waiting time (Range)	**No. of Service Users**	**Percentage**
<6 months	1	1.56%
6 months - 1 year	3	4.69%
1-2 years	24	37.50%
2-3 years	19	29.69%
3-4 years	7	10.94%
4+ years	10	15.63%
Total	**64**	**-**

Of those that did receive services, 81% (n = 204) specified the frequency of their service which ranged from once weekly to once a year. Public SLT services in Ireland are usually given in 6 week blocks. Based on participants' free text responses and a discrepancy between the session frequency and total number of sessions reported, it became apparent that those who indicated the frequency of their treatment to be weekly, were describing short blocks of therapy rather than the frequency of their sessions annually. These parents had interpreted the question as 'when you did receive therapy, how frequent was it?' rather than how frequent was it over the course of the year. The "Intermittent/infrequent" category captured responses from parents who described the frequency of their service in a free text response as either intermittent or infrequent without specifying. Responses are summarized in Figure 1 in supplemental material.

Ninety- three per cent specified the number of SLT sessions they received (see Table 3). Eighty-nine percent reported receiving ≤6 sessions over the course of the year; 8% received 6 sessions (in keeping with the practice of the 6-week block) and 56% received 0 sessions. These data were also analyzed by age group to highlight differences in service provision at different life stages. (see Table 4). Of those that did receive therapy, the mean number of sessions received across all age groups was five over the course of the year, with children between 6 and 12 years receiving the most sessions (approximately 6) and adults over 25 receiving the fewest sessions (an average of < 1).

Table 3: Frequency of number of public SLT sessions offered in 2019

Number of sessions	Number of people with Down syndrome	%	Cumulative %
0	290	55.6	55.6
1	16	3.1	58.6
2	31	5.9	64.6

3	30	5.7	70.3
4	32	6.1	76.4
5	23	4.4	80.8
6	42	8.0	88.9
7	6	1.1	90
8	18	3.4	93.5
9	3	.6	94.1
10	16	3.1	97.1
12	9	1.7	98.9
15	2	.4	99.2
16	2	.4	99.6
18	1	.2	99.8
20	1	.2	100
Total	**522**	**100**	

Table 4: Average number of public SLT sessions offered (according to age group) in 2019

Age groups	**Average number of SLT sessions offered**
0 - 2 years	4
3 - 5 years	5
6 - 12 years	6
13 - 17 years	5
18 - 25 years	< 4
25+ years	< 1
N= 234	

Type of service provided: The most common model of service provided was one to one sessions with those with DS. For 48% of the sample this was the only type of intervention received. This was followed by school visits, which was the model of intervention for 16% of the sample. Group sessions for children was the next most common model of service delivery (9%) and this was followed by one to one sessions for parents only (3%). A very small proportion of parents reported receiving group sessions with other parentis (1%). Of the remaining participants, 24% reported receiving a combination of different service types. The most frequent combination of services was one to one sessions for children with school visits (10%). Type of service provision was also analyzed by educational stage and is summarized in Figure 2 in supplemental material.

Educational stage was categorized by both age and education/occupation indicated by each parent. Early secondary included children from 13-15 years, while those in Upper Secondary were 16-19 years. One to one sessions were most common in the early years and through primary school, while school visits increased for those in secondary school. Some respondents selected school visits as a service provision type for adults. We have interpreted these responses as 1) referring to visits to an adult educational setting or 2) to recent school leavers where a school visit was provided while the adult with DS was still in school. Group sessions with people with DS increased as a model of therapy from upper secondary into adulthood. Interestingly, while there was no parental involvement in the therapy model at early secondary level, one to one sessions with parents was more common at upper secondary level than at any other educational stage.

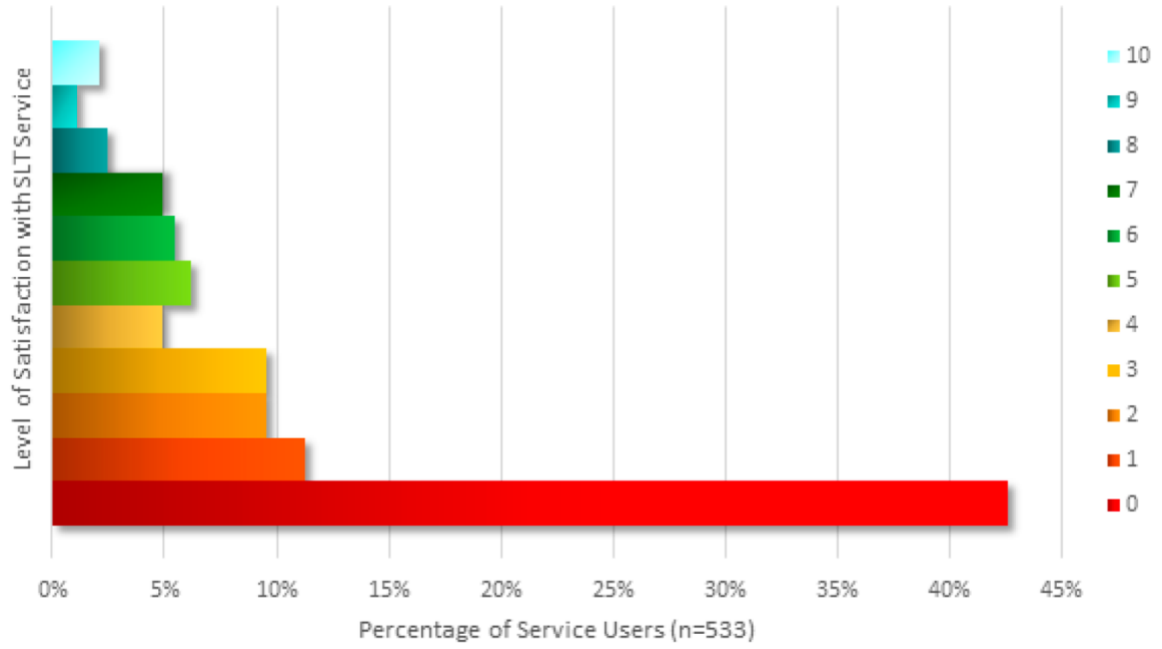
Responses from Adults with DS: Of the 33 adults that responded, none of them indicated that they received any public SLT services in 2019.

In our second research question we asked if there was a relationship between 1) the number of SLT sessions received and the age / educational stage of the person with DS. SLT provision

was operationalised as the number of sessions provided over the course of the year. A Spearman Rank correlation was conducted between age in years and number of SLT sessions received. Results indicated a strong negative correlation (r (234) = -.575, p <.001), indicating as individuals with DS get older, they receive fewer SLT sessions.

Our third question addressed the levels of satisfaction reported by 1) adults with DS and 2) parents with respect to the received level of public SLT service meeting their family's needs. Sixty- six percent (n = 19) of adults with Down syndrome indicated that they would like more speech therapy. Parent levels of satisfaction are summarized in Figure 1, which shows that over 40% of participants reported a satisfaction level of 0, with a further 30% reporting a satisfaction level of <3. Approximately 5% rated their satisfaction at 8 or higher, 92% of these received individual therapy and their average number of sessions annually was between 8 and 9. Further analysis revealed a strong positive correlation between number of sessions received and levels of parental satisfaction, (r (522) = .589, p <.001).

Figure 1: Level of satisfaction with SLT services



Legend: Satisfaction was rated on a scale from 0-10, where 0 indicated "Not at all satisfied" and 10 indicated "Extremely satisfied".

Qualitative Data

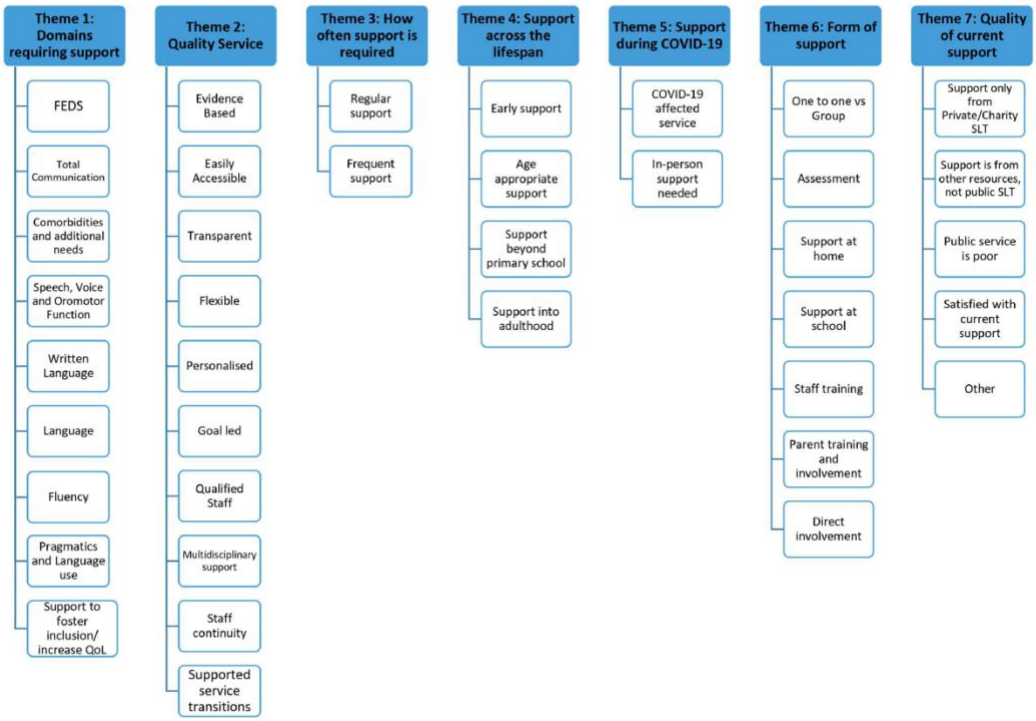
Our final research question addressed 1) the supports that parents/ carers believe they require from Speech and Language therapy 2) what adults with DS would like help with in therapy.

Responses from Parents: On completion of the analysis the final coding list contained 139 codes, which were grouped into 39 subthemes and seven main themes. The main themes were: (1) "Domains requiring support"; parents specified the range of domains across the areas of speech, language, communication and FEDS (feeding, eating drinking and swallowing) where individuals with DS require SLT support. (2) "Quality support"; parents outlined what they require from public speech and language therapy in terms of service quality for their children. (3) "How often support is required"; this was the most frequently raised issue by parents and addressed both the quantity and frequency of support provided. (4) "Support across the lifespan"; Parents emphasised the fact that support is important at all stages of their children's

lifespan (5) “Support during COVID-19”; although not specifically asked to comment on the impact of the COVID-19 pandemic, many parents highlighted the fact that their SLT input had ceased as a result of therapists’ redeployment. For those who did receive some therapy they highlighted difficulties in engaging with virtual services. (6) “Form of support”; parents specified the form they would like SLT support to take, including preferences for direct vs indirect models of therapy, one to one versus group therapy and where therapy is delivered (e.g. at home, at school). (7)” Quality of current support”; the majority of parents specified how the current public SLT was not meeting their families’ needs.

The themes and subthemes are illustrated in Figure 2. The full lists of themes, subthemes and codes are provided in Table 2 in the supporting information. Parent quotes reflecting each theme are also given in Table 3 in the supporting information. Insert Figure 2 about here.

Figure 2: What supports do you feel you and your family require from speech and language therapy?



Responses from Adults with DS : Responses were multiple choice and not mutually exclusive (*n*= 30). Seventy three per cent (*n*=22) expressed the need for help with "Speaking more clearly" and 53% (*n*=16) wanted help with "Practicing talking". Thirty per cent (*n*= 9) believed they needed help with "Learning new words"; 10% (*n*= 3) with using signs.; and 20% (*n*= 6) reported needing help with "Swallowing". Twenty per cent of adults with DS (*n* = 6) did not want therapy in any area.

Discussion

In the current study we aimed to document the SLT public service offered to people with DS, in Ireland, and to reference that service against the best available research evidence. The findings are clear, and show that there is a significant disparity between services offered, and what the research literature reports as being effective. It is disconcerting to find that more than half our sample received no therapy at all, and are therefore not been given the opportunity to maximize their communicative potential. Although a considerable proportion of those who did not receive any therapy were not on a waiting list (37% of the total sample), and therefore it could be inferred that they did not need or want therapy. However, given the strong positive correlation between number of sessions and levels of satisfaction as well as the significant speech language and communication needs of people with Down syndrome, this is unlikely to be the case for the majority of our sample.

Our finding that those who did receive therapy, received an average of only five sessions per year and that 89% of our sample received ≤6 sessions, is in stark contrast to what is reported as effective in the research literature. In the previously cited Cochrane review of parent mediated interventions for very young children with DS (O'Toole et al., 2018), the intervention with the largest intervention intensity (48 hours) was the only one to report significant gains on children's overall language ability. Similarly, in the systematic review by Smith et al., (2020), focused primarily on school aged children with DS, the mean length of interventions

was 4.5 months; most studies included had multiple sessions per week; and five of the eight had sessions 5 days a week (Baxter et al., 2018; Burgoyne et al., 2012; Goetz et al., 2008; MacDonald et al., 1974; Yoder et al., 2014). Rvachew and Folden's (2018) 6-week speech accuracy intervention was more similar in terms of overall treatment duration, to what many parents reported in this study. However, at 12 hours the total treatment time (40 minutes 3 times weekly) was more than double the mean reported here and similar to that reported by Hewitt et al., (2005). The need for increased intervention intensity is also supported by studies in which quantitative aspects of dosage have been manipulated. Although optimal dosage has not been established, findings show that children with DS have better outcomes with both increased dose and dose frequency (Neil & Jones, 2019; Yoder et al., 2014).

Our findings in relation to SLT services in Ireland, do not in any way approximate the levels of intervention intensity reported as effective in the literature and are also much lower than levels reported in other countries such as Australia (Meyer at al., 2017). This disparity between what individuals with DS are receiving in practice, and what is reported as effective, suggests that we may be operating well below a baseline dosage, where little or no effect can be expected. Consequently, therapists may conclude that speech language and communication disorders in people with DS are not responsive to therapy and are therefore not a good use of resources, thereby resulting in a further reduction in the amount of direct therapy offered. In addition, if therapy is so minimal as not to be effective, we place an unnecessary burden on parents and we run the risk of people with DS missing valuable opportunities for learning when being taken out of pre/school for SLT intervention.

In our second research question we asked if there was a relationship between the number of SLT sessions received and the age of the person with DS. Our findings indicated a strong relationship between these two variables, however, given the average number of sessions was low across the age range, the relationship is likely to have been driven by the negligible service

available to adults. Our lack of services has a number of implications at each stage of development.

The importance of early intervention to maximize potential has long been reported in the literature and early intervention has been found to be more effective than later intervention (Aparicio & Balana, 2002), even when intervention is delayed by only 2 months (Sanz & Menendez, 1996). This is a sobering thought considering the waiting times reported in our findings (38% waiting 1- 2 years).

Our finding of an average number of 6 sessions per year (for primary school aged children), along with the fact that current SLT services are predominantly given in clinical settings (IASLT, 2017), indicates a lack of a comprehensive SLT school service. This is in significant contrast to countries such as the UK (where service delivery forms part of an Education and Health Care Plan) and Australia where 80% of 5-18 year olds with DS receive an SLT service at school (Dyke et al., 2007). The lack of an SLT school service results in an inability to collaborate effectively with the teacher; to identify language demands in the curriculum; and to prompt the teacher to scaffold classroom learning, by pre-teaching key vocabulary and concepts in advance of introducing new topics. In addition, particularly pertinent to school, is the bi-directional relationship between language and literacy. While oral language skills have been shown to predict performance on a number of literacy measures in children and adolescents with DS (Boudreau, 2002), literacy acquisition is also thought to foster language development in children with DS (Buckley, 2003; Laws & Gunn, 2004).

The lack of service for adolescents is consistent with other literature (e.g. Meyer et al., 2017) and results in limited support for the development of social language skills, which are needed to build friendships during the teenage years. Consequently, many adolescents are reliant on their families for social contact into their early adult years. In Ireland, adolescents with DS are given accommodations such as a reader of a scribe when sitting state exams. These

accommodations result in pupils having a higher dependency on receptive and oral language skills and without the appropriate SLT input, (identifying the key topic, understanding question forms and other exam orientated words) students with DS are unable to make the best use of these supports.

With respect to adults, we can see that our public SLT service is negligible. This is particularly disappointing given that better communication has been linked with open employment and further education (Foley et al., 2013) and given suggestions that the young adult years may be the optimal time to focus on literacy development (Fowler et al., 1995; Moni & Jobling, 2001). Based on a socio-cultural model of literacy teaching and learning, which includes all aspects of literacy in an integrated approach (reading, writing, speaking and listening), there is, at the very least, a collaborative role for the SLT. Moni & Jobling (2001) report positive findings with respect to the LATCH-ON post-school literacy programme, however there were no comparison groups in their study. Overall, there is a lack of controlled trials measuring the effectiveness of literacy interventions in adults, and this appears to play a role in perpetuating the absence of instructional opportunities for this cohort.

The role of the SLT with adults with DS extends well beyond literacy skills, to facilitating self-advocacy through assessment of understanding when making life choices (e.g. with respect to money or health). The need to ascertain degrees of understanding and the provision of sufficient levels of support to help individuals make significant decisions, is central to the implementation of the Assisted Decision Making (Capacity) Act (2015). However, at the levels of SLT reported here it is unlikely that therapists can establish the relationships with adults with DS that would allow them to fulfill this role adequately.

Finally, adults with DS have an extremely high incidence of early onset dementia (Coppus et al., 2006) and are often not diagnosed until the condition has reached an advanced stage. Given the link between vocabulary use and early cognitive impairment (Aramaki et al., 2016), there

is a definite role for SLTs in this assessment process. In addition, communicative interventions which focus on protecting and maintaining communicative functioning have been shown to be effective with people with moderate-severe dementia, without DS (Swan et al., 2018). In keeping with the declaration of human rights, people with DS should be afforded the same intervention opportunities.

In our third research question we looked at the profile of service delivery model across each of the educational stages. Our results show clearly that one to one therapy is the most common model of service, in the preschool and primary years. Better outcomes are reported in the DS intervention literature if therapy is individualized (Karaaslan & Mahoney, 2013; Kaiser & Roberts, 2013), however, not at the dose frequency reported here. Our results also show that group work (with parents and children) is more evident in preschool than at any other stage. This model usually takes the form of parent-mediated interventions, for this age group in Ireland, and studies have reported intervention effects for parents (e.g. Girolametto et al., 1998). However, as previously stated we do not see effects for children's overall language, unless the dose frequency and cumulative intervention intensity are high (O'Toole et al., 2018). In addition, this places much of the responsibility for intervention on to parents without giving them the ongoing mentoring and support to deliver it effectively.

In our next research question, we asked how satisfied parents were with the current level of service and if adults with DS were happy with their SLT. Parent responses reflect a bleak level of satisfaction and it is clear that with such low levels of input, it is very difficult to form relationships; develop a support system; and develop the social aspects of collaboration, which are central to the success of intervention programmes that involve parents, therapists and teachers/ educators working together (Carroll & Sixsmith, 2016; McKean et al., 2017).

Lastly, we asked parents what supports they believe they need in relation to an adequate SLT service and what adults would like help with in therapy. Interestingly, the majority of adults

indicated that speaking clearly was something that was important to them and an area that they would like help with. Speech Intelligibility has been shown to improve in adults with DS following two 3-month intervention periods (Terband et al., 2017) and following 18 sessions over a six week period, and yet no such interventions were reported to be available for this group. Our finding in relation to parent responses, revealed 7 themes focusing on a broad range of areas. Families showed an awareness of the range of domains in which a speech and language therapist could have input; they were aware of the need for support across the life span; and the different forms that the support could take. They outlined what they believe would be a quality service and the need for the service to be regular and frequent as well as evidence based. They also expressed disappointment and anger at the quality of service currently offered. Individuals, and parents of those with DS, belong to an international community and are aware of the potential benefits that a more intensive service could have for their son / daughter.

The way forward

Clearly the situation is only going to be resolved with significant investment into SLT services. SLTs are required to support people with DS across all communication settings and to work collaboratively with significant others in the individual's life. The predominant current SLT service provision in clinical settings is problematic, and impacts on both the accessibility and efficiency of the service. Policy makers need to integrate SLT provision in to educational settings to minimise time away from education and to facilitate trans-disciplinary working and skill transfer. In their 2014 report, Inclusion Ireland highlighted that the current public SLT services cannot meet the needs of those with ID and their families in Ireland. However, it is clear that the health service is not prioritizing SLT services in how funds are being allocated.

The allocation of resources to support quality professional development is also essential to disseminate evidence based research and to ensure high standards of service delivery. In

addition, there is a need for clinical SLT specialists in the field of ID (a post that exists in other clinical areas of SLT practice) to help promote the systematic application of research findings to practice. Finally, given the current levels of satisfaction and the fight for services, people with DS and their families should be given the opportunity to be involved in strategic planning at both local and national levels.

Conclusion

In conclusion, our findings are clear, in indicating that our aspiration for evidence based SLT practice is far from being realized. In this paper we explored aspects of two out of the three pillars of evidence-based practice (the client's needs and preferences and the best available research evidence), however we did not formally explore the contribution of the clinical practitioner, in determining what and how SLT services are offered. It is therefore possible that their opinion is taking precedent in service delivery. However, it would seem far more likely that services are determined by what funding models insist on. Under financial pressure, the solution used is to give as many people possible some interaction with the service, regardless of the evidence of whether it is sufficient to affect outcomes. HSE performance indicators are how many people have been seen for assessment within 1 year and for treatment within an additional year. The service has therefore become so diluted that there is not enough input to ensure that any individual reaches their potential. Clearly, targeted and strategic investment is needed to allow practice to be aligned with best evidence and to support and treat people with DS effectively, thereby allowing them to achieve their life goals and to exercise their right to communicate.

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Supporting Information

Figure S1: Frequency of SLT sessions received during 2019 by age group

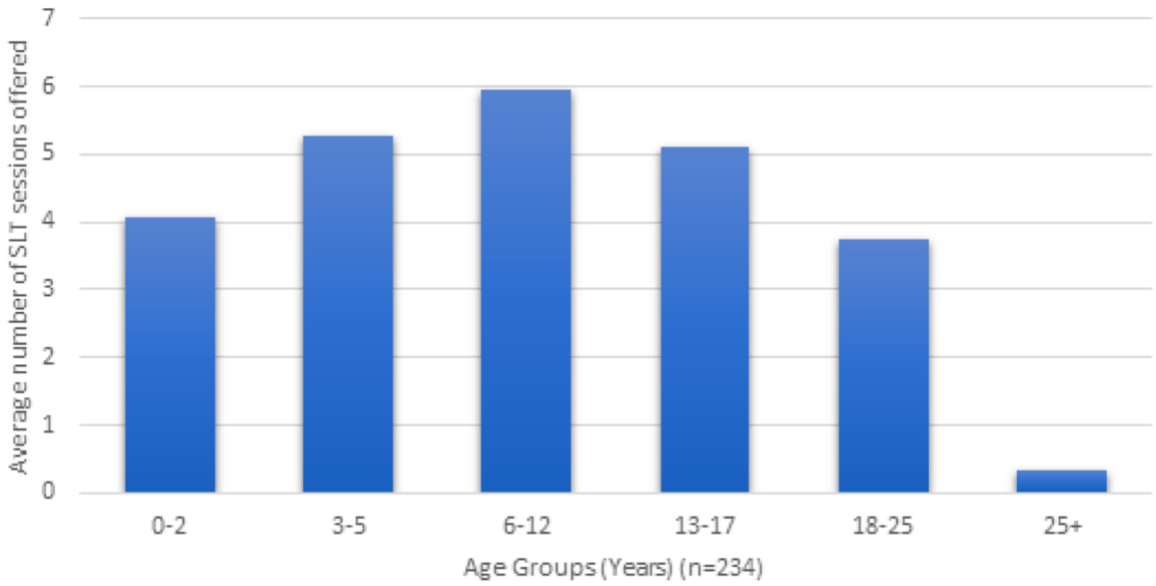


Figure S2: Type of Service Provision by Educational Stage

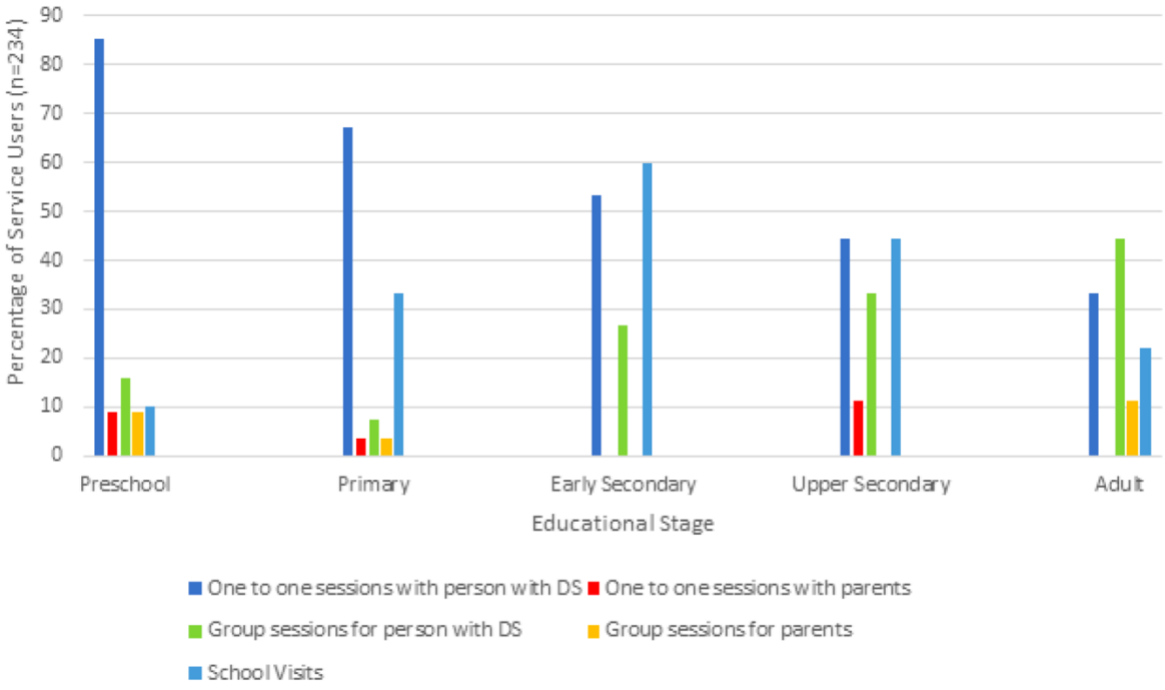


Table S1: Counties of Residence of survey respondents

Parents of children/adults with Down Syndrome Respondents		
County of Residence	**n**	**Percentage %**
Carlow	3	1.2%
Cavan	7	2.8%
Clare	7	2.8%
Cork	26	10.3%
Donegal	3	1.2%
Dublin	28	11.1%
Galway	21	8.3%
Kerry	9	3.6%
Kildare	10	3.9%
Kilkenny	6	2.4%
Laois	2	0.8%
Leitrim	2	0.8%
Limerick	8	3.2%
Louth	5	1.9%
Mayo	34	13.5%
Meath	23	9.1%
Monaghan	4	1.6%
Offaly	3	1.2%
Roscommon	4	1.6%
Sligo	9	3.6%
Tipperary	9	3.6%
Waterford	13	5.2%
Westmeath	3	1.2%
Wexford	11	4.4%
Wicklow	2	0.8%
Total	252	-

Note: county information was only required where participants responded 'yes' to 'Was your son/daughter offered speech and language therapy services in 2019?'.

Table S2: List of Themes, Subthemes and Codes

Theme	**Domains requiring support**						
Subthemes	FEDS Support	Total Communication Support	Comorbidities and additional needs	Speech, Voice and Oromotor Function	Written Language	Language	Fluency
Codes	-Baby/ paediatric FEDS -FEDS general -FEDS Assessment -Specialist FEDS support	-Lamh support -Technology use -AAC -PECS	-Hearing support -Cleft palate support -Bilingual support -Autism support	-Speech sound production support -Apraxia of speech support -Non-verbal support	-Phonics -Reading support	-Language support (syntax/sentence production) -Language support (general) -Language (grammar)	-Stutteri

				-Oromotor structure & function -Intelligibility -Voice support		-Language support (receptive) -Language (vocab) -Memory	
Theme	**Quality Service**						
Subthemes	Evidence Based	Easily Accessible	Transparent	Flexible	Personalised	Goal-lead	Qualifie
Codes	-Support in line with best practice guidelines -Research/ evidence based practice	-Had to advocate for support -Had to complain to get support -More easily accessible service- without bureaucracy - Locally accessible support	- More transparent process around accessing service -Transpar ency around waiting list	-Support that suits parent schedule -More flexibility with appointments from service	-More attentive support -Personal ised support, not generic parent advice -Personal ised support- not see & learn -Individual ised support -Appropriate to skill level -Enjoyable therapy - Functional therapy	-Goal setting -Planned approach	-Qualifi staff -Experie /qualifie -Experie /qualifie not stud -Qualifi therapis specialis DS
Theme:	**How often is support required?**						
Subthemes	Regular Support	Frequent Support					
Codes	-More regular support -Regular/ continuous support	-More frequent support					
Theme:	**Support across the lifespan**						
Subthemes	Early support	Age appropriate support	Support beyond primary school years	Support into adulthood			
Codes	-Early language support -Early support of any kind -Regular support early on -Early support- prior to starting school -Early support is essential	- Age appropriate support -Age appropriate/ad olescent support	-Support beyond primary school years -Support into secondary and beyond -Support beyond primary/early secondary	-Support into adulthood -Long term/ongoing support -Support beyond school years			
Theme	**Support during COVID-19**						

Subthemes	COVID affected service	In person support needed					
Codes	-Support during COVID needed -COVID affected service	-In person support needed -Face to face support needed					
Theme	**Form of support**						
Subthemes	One to one vs Group	Assessment	Support at home	Support at school	Staff training	Parent training and involvement	Direct s
Codes	- One to one support -One to one support not group -Group support -small group support	-Assessment -Regular assessment	-Home activities -More concrete support around home activities -Resources for use at home -Practical/ achievable home activities - Home visits -Support at home	-More collaboration with school -Support in school-mainstream -School visits -Therapy delivered in school -Language goals integrated with school/academic goals	-Teacher training -Day centre staff training	-Parent training -Parent support -Communication with parents -Parent/ family involved -early language support (see and learn) -Early language support (hanen) -Advice/ knowledge of language development	-Direct support parent a -Direct support home activitie -Direct parent le -Direct support-teacher training -Direct support-relying parents/rs -Less homewo ance on parents - Therap assessm
Theme	**Quality of current support**						
Subthemes	Support only from private/charity SLT	Support is from other resources, not public SLT	Public service is poor	Satisfied with current support	Other		
Codes	-Private SLT -Charity SLT	-Support coming from other resources not SLT -Support coming from parent initiative - Public SLT not responsible for progress	-Frustrating lack of support -Good therapists but bad infrastructure -Waiting lists -Public service poor	-Happy with service -Support in school is good -Very satisfied -Satisfied -Excellent therapist -Therapy is good when provided -Service accessible if needed -No support needed	-No support recently -Not sure/don't know		

Themes total:	7
Subthemes total:	39
Codes total:	139

Table S3: Themes, subthemes and supporting quotes: "What supports do you and your family require from speech and language therapy?"

Main Theme	Subtheme	Quotes
Domains requiring support	FEDS	"Immediately when born tips on bottle and breast feeding"
		"My son has an eating and speech disorder […] since he turned 18 there's been NO speech and language services at all."
	Total Communication	"He uses AAC but no support for this either"
		"Information & use of Lámh at an early stage for the whole family - baby & older siblings & parents"
	Comorbidities and additional needs	"[…] especially with a child who has hearing issues should be a priority extra support.
		"My child is non verbal and has autism as well so a lot more input in terms of one on one intensive therapy"
		"he also has a cleft palate which was repaired when he was 1 year old"
		"I'm Spanish and I work really hard with my daughter every day, so she can talk and understand English and Spanish".
	Speech, Voice and Oromotor Function	"How to articulate properly… He gets so frustrated when people don't understand him"
		"his speech is not always clear and he does not always project his voice"
	Written Language	"Emphasis at this stage on […] expanding reading and comprehension"
	Language	"It would be helpful to him to have help in forming a proper sentence"
		"Help with vocabulary and communication"
	Fluency	"Clarity of speech and fluidity"
	Pragmatics	"Group sessions with other young adults to encourage him to speak in

		more detail, and to form lasting friendship".
	Support to foster inclusion/increase quality of life	"Support being able to communicate in the community better"
		"Developing confidence to communicate in different social and employment situations"
Quality Service	Evidence Based	"I feel no new techniques, new approaches or models or extensive investigations are done to why children with DS take so long to speak."
	Easily Accessible	"More sessions without having to fill out referral forms every time a block of sessions ends"
		"It has been the one service we have had to constantly fight for, for him"
		"I had to complete a "your service your say" in order to just meet with the SLT in Galway EI"
	Transparent	"[…] at the very least communication from them informing us of where we are on the list"
	Flexible	"we managed to get two sessions I think at extremely inconvenient times with no regard to my other kids whom I also need to collect or drop to school. […] Therapist need to work better at arranging appointments."
	Personalised	"Appropriate progressive SLT that addresses his individual needs. Group work could be part of this but it must fit my child's SLT needs profile not just be put into a group and the services report that my son is being seen by SLT services to tick a box of service provision"
		"There was very little in the way of tailored guidance specific to her needs. Everything was generic",
	Goal led	"a plan in place with goals to be attained. This has never been offered"
		"More guidance & setting goals to be able to move on"
	Qualified Staff	"Regular sessions with qualified SLT specialising in Down Syndrome"
		"continuous therapy from a qualified therapist with actual work experience"

	Multidisciplinary support	"[there is] no joining up of therapies e.g. liaising with Physio/OT"
	Staff continuity	"Consistency of therapy and therapists. Therapists constantly change. Hard for child to build any relationship"
		"I would like to see a consistent monthly appointment being given to my daughter - ideally seen by the same therapist. Each time she receive[s] public SLT it is a completely new therapist and it takes a few weeks for them to get to know the needs, strengths and weaknesses. It seems that she has more new assessments that interventions"
		"The HSE Speech and Language Therapist went on maternity leave and no cover was provided, our children were forgotten about."
	Support service transitions	"when we moved services and were not given admission to the other service provider in the way they had told us we would"
How often support is required	Regular support	"Public Speech and language therapy lacks any consistency. When my daughter attends such therapy (once a year!) she is assessed just to see where she is at because they don't know her level due to a complete lack of any regular appointments and no consistency".
	Frequent support	"The only service she had at moment is through the KIDS team and only having 2 sessions a year is way too little feel she should have a service every 2 weeks"
		"MORE speech & language sessions. Everything has been cut and being seen once every 6 weeks or so is scandalous and very hard to see progress"
		"Any sessions would be nice
		"Simply any form of speech therapy"
Support across the lifespan	Early support	"Every child - Early Intervention - should receive it weekly. early years are crucial for their development",
		"In my opinion, seeing an SLT once every few months, at best, does not equate to early intervention".

	Age appropriate support	"Plans or services provided are too babyish fit our daughter and have not changed"
		"Given my daughter's age, she now requires group sessions with her peers, around social communication, developing her speech and language skills in a manner that is age appropriate"
	Support beyond primary school	"when he was 13 as he would get speech therapy at school. He did speech therapy in the 1st year and 2nd of secondary school but has received no therapy in last couple of years"
		"after he was 14 we were told he does not need [therapy] no more!"
	Support into adulthood	"Comprehensive and regular service as speech seems to deteriorate in Adults in a lot of cases and definitely in ours"
Support during COVID-19	COVID-19 affected service	"Due to COVID there hasn't been any sessions... despite my efforts at home my child's speech has regressed and she has developed a stammer"
		"More therapy... very few services offered. And especially now in COVID times we have had absolutely nothing Since January"
	In-person support needed	"I do know with Covid things are a lot harder but my daughter does need a one to one. We did a feeding review via zoom last week but this is practical going forward as her Dad has to take time off work to hold the phone during review as I had to feed [her]"
		"at moment because of covid we have no speech therapy getting handout in the post is not very helpful parents are tired and exhausted especially now after months of home schooling on top of every other service we expected to deliver."
Form of support	One to one vs group	"More individualised therapy rather than class based where students are at different levels of speech"
		"to receive regular therapy particularly group sessions to encourage confidence in social situations"
	Assessment	"An annual review/ assessment would be very helpful measure improvements and set goals for further work"

	Support at home	"We require experienced SLT, 1hr fortnightly, at home service as our own environment will see the most progress"
	Support at school	"One on one SLT that could be provided in the school setting as the service is just across the road from the school. My son is not cooperative when he goes to the service that's why the school setting suits"
	Staff training	"we hope (if we are lucky to be able) to continue with the public therapist to have her focused on the school and giving supports to the teachers who very much need it to ensure my son's integration in school."
		"Regular sessions in day unit as staff often leave so training needs to be ongoing"
		"She has had an introduction to PECS which worked well for her, but carers in her day centre don't use it"
	Parent training and involvement	"sessions with family to update on how we can add benefit to the process at home on a continuous basis"
		"Parental attendance to see and learn the therapies and be able to reproduce them at home"
	Direct involvement	"a hands on approach from therapist not expecting us parents to be the speech therapist which I have experienced over the years"
		"Therapists content to do the bare minimum. Passing the baton all too eagerly to an already overburdened parent or the SET teacher. Far from satisfactory."
Quality of current support	Support only from Private/Charity SLT	"Her needs are being met by us, her parents and through access to private Speech and Language Therapy which is regularly adjusted according to her progress or difficulties"
	Support is from other resources not public SLT	"What progress our child has made is entirely due to our local branch Saturday school and the private Speech Therapy we have been able to access (and able to pay for!) and the fact that I have over 10 years experience working with Infant children as a Primary teacher"

	Public service is poor	“My son has an on-going need for therapy and probably always will but as a family we know this will be done privately. What is offered for "free" is not satisfactory.”
		“A SLT service free from the state that is fit for purpose”
	Satisfied with current support	“I am very satisfied with the SLT services we received in 2019 as my son receives them at school.”
	Other	“Don’t know”
		“Not sure”
		“She currently does not require speech therapy”

Speech and Language Therapy Services for people with Down Syndrome of all ages

If you want to take part in the survey please tick the boxes to give consent and then go on to the survey. This survey will take only 2 - 3 minutes. If you have any questions, please contact Nicola Hart at Down Syndrome Ireland.

Consent

1. I understand that this is a research study run by Down Syndrome Ireland and that UCC are assisting us with this project. I understand that the results may be published and used to highlight strengths and weaknesses of current therapy provision. All data gathered will be anonymous.

   Yes ☐

   No ☐

2. I consent to participate in the study

   Yes ☐

   No ☐

Criteria

3. Please choose the one that applies to you

   ☐ I am the parent/guardian of a child or adult with Down Syndrome

   ☐ I am the parent/guardian of a child or adult with another disability

   ☐ I am an adult with Down Syndrome

General Information

Questions should be answered based on your experiences of public Speech and Language Therapy services during 2019 (1st January - 31st December 2019)

4. How old is your son or daughter?

5. What does your son or daughter do in the day usually? (Tick all that apply)

☐ At home

☐ Mainstream preschool

☐ Special preschool

☐ Mainstream primary school

☐ Mainstream post primary school

☐ Special class in mainstream school

☐ Special School

☐ Adult day service

☐ Adult education

☐ Work experience or voluntary work

☐ Paid employment

☐ Residential service

Other

Speech and Language Therapy

Questions should be answered based on your experiences of public Speech and Language Therapy services during 2019 (1st January - 31st December 2019)

6. Was your son or daughter offered public Speech and Language Therapy during 2019? (Speech and Language Therapy that you did not pay for)

   Yes ☐

   No ☐

7. If No, is your son or daughter on a waiting list for Speech and Language Therapy?

   Yes ☐

   No ☐

8. If Yes, How long has your son or daughter been on a waiting list for Speech and Language Therapy?

9. What county does your son or daughter access Speech and Language Therapy in?

10. What town does your son or daughter access Speech and Language Therapy in?

11. How often was this Speech and Language Therapy service offered during 2019?

    ☐ Weekly

    ☐ Fortnightly

    ☐ Monthly

    Other

12. What was the approximate number of sessions you received between January 2019 and December 2019?

13. How was this Speech and Language Therapy service provided? (Tick all that apply)

☐ One to one sessions for your son/daughter

☐ Group sessions for your son/daughter

☐ One to one sessions for parents

☐ Group sessions with other parents

☐ School visits

14. Please tick the areas of need your son or daughter was receiving support for from Speech and Language Therapy

☐ Speech, Language or Communication

☐ Feeding, Eating, Drinking or Swallowing Difficulties

15. How satisfied are you that the services provided by public Speech and Language Therapy services met your family's needs in 2019?
Please rate your level of satisfaction along the scale

0	1	2	3	4	5	6	7	8	9	10

Not at all satisfied Extremely satisfied

16. What supports do you feel you and your son or daughter requires from Speech and Language Therapy? Please describe

Easy-Read version for adults with Down Syndrome

General Information

Please answer the questions about any Speech and Language therapy you got during 2019.

1. How old are you?

2. What do you usually do in the day (before the lock down): Tick all the things you do

   ☐ At home

   ☐ Work experience

   ☐ Volunteer work

   ☐ Paid work

   ☐ Adult education

   ☐ Day centre

   Other (please tell us)

3. Did you go to Speech Therapy in 2019?

   Yes ☐

   No ☐

4. If yes, where do you go to speech therapy?

5. Are you still waiting for speech therapy?

   Yes ☐

   No ☐

6. How many times?

7. Did you have therapy on your own?

   Yes ☐

   No ☐

8. Did you have therapy in a group?

   Yes ☐

   No ☐

9. Was the therapist helping you with talking or signing?

   Yes ☐

   No ☐

10. Was the therapist helping you with eating and swallowing?

Yes ☐

No ☐

11. Are you happy with your speech therapy?

Yes ☐

No ☐

12. Would you like a speech therapist to help you with any of these?

☐ Speaking more clearly

☐ Learning new words

☐ Practicing talking

☐ Practicing signing

☐ Swallowing

☐ No thanks

Something else (please tell us)

13. Would you like more or less speech therapy?

☐ More

☐ Less

☐ The same