

Examining Factors Affecting Parent/Carer Satisfaction of NHS SLT Provision for Primary School Aged Children with Down's Syndrome

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Examining Factors Affecting Parent/Carer Satisfaction of NHS SLT Provision for Primary School Aged Children with Down's Syndrome

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Abstract

Background: This study investigated parent and carer satisfaction with National Health Service (NHS) speech and language therapy (SLT) provision for primary school aged children with Down's Syndrome (DS). Children with DS commonly experience speech, language and communication needs, yet little is known about how families experience NHS SLT provision in practice.

Aims: The study aimed to examine whether age of first support, intervention content breadth, dosage, and access to parent training predicted satisfaction. It was hypothesised that earlier support, broader intervention content, greater dosage, and access to parent training would each be associated with higher satisfaction.

Method: A quantitative cross-sectional survey design was used, recruiting parents and carers online through support networks and social media. Data was collected using an anonymous survey and analysed using descriptive statistics, assumption testing, simultaneous multiple linear regression, and an exploratory model examining perceived child progress and external support factors.

Results: The final sample comprised 199 participants, the majority of whom were women, aged 35-54, and university educated. Most families reported low satisfaction with NHS SLT provision. Dosage was the strongest predictor of satisfaction, followed by intervention content and parent training, while age of first support was not a significant predictor. Higher satisfaction was also associated with greater parent-reported progress, and external support appeared to strengthen, but not replace, NHS provision.

Conclusions: These findings suggest that family satisfaction is shaped more by the consistency and breadth of current provision than by how early support began. Improving access, widening intervention content, and increasing parent training may improve family experience of NHS SLT services for children with DS.

Keywords: *Down's Syndrome; NHS speech and language therapy; parent/carer satisfaction; primary school aged children; service provision*

What this study contributes

Children with Down's Syndrome (DS) commonly experience speech, language and communication needs requiring specialist speech and language therapy (SLT). Previous literature identifies variation in provision and concerns about service adequacy, but limited recent evidence exists on how parents and carers experience NHS SLT provision in practice.

This study finds that parent/carer satisfaction with NHS SLT provision for primary school aged children with DS is low. It shows that satisfaction is more strongly associated with dosage, breadth of intervention content, and parent training than with age of first support, and suggests that external support does not fully offset dissatisfaction with NHS provision.

Accessible summary

- This study explored parents' and carers' satisfaction with NHS speech and language therapy (SLT) for children with Down's Syndrome (DS).
- This matters because children with DS require regular, specialist communication support. When help is limited or inconsistent, families may feel unsupported and children may have fewer chances to make progress with their speech and communication.
- Most families reported low satisfaction with NHS SLT services. Satisfaction was higher when support was more frequent, covered a broader range of intervention content, and included parent training.
- These findings reflect family experience, not direct clinical outcomes. Even so, they suggest that improving access, increasing parent training, and making support more consistent may improve satisfaction and experience.

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Contents

Pg. 1 **Introduction**

Pg. 6 **Method**

Pg. 11 **Results**

Pg. 19 **Discussion**

Pg. 27 **References**

Supplementary Materials:

Pg. 35 Advert

Pg. 36 Survey

Pg. 44 Supplementary Exit Survey

Pg. 45 Survey Insights (pre and post amendment)

Pg. 46 Survey Design - layout issue

Pg. 47 Raw Data Sample

Pg. 48 Data Sample after Preparation and Cleaning

Pg. 49 SPSS/Data analysis software output

Pg. 54 Supplementary Results Data

Pg. 55 Unsolicited Comments

Pg. 57 Electronic Storage Form

Introduction

Background

Each year in the UK, 700–750 babies are born with Down's Syndrome (DS), a genetic condition caused by an extra 21st chromosome (National Health Service [NHS], 2022). Characteristics of DS include low muscle tone (hypotonia), oral-motor difficulties, and neurological differences that result in speech, language, and communication needs (SLCN) in approximately 95% of cases (Miller, 2003). Impairments typically include reduced speech clarity, articulation errors, challenges with phonological processing, fluency disorders, and delayed speech and language acquisition (Baxter, 2025). Abbeduto et al. (2007) describe SLCN as the most significant constraining factor for people with DS, affecting relationships, independence, opportunities and overall quality of life. It is therefore crucial that consistent, high quality, evidence-based Speech and Language Therapy (SLT) is available for this population (Buckley et al., 2024; Burgoyne, 2020; Smith et al., 2020).

Despite this recognised need, less is known about how families experience NHS SLT provision in practice (Department of Health and Social Care [DHSC], 2025b). This study therefore examined parent/carer satisfaction with NHS SLT communication provision for primary school aged children with DS, using a survey design to investigate whether intervention timing, intervention content breadth, dosage, and access to parent training predicted satisfaction.

Intervention Timing

Current evidence shows that early SLT involvement can improve long term outcomes for children with DS, with support recommended from birth (Buckley et al., 2024; Smith, Hokstad and Næss, 2020). Burgoyne (2020) reasons that intervention during the pre-linguistic period is critical for building foundational language skills, for example, targeting early social communicative skills such as eye contact, turn taking, imitation, gesture and joint attention. Supporting this, Seager (2017) found that infants with DS who received a 10-week joint attention intervention achieved higher receptive vocabulary scores one year later compared to a control group, suggesting that such interventions may provide skills for faster vocabulary acquisition. However,

while results are compelling, the small sample size (*n* = 16) and reliance on parent reported measures via the MacArthur-Bates Communicative Development Inventory (MB CDI), limit generalisability (Marchman et al., 2023). More robust conclusions can be seen in Seager et al.'s (2022) systematic review of 11 studies, which highlights a major research gap: no standardised intervention exists for children with DS and clinical practice is poorly documented. This gap limits conclusions regarding the efficacy of interventions and highlights the importance of gathering detailed, descriptive data on current SLT experiences (Baksi, 2006; Down's Syndrome Association [DSA], 2021).

Intervention Content

The Down Syndrome Act 2022 brought increased attention to NHS SLT provision, with the government recognising a need for national standards (DHSC, 2025a). The call for evidence from the Royal College of Speech and Language Therapists (RCSLT, 2022, p. 5) found examples of good practice across the country but also identified significant local variation. A 2021 DSA guidance and survey report similarly highlights inconsistent SLT knowledge leading to inappropriate or insufficient support.

While children with DS exhibit individual differences with varied rates of progress, a typical communication profile exists (Burgoyne, 2020). This profile includes relative strengths in receptive language alongside substantial impairments in expressive language, phonology and pragmatics. Grammar also provides a particular challenge, and individuals with DS commonly use telegraphic speech, omitting grammatical markers and key words (Burgoyne, 2020; Næss et al., 2011; Smith et al., 2020). It is therefore important that any SLT working with a child with DS follows evidence-based practice by including therapy interventions covering the following four key components: communication, vocabulary, grammar and speech work (Buckley and Le Prèvost, 2019; DSA, 2021). In the present study, intervention content breadth refers to the extent to which provision covered these four recommended areas.

Dosage

Evidence shows that therapy for children with DS should be 'frequent, intensive and sustained' to ensure progress over time, with Burgoyne et al. (2012) suggesting a minimum of monthly sessions supported by daily practice (Burgoyne, 2020, p. 26;

Seager et al., 2022). Despite a high level of need, SLT provision for children with DS has been historically varied and limited, revealing disparity between research and practice (Frizelle et al., 2021; Laws et al., 2000). For example, Frizelle et al. (2021) found that children and adults with DS received an average of five sessions per year, with almost half of the children offered no service at all. Although this study is limited to Ireland, the findings echo qualitative themes identified across the UK, where provision is often described as a 'postcode lottery', with a lack of funding and therapists presenting parents with no alternative but to pay privately, use charity services or forgo the SLT support their child needs (Baksi, 2006; DSA, 2021; Kendall, 2017; RCSLT, 2018a; Robertson, 2025). This study aimed to update the literature on what service dosage typically looks like, as well as how it relates to parent/carer satisfaction.

Parent Training

Due to the gap between clinical need and available support, parent-led interventions are increasingly recognised as an important area of development within SLT, particularly where direct service provision is limited (Davies et al., 2019; Pritchard et al., 2024). Seager et al. (2022) found positive effects when interventions were co-delivered by parents, and notable changes in parental behaviour including increased responsiveness and improved therapy engagement. Benefits were also seen in Seager's 2017 study, which taught parents the strategy of Responding to Joint Attention; since SLT input was limited to weekly sessions, parent training enabled a consistent, integrated approach. Indeed, parent training acts as a protective factor when SLT input is limited, with long-term benefits well-documented (Goldberg, 2010; O'Toole et al., 2018; Pentimonti et al., 2022; Yoder et al., 2014). Furthermore, parent training can address the 'knowledge burden' often experienced by caregivers, providing a proactive approach that benefits the child and supports the wellbeing of the parent or carer (Barlow et al., 2014). This 'knowledge burden' refers to feelings of exhaustion experienced by parents of children with additional needs who feel responsible for their child's progress but lack the skills to effectively support them (Bøttcher and Dammeyer, 2025; Neilson and Ceng, 2024).

This study collected data on parent training to examine its prevalence and effect on parent/carer satisfaction and perceived progress. Current evidence suggests that

appropriate parent training for this population includes a range of approaches, with the following included in the survey:

- **Makaton**: A language system of signs and gestures used alongside spoken words. Makaton can enhance communication for individuals with DS, playing to relative visual strengths and supporting speech clarity (Clibbens and Powell, 1994; Clibbens, 2001; Groen et al., 2006).
- **Communication Partner Training for Augmentative and Alternative Communication (AAC)**: An approach that uses tools and systems to support or replace speech to reduce the linguistic and articulatory demands of spoken language, providing a functional method of communicating when speech is unclear or vocabulary is limited (Clibbens, 2001). AAC avoids any requirement for communication partners to be knowledgeable of a specialised language system (e.g., Makaton), making interactions more accessible.
- **Total Communication**: An approach where all methods of communication are accepted (speech, sign, gesture, text or symbols e.g., AAC) (RCSLT, 2023).
- **Parent-Child Interaction (PCI):** A type of intervention that teaches caregivers to follow a child's lead and increase communication opportunities, similar to the early social communication strategies described by Seager (2017) (Falkus et al., 2015; O'Toole et al., 2020; Pennington and Thomson, 2007). A recent, yet unpublished, feasibility trial used a DS-adapted version of the parent-led programme Parents and Children Together (PACT-DS) (Burgoyne et al., 2023).

Study Context and Purpose

The goal of this observational study was to examine parent/carer satisfaction with NHS SLT provision for children with DS, excluding feeding support and specialist clinics or pathways, to provide recent data on typical service access. The DHSC Equality Impact Assessment accompanying the Down Syndrome Act (DHSC, 2025b) identified limited evidence capturing the lived experiences of people with DS, especially regarding service provision. Consequently, incorporating parent and carer perspectives into this study was essential to help address this gap.

Previous research suggests satisfaction is likely to be low: Frizelle (2021) reported that almost 40% of parents selected “0” on a 10-point satisfaction scale, and the DSA (2021) found over two thirds of families felt provision did not meet their child’s needs. To address this gap, data was collected on intervention timing, intervention content breadth, dosage, parent training, and parent/carer satisfaction, alongside perceived progress. These variables were selected because they reflect the most consistently reported areas of need and variation in provision for children with DS. Understanding which specific factors drive satisfaction can highlight exactly where services need to improve and support ongoing calls for national standards.

Aim

The primary objective of this study was to examine how parent/carer satisfaction with NHS SLT provision was associated with the following factors, and to identify which had the strongest association:

- **Intervention timing**: How soon after birth did the child see a therapist?
- **Intervention content breadth**: Does the therapy cover the four key areas of communication, vocabulary, grammar, and speech work, as per Buckley and Le Prèvost (2019)?
- **Dosage:** How often do therapy sessions happen?
- **Parent Training**: What is offered?

Hypothesis

It was hypothesised that greater dosage, earlier intervention, access to parent training, and broader intervention content would be positively associated with higher parent/carer satisfaction.

Method

Design

This study adopted a post-positivist approach (Phillips and Burbules, 2000), utilising a quantitative predictive correlational design to examine how clinical factors predict parent/carer satisfaction. To mitigate subjective bias, the survey was standardised so that parent/carer subjective ratings could be analysed alongside objective service variables such as age of first support and session frequency. Single-item questions and checklists were used to capture clinical variables, rendering traditional internal consistency measures such as Cronbach's Alpha inapplicable (Laerd Statistics, 2018). A 4-point Likert scale captured NHS SLT satisfaction and child-specific progress scores to eliminate neutral options and central tendency bias (Chang, 1994), aligning with recent SLT questionnaires (Ikeda and Sasada, 2022; RCSLT, 2025). The survey was designed following accessible standards and guidance as per Communication Access UK (2026).

Content validity was supported through alignment with established clinical guidance. The four intervention content domains (communication, vocabulary, grammar, speech work) were drawn directly from Buckley and Le Prèvost's (2019) evidence-based recommendations for SLT provision for children with DS. Additionally, the draft survey was reviewed by the research supervisor to ensure item wording accurately reflected the intended constructs and was suitable for the target population.

The survey was pretested with a parent/carer focus group (N = 6) as per Lally et al. (2025) and Reem (2025). Members completed the survey independently before discussion. Feedback resulted in three revisions: simplifying intervention content descriptors, adding dosage band options, and including school input as an external factor. Participants confirmed items were interpreted as intended and completable within 15 minutes. Face validity was therefore supported, although test-retest reliability was not formally assessed due to time constraints.

Simultaneous multiple linear regression tested the hypothesis that earlier intervention, broader intervention content, greater service dosage, and access to parent training would positively predict parent/carer satisfaction with NHS SLT services.

Participants

Purposive sampling recruited UK-based parents and carers of primary school aged children with DS aged 4–12 years (allowing for deferred school entry). This range ensured sufficient experience with early SLT provision, whilst minimising recall bias and maintaining clinical relevance.

Eligibility items confirmed that participants were over 18 years old, comfortable completing the survey in English and fully knowledgeable about their child's NHS SLT input. The child must have lived in the UK from birth and be in receipt of NHS SLT support for communication.

To maintain a focus on standard SLT provision and ensure generalisability, children with co-occurring conditions impacting communication, such as structural differences (e.g., cleft palate) or neurobiological conditions (e.g., Autism Spectrum Disorder [ASD]), were excluded via an initial screening tool. The final sample consisted of 199 completed responses, exceeding Green's (1991) recommended minimum ($N \geq 82$) for a four-predictor regression.

Materials

Data was collected via an 18-item survey hosted on Jisc Online Surveys, chosen for its accessibility, ease of distribution, and suitability for collecting large volumes of data. As parents of children with additional needs are frequently described as 'time poor' (McCann et al., 2012), the survey was designed to take under 15 minutes to minimise attrition (Lally et al., 2025).

The survey comprised four sections: eligibility screening (7 items), demographics (4 items, covering parent/carer gender, age, educational level, and child age), service experience (1 item covering age of first SLT support) and intervention details (5 items covering types of intervention, session frequency, and parent training). As retrospective satisfaction may be misremembered (Reem, 2025), brief examples of each intervention category were provided to improve recall accuracy, reduce ambiguity, and increase consistency of interpretation. (See *Survey*; *Supplementary Materials*)

Two outcome measures were collected within the intervention section. The first measured parent/carer satisfaction with NHS SLT service provision, and the second

measured perceived child progress, which was child-specific and included an associated item for justification.

Response formats included multiple-choice and select-all-that-apply items. Session identifiers prevented duplicates, and no cookies or IP addresses were collected. Examples:

- Satisfaction: "*How would you describe your overall level of satisfaction regarding the support your child has received from NHS SLT services for speech and communication?*", rated from 1 (Very Dissatisfied) to 4 (Very Satisfied).
- Dosage: "*On average, how often is your child seen by NHS SLT services for communication?",* multiple-choice (bands of twice weekly up to 12 months+)

Procedure

Ethical approval was granted by the Manchester Metropolitan University Faculty of Health and Education Research Ethics Committee (Ref: 90013). The survey was live from 1st April to 10th May 2026.

Recruitment utilised an open online invitation. A digital advert containing a study description, QR code, and survey hyperlink was shared across social media platforms and national and regional DS support groups, including the DSA. An ethical amendment midway through data collection permitted in-person recruitment at Chatterbox, a monthly support group run by the South Manchester Down's Syndrome Support Group (SMDSSG), where printed copies of the advert were distributed.

Participants reviewed an electronic participant information sheet (PIS) and provided mandatory electronic consent before accessing the survey. Mandatory response validation applied to all items prevented missing data. A layout issue causing 48 incomplete responses was resolved, and the recruitment period was extended by seven days, increasing the sample to 199. (See *Survey Design - layout issue; Supplementary Materials)*

Participants screened out due to ineligibility were directed to a voluntary two-question supplementary exit survey exploring reasons for non-completion. As this measure was introduced later in the recruitment period, only 15 responses were obtained.

Data Analysis Plan

Following Meersman and Mathieson (2019), quantitative analyses were conducted using IBM SPSS Statistics (Version 30). Although measured via single items, satisfaction, perceived child progress, age of first support, and service dosage were treated as continuous variables, as parametric linear models are robust to restricted categorical ranges when categories follow a sequential, equal-interval progression (Carifio and Perla, 2007; Norman, 2010; Sullivan and Artino, 2013).

Intervention content checklist variables were summed to create a continuous intervention content breadth score, whilst the child-specific progress driver scale was treated as a continuous predictor. Parent training was dummy coded as a binary variable (0 = no, 1 = yes; see *Supplementary Materials* for the full coding key*).*

Descriptive statistics were calculated for all variables, with frequency distributions visualised using histograms and bar charts. Assumptions of normality (Shapiro-Wilk) and multicollinearity (Variance Inflation Factors) were verified prior to analysis.

Simultaneous multiple linear regression tested how earlier intervention, greater service dosage, broader intervention content, and access to parent training predicted parent/carer satisfaction with NHS SLT services. Moderation analyses utilising the PROCESS macro (Model 1; Hayes, 2022) evaluated whether external supports (private SLT, school provision, and parent-led intervention) moderated the satisfaction-progress relationship. This was exploratory, drawing on evidence that families often compensate for limited NHS provision (DSA, 2021; Frizelle et al., 2021). Findings should be interpreted cautiously and require replication.

Some participants and non-participants provided comments on Facebook posts advertising the survey. These were not systematically coded or analysed using qualitative methodology and therefore excluded from the statistical analysis. Those from consenting participants were reviewed and utilised to provide context to specific issues.

Ethical Considerations

Participation was voluntary, confidential and grounded in informed consent. Participants could withdraw at any point before submission by closing their browser. Pseudonymised data was stored securely on a password protected, university

approved OneDrive network, with access restricted to the researcher and supervisor. In accordance with GDPR guidelines, raw data will be destroyed after two years.

Potential emotional distress from reflecting on service delivery was explicitly flagged in the PIS. Items were framed sensitively, clarifying that SLT support is individualised, meaning children were not expected to have received all listed interventions. Upon completion, participants were signposted to DS SLT resources, support groups and organisations.

Reflexivity Statement

As a student Speech and Language Therapist and the parent of a child with DS, my dual positionality provided deep insights into participant experience but also introduced potential bias. To protect analytical objectivity, all research aims, screening protocols, and data analysis plans were predetermined, with ongoing supervisory support used to maintain reflexivity and objectivity throughout the research process.

Results

Data analysis was conducted in accordance with the data analysis plan across three phases: data preparation and cleaning, preliminary assumption testing, and inferential testing. The primary inferential analyses were designed to examine which service-related factors were most strongly associated with parent/carer satisfaction.

Data preparation and cleaning

Raw data was exported from Jisc Online Surveys into Microsoft Excel for initial screening and variable coding (see *Supplementary Materials* for data samples). This dataset was examined for completeness; however, because mandatory response validation had been enabled within the survey platform, no missing data patterns were identified. The cleaned and prepared dataset was imported into IBM SPSS Statistics for analysis with a final sample of $N = 199$.

Descriptive Statistics and Preliminary Assumption Testing

Initial descriptive analyses examined the distribution of data across the sample and indicated moderate variability in the main study variables. (See *Table 1*)

To assess the assumption of normality, the data distributions of parent satisfaction and perceived child progress were first inspected visually using histograms and then assessed statistically using the Shapiro-Wilk test. The results indicated that both variables deviated from strict normality: perceived progress ($W(199) = .860$, $p < .001$) and satisfaction ($W(199) = .835$, $p < .001$). Despite this, multiple regression was retained because the sample size was sufficiently large ($N = 199$), providing statistical robustness against normality violations such as these (Ghasemi and Zahediasl, 2012).

To assess multicollinearity among the four independent variables, Variance Inflation Factors (VIF) and collinearity diagnostics were examined during regression analysis, as per Kim (2019). A strict diagnostic cutoff of VIF < 5 was applied, and all predictors fell well within this boundary, with VIF values ranging from 1.034 to 1.161. Collinearity diagnostics further confirmed acceptable variance inflation, with eigenvalues ranging from 4.133 to .049 and a maximum condition index of 9.190, which remained substantially below the standard threshold of 30. These findings

indicated that the four service factors were not excessively intercorrelated and that the assumption of multicollinearity was satisfied.

Table 1 presents a summary of the descriptive indicators, normality test results, and multicollinearity diagnostics.

Table 1: *Descriptive Statistics, Normality Tests, and Collinearity Diagnostics (N = 199)*

Variable	Measurement Type	Mean / Mode (Percentage)	SD	Skewness	Kurtosis	Shapiro-Wilk (*W*)	VIF
Satisfaction (DV)	Continuous (1–4)	(*M* = 1.93)	.835	.439	-.687	.835*	—
Perceived Progress	Continuous (1–4)	(*M* = 2.22)	.996	.195	-1.104	.860*	—
Service Dosage	Ordinal (1–9)	Mode: 12 months+ (35.2%)	—	—		—	1.127
Intervention Content	Continuous Sum (0–4)	(*M* = 2.29)	1.151	-.288		.853*	1.161
Parent Training	Binary Dummy (0–1)	Mode: Offered Training (52.8%)	—	—		—	1.034
Intervention Timing	Ordinal (1–8)	Mode: 1–2 years (24.6%)	—	—		—	1.036
External Support	Continuous Sum (0–3)	(*M* = 1.49)	.812	-.114	-.892	.841*	—

**Note.* SD = Standard Deviation; VIF = Variance Inflation Factor; DV = Dependent Variable. Model VIF checks were run concurrently during regression steps. *p < .001.

Descriptive analysis of the remaining service predictors revealed distinct trends in NHS SLT provision. These descriptive findings provide contextual information about the service-related factors before testing their association with parent/carer satisfaction.

For service dosage, the distribution was strongly skewed towards low-frequency provision. Over one-third of children (35.2%, *n* = 70) were seen only once every 12 months or more, and a further 11.1% (*n* = 22) were seen every 6–9 months.

Conversely, intensive provision was rare: weekly (*n* = 4, 2.0%) and twice-weekly (*n* = 2, 1.0%) sessions together accounted for only 3.0% of the sample (see *Figure 1*).

For intervention timing, most children accessed services before the age of 2 years (61.8%, *n* = 122), with the largest single group beginning intervention between 1 and 2 years of age (24.6%, *n* = 49). A relatively small minority (9.5%, *n* = 19) did not receive any input until age 4 or after (see *Figure 2*).

For intervention content, communication support was almost universal, reported for 95.5% of the sample (*n* = 190). Other content areas were targeted less frequently, with around half the sample receiving speech work (55.3%, *n* = 110) or vocabulary intervention (44.2%, *n* = 88), with grammar the least frequently targeted domain (35.2%, *n* = 70) (see *Figure 3*). Overall, the content breadth score indicated that children received support across just over two of the four intervention areas on average (*M* = 2.29, *SD* = 1.151).

Finally, for parent training, 52.8% (*n* = 105) of parents reported having been offered training, whereas 47.2% (*n* = 94) had not received any parent training input. Among those offered training, Makaton/signing was the most common (44.7%, *n* = 89), whilst AAC partner training (7.0%, *n* = 14) and Parent-Child Interaction sessions (11.1%), (*n* = 22) were comparatively underrepresented (see *Figure 4*).

Figure 1: *Distribution of NHS SLT Service Dosage (Session Frequency) (N = 199)*

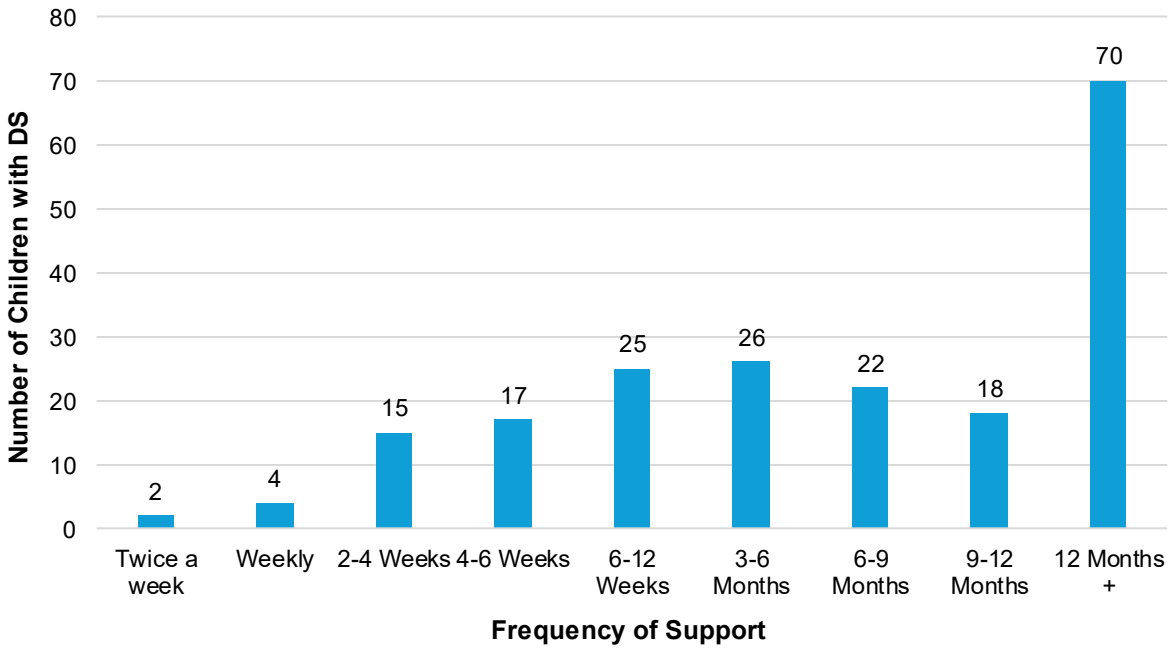


Figure 2: *Distribution of age of First NHS SLT Communication Support (N = 199)*

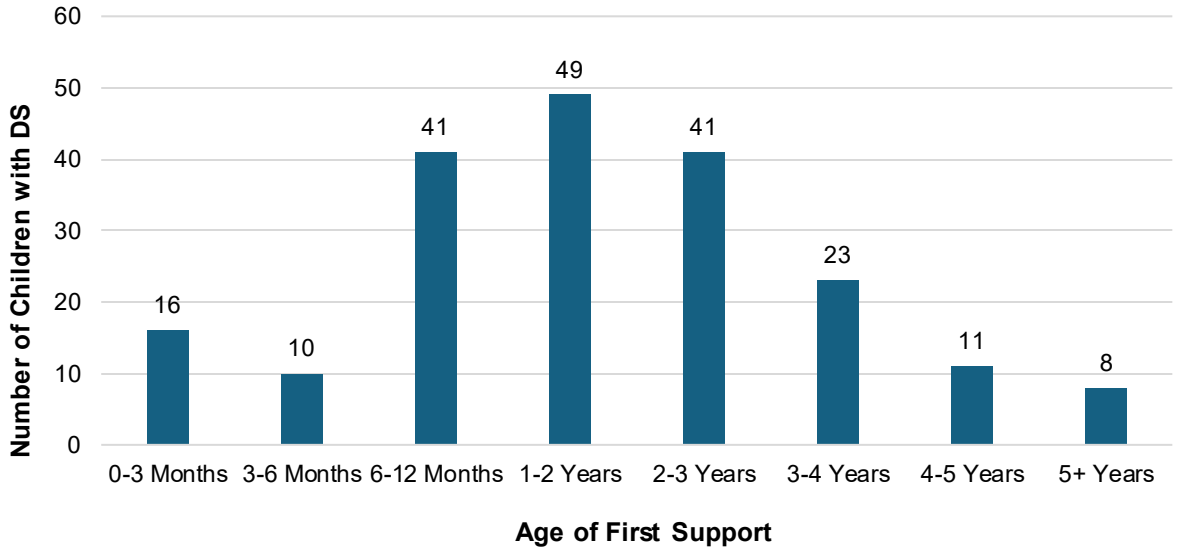


Figure 3: *Distribution of Four Targeted Areas within NHS SLT Intervention (N = 199)*

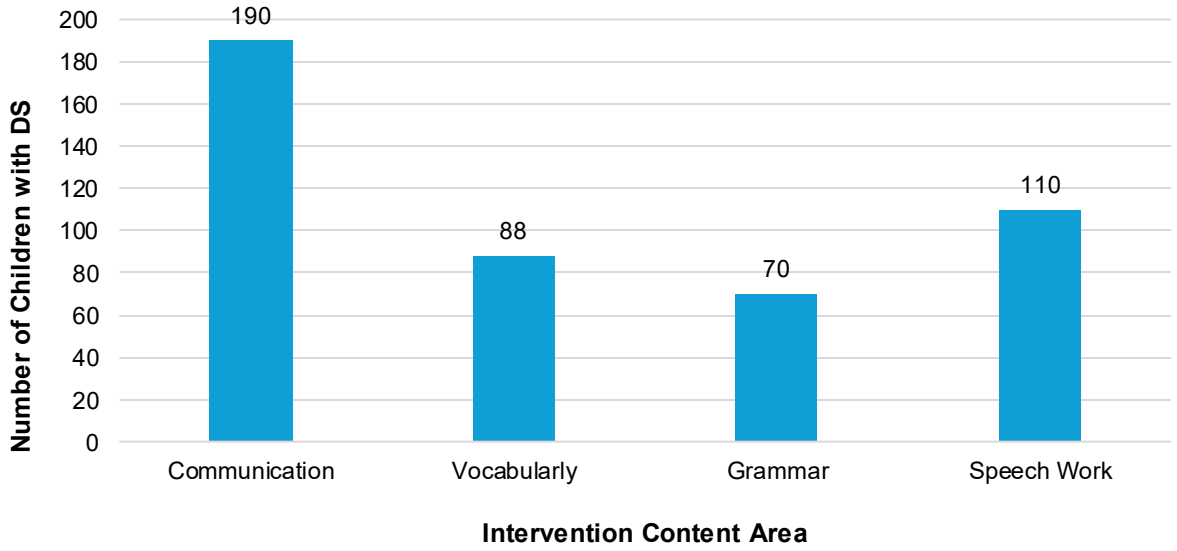
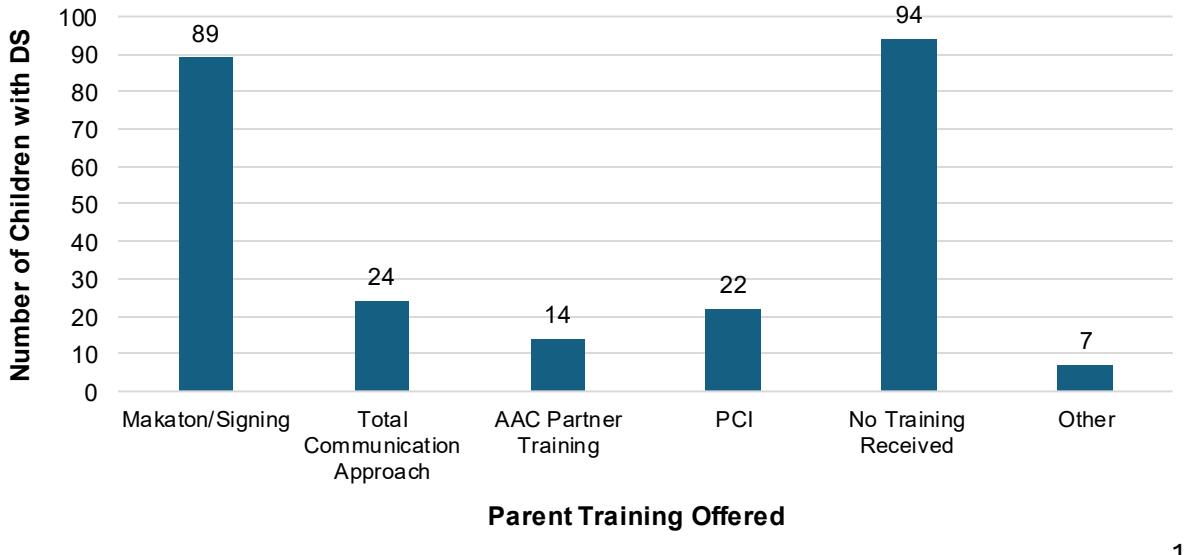


Figure 4: *Distribution and types of Parent Training Offered by NHS SLT Services (N = 199)*



Inferential Testing

Primary Hypothesis Testing

To address the primary study objective, a simultaneous multiple linear regression was conducted to test the hypothesis that earlier intervention timing, greater service dosage, broader intervention content, and access to parent training would predict higher levels of parent/carer satisfaction. The overall model was statistically significant, F (4, 194) = 14.873, p < .001, and explained 23.5% of the variance in satisfaction scores (R^2 = .235, adjusted R^2 = .219).

Standardised regression coefficients were examined to determine the relative contribution of each predictor. Three of the four predictors were statistically significant. Service dosage emerged as the strongest predictor of satisfaction, β = .243, t = 3.638, p < .001, followed by intervention content breadth, β = .229, t = 3.383, p < .001, and parent training, β = .213, t = 3.330, p = .001. Intervention timing was not a statistically significant predictor (β = -.112, t = -1.746, p = .082).

Overall, these findings indicate that the four service factors were not equally associated with parent/carer satisfaction. These findings directly addressed the primary study objective by showing that greater service dosage, broader intervention content, and access to parent training were each associated with higher satisfaction, whereas intervention timing was not a significant predictor. Of the variables included in the model, service dosage had the largest unique contribution.

Full regression parameters are presented in *Table 2*.

Table 2: *Simultaneous Multiple Linear Regression Results Predicting Parent Satisfaction (N = 199)*

Predictor	B	SE	β	t	p	95% CI
(Constant)	1.281	.196	—	6.522	< .001	[.894, 1.669]
Service Dosage	.092	.025	.243	3.638	< .001	[.042, .141]
Intervention Content	.170	.050	.229	3.383	< .001	[.071, .270]
Parent Training	.355	.107	.213	3.330	.001	[.145, .566]
Intervention Timing	-.055	.031	-.112	-1.746	.082	[-.116, .007]

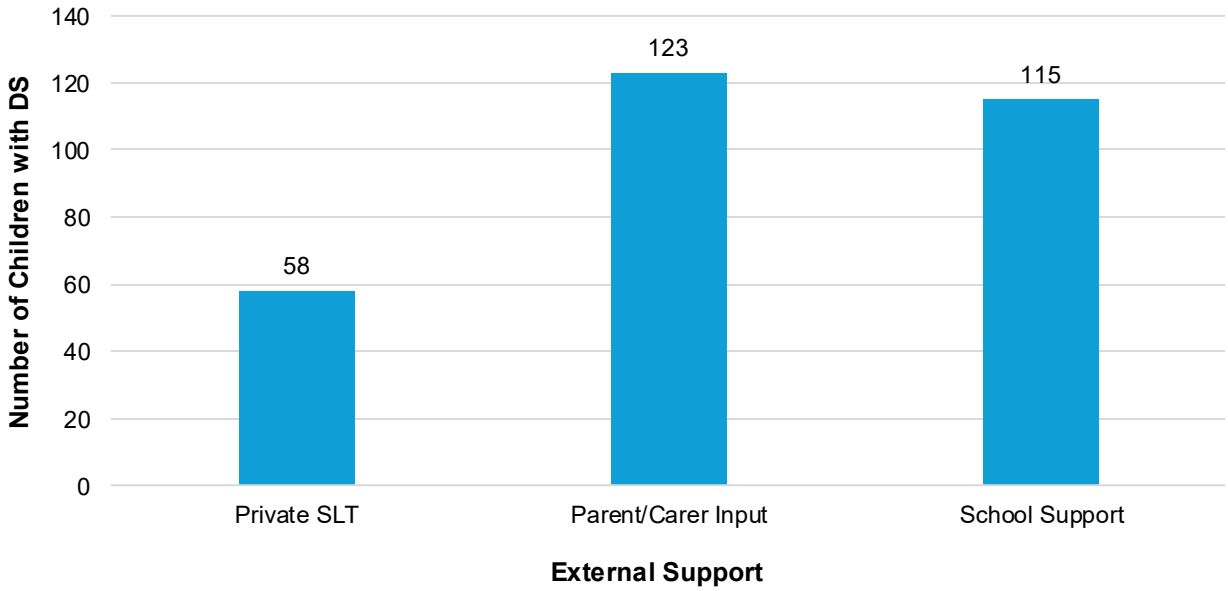
Note. B = unstandardised coefficient; SE = standard error; β = standardised coefficient; CI = confidence interval [Lower Bound, Upper Bound].

Exploratory Analysis

In addition to the primary hypothesis testing, a non-parametric bivariate correlation was conducted to evaluate the relationship between parent satisfaction and perceived child progress. As the data departed from strict normality, Spearman's rho (ρ) was used. The analysis revealed a significant, weak positive correlation between the two variables, ρ (199) = .252, $p < .001$. This suggests that higher levels of parent satisfaction are associated with greater perceived child progress.

The three external support variables from Question 17 (progress driver checklist) were summed to create External_Sum. A substantial proportion of parent/carers attributed their child's progress to parent/carer input (61.8%), $n = 123$), just over half identified school support (57.8%, $n = 115$) and 29.1% reported private SLT involvement as a contributing factor ($n = 58$) (see *Figure 8*). Other checklist options included illness, COVID, quantity/quality of NHS SLT support and expected progress figures, but these were not included in the external support sum because they were considered child-specific or context-specific factors.

Figure 8: *Distribution of External_Sum progress drivers (N = 199)*



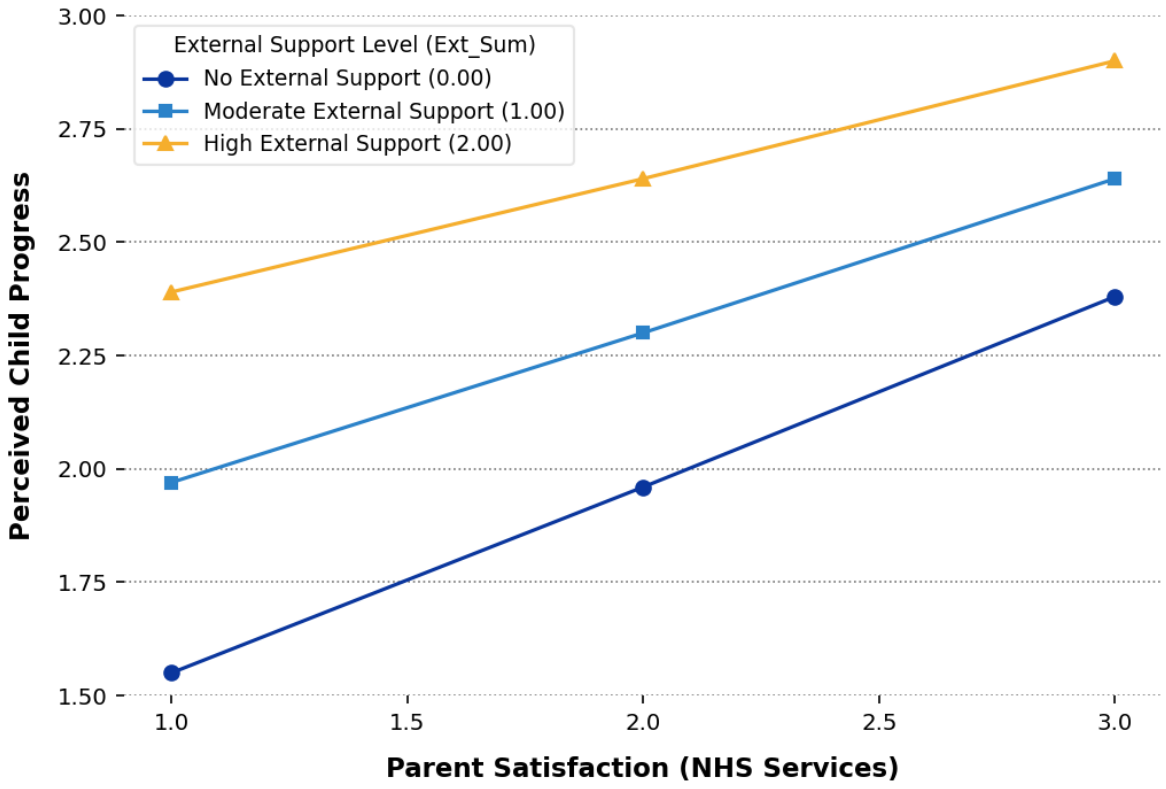
A moderated multiple regression using the PROCESS macro (Model 1; Hayes, 2022) was subsequently conducted to examine whether external support moderated the relationship between parent satisfaction (*X*) and perceived child progress (*Y*). The

overall model was statistically significant, $F(3, 195) = 12.42$, $p < .001$, and accounted for 16.0% of the variance in perceived child progress scores ($R^2 = .160$).

Parent satisfaction significantly predicted perceived child progress ($b = 0.413$, $t = 3.48$, $p < .001$, 95% CI [0.179, 0.647]), and external support also independently predicted perceived child progress ($b = 0.501$, $t = 2.45$, $p = .015$, 95% CI [0.097, 0.905]). However, the interaction between parent satisfaction and external support was not statistically significant ($b = -0.081$, $t = -0.78$, $p = .435$, 95% CI [-0.284, 0.123]).The addition of the interaction term accounted for only a non-significant increase in explained variance, $\Delta R^2 = .0026$, $F(1, 195) = 0.613$, $p = .435$.

As illustrated in the simple slopes plot (see *Figure 9*), both higher NHS satisfaction and greater external support were independently associated with higher perceived child progress; however, the relationship between satisfaction and progress remained stable across varying levels of external support. These findings suggest that external support did not moderate the relationship between NHS satisfaction and perceived child progress.

Figure 9: *Simple Slopes Plot Showing the Relationship Between Parent Satisfaction and Perceived Child Progress Across Levels of External Support (N = 199).*



Demographics

A total of 199 parents and carers met the full inclusion criteria for the study. The sample was highly educated, with 73% (*n* = 145) reporting university-level education, and consisted primarily of women, who accounted for 96% of respondents (*n* = 192). Most participants were aged between 35 and 54 years (91%, (*n* = 180). Children were distributed across the target range of 4-12 years, with a mean age of 7.6 years.

Supplementary Non-Completion Metrics

A brief supplementary exit survey was completed by participants excluded during screening procedures (*n* = 15). This data was descriptive only and was not included in inferential analyses because of the limited sample size. A full breakdown is provided in *Figure 10*; *Supplementary Materials.*

Unsolicited Comments

A full list of comments from consenting participants can be found in *Supplementary Materials.*

Insights

Survey platform metrics indicated a 43% completion rate, with 121 dropouts recorded, including 48 on the survey completion page, and 139 participants screened out. (See *Survey Insights*; *Supplementary Materials*).

Discussion

Most parents and carers (*N* = 199) had low satisfaction levels with NHS SLT communication provision, with a median rating of 2 ("unsatisfied"), consistent with previous literature (Baksi, 2006; DSA, 2021; Kendall, 2017; RCSLT, 2018a; Robertson, 2025). The findings partially supported the study hypothesis since dosage, breadth of intervention content and parent training were each independently associated with higher satisfaction, whereas age of first support was not. However, these findings reflect parent/carer experience rather than direct evidence of clinical effectiveness, so alternative explanations such as recall bias and unmeasured variation in service delivery must also be considered.

Dosage

Dosage was the strongest predictor of parent/carer satisfaction ($\beta = .243$; $t = 3.638$; $p < .001$), supporting the hypothesis. This is unsurprising given the severe skew towards low-frequency provision, with 55% of children seen every 6 months or more, 35.2% seen yearly or more and only 20% seen within bands up to every 4-6 weeks. This pattern contrasts with evidence suggesting that children with DS benefit from frequent, intensive and sustained intervention, e.g., monthly sessions with daily practice (Buckley and Le Prèvost, 2019; Burgoyne et al., 2012; Burgoyne et al., 2020; McFaul et al., 2022). From a parent/carer perspective, infrequent contact is likely to limit opportunities for progress and reduce feelings of support, which may explain its strong association with satisfaction (Meersman and Mathieson, 2019; RCSLT, 2021).

The issue of therapy 'blocks' may also be relevant, with one participant commenting:

> *"…SLT was delivered in 6 session batches …"* (*Unsolicited Comment 6; Supplementary Materials)*

Because the survey recorded frequency only as a typical interval, it does not distinguish between consistently low provision and block-based delivery averaged over time. It also does not provide data on the prevalence of blocks, limiting understanding of their impact. While blocks help manage caseloads, evidence for their effectiveness in isolation is limited (Law and Conti-Ramsden, 2000; RCSLT, 2018). Furthermore, a block and gap pattern is highly problematic for this population

due to regression risks associated with memory and motor planning constraints linked to phonological loop impairment (Buckley and Le Prèvost, 2019; Jarrold et al., 1999). This service model may therefore demonstrate a gap between evidence and current practice (Baksi, 2006; Kendall, 2017; Robertson, 2025), unless used strategically to train school staff and parents to deliver daily practice (Buckley and Le Prèvost, 2019; Yoder et al., 2015). Ultimately, frequency metrics fail to capture session quality, duration, or appropriateness, but findings suggest a clear parental perception that few children received therapy at meaningful intervals.

Intervention Content

Intervention content was the second strongest predictor of satisfaction ($\beta = .229$; $t = 3.383$; $p < .001$), again broadly supporting the hypothesis. Across the four domains (communication, vocabulary, grammar and speech work) intervention content averaged 2.29 domains per child, suggesting partial rather than the comprehensive DS specific support advocated by Buckley and Le Prèvost (2019).

Communication support was near universal (95.5%), but remaining areas were reported as below 56%. Given the expressive and oral-motor difficulties commonly associated with children with DS, it is notable that only 44.2% of children were reported as receiving interventions on vocabulary, and 55.3% on speech work (Baxter, 2025). Comparison with Baxter (2022) suggests somewhat higher targeting of these areas documented elsewhere, although the studies are not directly comparable due to different sample sizes, grouping methods and service types. Baxter's data was based on SLT target records, whereas this study relied on parent/carer reports. Consequently, the present data is better interpreted as a reflection of perceived breadth of provision, than as a direct measure of intervention fidelity or effectiveness.

Some discrepancy may exist between what was delivered and what parents recalled, particularly if therapy occurred in school where parent/carers are less involved (Ofsted, 2021). However, the survey required respondents to have sufficient knowledge of their child's SLT experience, with 37% of dropouts occurring on the provision information page. This suggests that parents lacking sufficient knowledge self-screened out, enhancing the reliability of the final sample.

Grammar intervention was reported by only 35.2% of participants, despite being a well-established area of difficulty for those with DS (Næss et al., 2011; Burgoyne, 2020; Smith et al., 2020). Baxter (2022) also found grammar targets to be less common (< 10%), confirming this domain often has a low clinical importance. An explanation for this could be that some children may not be judged as being developmentally ready or as having sufficient functional vocabulary to enable 'lexical bootstrapping' to occur. Although this is true for typical children, for individuals with DS, vocabulary and grammar often dissociate as expressive language lags behind. This means that if an SLT practitioner waited for a 'typical' vocabulary threshold, an indefinite delay to morphosyntax could occur (Down Syndrome Education International, 2015; Goodman, 1997). Recent work supports addressing vocabulary and grammar simultaneously (Neitzel, 2024), and Baxter (2022) found that children with DS could learn and generalise grammatical rules even when expressive grammar was scored as zero. Taken together, these findings may indicate gaps in DS-specific knowledge, which is consistent with DSA concerns regarding inconsistent practitioner expertise (DSA, 2021) and illustrated by the following comment (*Unsolicited Comment 7; Supplementary Materials):*

> *"…none of the NHS salt have specific training to work with children with DS and so just use general strategies that aren't suitable…"*

Parent Training

Parent training was also independently associated with higher satisfaction (β = .213; t = 3.330; p = .001), supporting the hypothesis. Despite the high need for parent training to bridge the gap between provision and the intensity and consistency required for this population, only 52.8% of caregivers reported being offered any (Davies et al., 2019; Pritchard et al., 2024). Specifically, Parent-Child Interaction (11.1%) and AAC partner training (7%) were underrepresented. Although training in a Total Communication Approach was reported by only 12%, Makaton/signing was offered more frequently (44.7%), which is consistent with recommendations for this population (Clibbens, 2001).

These findings align with literature suggesting that a lack of SLT contact and guidance damages caregiver confidence and satisfaction (Beard et al., 2025; Roberts and Kaiser, 2011). They also sit uneasily with the RCSLT emphasis on a

‘Balanced System’ approach that builds capability around the child by training parents, carers and educators (Better Communication CIC, 2026; Gascoigne, 2006, RCSLT, 2023). Low reported access to parent training may therefore reflect a gap between policy ideals and lived experience; however, a more cautious interpretation is needed. Some participants may have received informal modelling or advice that they did not identify as ‘training’, meaning some elements of training may be underreported.

In addition, 62% of parents/carers believed that their child’s progress was partly due to their own input (*Figure 8*). Although parental involvement is a core expectation of effective intervention, data may also be representative of caregivers compensating for insufficient provision. This in turn increases caregiver burden and negatively affects satisfaction (Barlow et al., 2008; DSA, 2021). As present data on parent training is limited, these two possibilities cannot be clearly separated.

Timing

Timing of first support did not significantly predict satisfaction (β = -.112; t = -1.746; p = .082), contrary to the hypothesis. Although 61.8% of children accessed services before the age of 2, only 13% were seen before 6 months and 21% between 6 and 12 months. This is at odds with evidence favouring support from birth and with early communication at the pre-linguistic stage (Buckley et al., 2024; Smith, Hokstad and Næss, 2020).

One interpretation of this may be that the age of first support is less important to parents than the quality and consistency of current provision. Early support may also be nullified if not followed by sustained input, with its effect on later satisfaction being minimal. However, a more cautious explanation is that parent/carer recall of earlier intervention may be less accurate, and a global parent rating in later childhood may simply be too blunt to capture the subtle benefits of earlier intervention. In that sense, the finding may reflect the limits of the measurement tool as much as the limits of early intervention itself.

Progress

Exploratory analysis suggested that higher satisfaction was associated with greater perceived progress (b = .41; t (195) = 3.48; p < .001), consistent with previous

literature (Roberts and Kaiser, 2011). However, progress in this study was parent-reported rather than clinically verified, and ratings were child-specific rather than attributed solely to NHS provision. These results therefore reflect perceived rather than objective aims.

External support factors (ESF; private SLT, school input, or parental input) appeared to act as a multiplier and strengthen perceived progress, but they did not compensate fully for a negative NHS experience. The highest progress scores were observed when NHS SLT provision (acting as the main driver) and ESF were both present (b = .50; t (195) = 2.45; p = .015). This suggests that NHS SLT may remain central even when other forms of support are available. It also raises concerns about inequality, since access to additional support is likely to vary by family resources and geography (Longfield, 2019; Suphi, 2025). Given the observational and parent-reported nature of the data, these associations should be interpreted cautiously rather than as definitive proof of causal effects.

Demographics

The sample was heavily skewed towards women (96%), participants aged 35-54 (91%), and university-educated respondents (73%). This is partly consistent with literature identifying mothers as primary caregivers and with the higher incidence of DS among older mothers (Crane and Morris, 2006; Yaman et al., 2025; Zhang et al., 2025). However, it also limits generalisability, particularly in relation to socioeconomic diversity.

Recruitment through support networks may have resulted in an overrepresentation of highly engaged parents, although this may also reflect the reality that families of children with additional needs often have to coordinate multiple services and become more proactive as a result (DSA, 2021; McCann et al., 2012; Topolovec-Vranic and Natarajan, 2016).

The mean child age was 7.6 years. In Ireland, Frizelle et al. (2021) found that increased age coincided with reduced NHS SLT support. While it is unclear whether this survey yields similar results due to the averaging of experience over years, 58% of parents cited school input as an ESF. This suggests that therapy input increasingly sits within educational settings at primary school age, which, if staff are trained

correctly and accompanied by regular professional SLT input, is entirely appropriate (Buckley and Le Prèvost, 2019; Burgoyne et al., 2012).

Limitations

The simultaneous regression model used to test the primary hypothesis is statistically robust with a large sample size that protects the validity of *p*-values (R^2 = .235; Adjusted R^2 = .219; $F(4,194) = 14.873$, $p < .001$). Likewise, the exploratory model was statistically significant (R^2 = .1604; $F(3,195) = 12.42$, $p < .001$). However, since satisfaction was measured using a 4-point Likert scale, although findings support the existence of associations, effect sizes should be treated with caution (Rhemtulla et al., 2012). It is also the case that the parent-report design means that causal inferences about the impact of these factors should be interpreted as reflecting perceived service experience rather than definitive evidence of clinical effectiveness. This is particularly relevant in relation to intervention content and perceived progress, where intensity, fidelity and independent outcome measurement were not available.

In terms of sample size, Cochran's Formula suggests an optimal sample of 356 participants for a 95% confidence level and a (+-5%) margin of error for generalising findings at population level (Smith and Cochran, 1964). This target was worked out using an estimated population size of 4,800 primary school aged children with DS, calculated using Manikam et al., (2020) = 750 DS births per year x 8 years and figures from the DSA (2025) = 20% co-occurring ASD excluded (StatStudyHub.com, 2026). To note, this figure does not consider higher infant mortality rates for this cohort (Office for National Statistics (ONS), 2025). Despite the sample falling below ideal population metrics (*N* = 199; 85% confidence rating), robust statistical power was maintained through size for multiple linear regression (Green, 1991).

The survey did not consider whether the child was in a mainstream or Special Educational Needs (SEN) school, which is important since provision would differ in these circumstances i.e., less NHS involvement due to tailored SEN support (Lindsay et al., 2012, Speech and Language UK, 2025). It does not consider Education, Health and Care Plans, which limits this study's ability to isolate whether satisfaction was driven by standard NHS provision or extra funding obligations as per the Children and Families Act (UK Parliament, 2014). The survey also does not

include blocks of therapy or all aspects of dosage (e.g. session times), and given more scope, could have benefited from including geographical information to further analyse variation. Taken together, these gaps mean that alternative explanations for satisfaction cannot be fully ruled out.

Time constraints limited the survey to 39 days, with more participants likely with a longer recruitment window. Recruitment was amended to allow for physical recruitment, demonstrating a reflexive and proactive method, with adaptations made in response to poor survey design. This indicates that although the survey was checked for usability by 6 parent/carers, more time spent designing and testing would have been prudent. Finally, more exclusion data could have been collected on non-participation had the exit survey been included from the start (n = 15). Within this sample it was recorded that 33% of people could not complete due to receiving no service at all, so it would have been useful to know how many of the 139 participants screened out would have cited this (*Figure 10; Supplementary Materials).*

Although unsolicited comments provided helpful contextual information that also complemented quantitative data collected, they were not analysed using formal methodology and therefore can't be considered as representative.

Implications

Despite these limitations, this study provides current empirical data on parent/carer satisfaction with NHS SLT provision for children with DS and provides useful data on scarcely documented intervention content and timing of first support. Results allowed for a comprehensive analysis of a range of service factors affecting satisfaction and findings align with existing studies, suggesting persistent gaps between evidence-based recommendations and family experience. Low dosage, limited parent training and a lack of comprehensive intervention content suggests an undermining of person-centred principles (RCSLT, 2018b).

The study also suggests that additional external support does not fully offset dissatisfaction with NHS SLT provision, thereby demonstrating a critical reliance on NHS SLT. However, due to the subjective nature of the study, this finding should be treated as indicative rather than conclusive.

Given the current climate of NHS SLT service constraints, realistic first steps may be to provide wider access to parent training through a Balanced System approach (RCSLT, 2023). Furthermore, consistent national standards of care should be prioritised through the Downs Syndrome Act (DHSC, 2025a). For example, creating a clear national pathway and commissioning DS specific training of SLTs, as advocated by the Downs Syndrome Clinical Excellence Network (DS CEN) (2026). This would enable more appropriate care from knowledgeable practitioners, resulting in improved caregiver satisfaction and child outcomes.

Further Study

Further research would benefit from combining parent/carer and SLT perspectives, drawing on clinical outcome data to provide a more comprehensive picture of provision and effectiveness - as per Sales and Vincent (2018) and Baxter (2022). As a lack of practitioner training and knowledge has been highlighted in the literature, alongside persistent evidence of gaps between suggested recommendations and current practice, it would be worthwhile to collect data on training and SLT knowledge with a view to understanding where improvements can be made. More data is also needed on specific interventions (DSA, 2021; Seager et al., 2022), including what interventions are being used and associated clinical data on progress. This would help to establish a bank of suitable, evidence-based intervention strategies for children with DS, which is something that does not currently exist.

Many parents and carers had lots to say, and varying contexts that did not 'fit the mould' were lost due to the rigidity of the survey design (See *Unsolicited Comments; Supplementary Materials).* Furthermore, a number of non-participants also provided unsolicited comments which had to be excluded due to a lack of formal consent. This underscores a clear willingness among families to share their experiences for the benefit of improved provision. To address this, future studies on service provision should adopt a mixed-methods framework to capture robust quantitative data alongside the nuanced lived experiences often neglected (DHSC, 2025b).

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Supplementary Materials

Advert

Are you a parent/carer of a primary school aged child with Down's Syndrome?

SCAN ME!



Participants required for a study of speech and language therapy (SLT) provision

This study seeks to add to the literature currently available, exploring parental satisfaction with **NHS SLT provision for children with Down's Syndrome. Factors which impact on parental satisfaction will be collected, including data on intervention and dose.**

The results of this study will be shared via the DSCEN, DSA and Future of Downs Facebook group.

The study will take approximately 10-15 minutes to complete. Closes Friday 1st May.

Who can complete the survey?

Inclusion Criteria: Parent/carer of a primary school aged child with DS (4-12 years) who has received NHS SLT support for communication. Parent/carer to be comfortable with completing survey in English with the child living in the UK from birth.

Exclusion criteria: Child with additional, non-DS related conditions that have substantially impacted communication. For example, any co-occurring neurological conditions such as Autism Spectrum Disorder (ASD) or additional structural diagnosis to the mouth e.g. cleft palate.

All results will be anonymous.
Further information on participation and consent can be found at the start of the survey.

Researcher: Holly Shevlin
Contact: 14022942@stu.mmu.ac.uk
EthOS approval ID: 90013

Manchester Metropolitan University

https://app.onlinesurveys.jisc.ac.uk/s/mmu/parent-carer-satisfaction-of-nhs-slt-provision-ds

***Survey,* Section 1 (Eligibility Screening):**

Examining factors affecting Parent/carer satisfaction of NHS SLT provision for primary school aged children with Down's Syndrome

Closes Sunday 10th May 11.30pm

Participant Information and Invitation to Research

My name is Holly Shevlin and I am a final year Speech and Language Therapy (SLT) MSc student at the Manchester Metropolitan University. Thank you for your interest in this study of NHS SLT provision for children with Down's Syndrome (DS) from a parent/carer perspective.

The goal of this observational study is to measure levels of parent/carer satisfaction in relation to Speech and Language Therapy (SLT) provided by NHS SLT services for primary aged children with Down's Syndrome.
This study specifically examines speech and language provision, with the exclusion of feeding-related support.

A survey design is being used to collect data.

The main questions it aims to answer are:

- What is the impact on satisfaction of **intervention timing?**
- What is the impact on satisfaction of **dose?**
- What is the impact on satisfaction of **types of intervention?**
- What is the **overall variability of parent/carer satisfaction**, and which of the above areas has the largest effect?

Why have I been invited?
This is an open invitation to parent/carers of a child with Down's Syndrome who are of primary school age and living in the UK.

Exclusion and inclusion criteria apply as follows:
Inclusion Criteria: *To be completed by a parent/carer of a primary school aged child with DS who has received NHS SLT support for communication. Parent/carer to be comfortable with completing the survey in English. The child has lived in the UK from birth.*
Exclusion criteria*: Child with additional, non-DS related conditions that have substantially impacted communication.*

Do I have to take part?
Participation is voluntary.

What will I be asked to do?
You will be asked to complete an online survey that will take around 10-15 minutes to complete. The survey will close on Friday 1st May 2026.

Are there any risks if I participate?
Completing the survey may cause psychological/emotional distress if your child has had limited SLT NHS input, or has made less progress with speech and communication than you expected. With this in mind, signposted at the end of the survey are support groups and current SLT recommendations for children with Down's Syndrome.

Informed consent
By completing and submitting the survey, you agree to participate in this study.

What information about me will you collect and why?
Demographic information will be collected to ensure results are representative. Questions are asked regarding the input your child has received and levels of parent/carer satisfaction. The information gathered will be used to quantify and understand the effects of intervention timing, dose and types of intervention on parent/carer satisfaction.

How will my information be stored and how will you look after it?
Your data will be stored securely on the university OneDrive. Your data will be destroyed after 2 years.

How will you use my information?
Your participation is voluntary and anonymous, and no identifying information will be collected.

Will my data be sent anywhere else, or shared with other people or organisations?
Your anonymised data may be shared with the DSCEN and other DS organisations.

Data Protection Law
Data protection legislation requires that we state the 'legal basis' for processing information about you. In the case of research, this is 'a task in the public interest.' If we use more sensitive information about you, such as information about your health, religion, or ethnicity (called 'special category' information), our basis lies in research in the public interest. Manchester Metropolitan is the Controller for this information and is responsible for looking after your data and using it in line with the requirements of the data protection legislation applicable in the UK.
You have the right to make choices about your information under the data protection legislation, such as the right of access and the right to object, although in some circumstances these rights are not absolute. If you have any questions, or would like to exercise these rights, please contact the researcher or the University Data Protection Officer using the details below.
You can stop being a part of the study at any time, without giving a reason, by not completing the online survey. Session identifiers will be used to ensure no duplicate responses, but no cookies or IP will be used for tracking. Therefore, you will not be able to withdraw your data once the survey has been submitted, because we will not know which data is yours.

What will happen to the results of the research study?
The results of this survey will be analysed and discussed in my completed dissertation.

Who has reviewed this research project?
Emma Olyott
Who do I contact if I have concerns about this study or I wish to complain?
Researcher *Holly Shevlin 14022942@stu.mmu.ac.uk*
Project supervisor *Emma Olyott E.Olyott@mmu.ac.uk*
Head of Research Ethics and Governance for the Faculty of Health and Education *- FOHE-Ethics@mmu.ac.uk*
OManchester Metropolitan Data Protection Officer *Our Data Protection Officer can be contacted using the* ***dataprotection@mmu.ac.uk*** *e-mail address, by calling +44 (0)7584 330586 or in writing to: Data Protection Officer, Legal & Governance, Ormond Building, Lower Ormond Street, Manchester, M15 6BX*
UK Information Commissioner's Office
You have the right to complain directly to the Information Commissioner's Office if you would like to complain about how we process your personal data:
https://ico.org.uk/global/contact-us/

THANK YOU FOR PARTICIPATING IN THIS PROJECT

1. I am a parent or carer of a **primary school aged** child with Down's Syndrome (4-12 years)
   *

◯ Yes
◯ No

2. **Please confirm that you are at least 18 years of age and that you understand the information above**
   *

◯ I confirm I understand and are happy to proceed
◯ I do not wish to continue with this survey

3. **Does your child have any <u>additional, non-DS related conditions</u> that have substantially impacted communication?**
   For example, any co-occurring neurological conditions such as Autism Spectrum Disorder (ASD) or additional structural diagnosis to the mouth e.g. cleft palate, apart from those expected with Down's Syndrome (DS) that have impacted communication.

   Expected conditions include: Hypotonia (low muscle tone), high palate, small mouth, enlarged tongue or tonsils. Conductive hear loss, including glue ear. Developmental delay or delayed speech, slower processing times, difficulties with memory, speech sound challenges (e.g. they are harder to understand when speaking, they struggle to use the right sounds).
   *

◯ Yes
◯ No

4. I can confirm that my child has had input from NHS Speech and Language Therapy (SLT) services for **speech and communication.**
   *

◯ Yes
◯ No

5. I can complete this survey with **full knowledge** of the input my child has received from NHS Speech and Language Therapy services.
   *

◯ Yes
◯ No

6. I can confirm that the child has **lived in the UK** from birth
   *

◯ Yes
◯ No

7. I am comfortable with completing this survey in **English**.
   *

◯ Yes
◯ No

Section 2 (Demographics):

Please provide the following information before completing the survey.

Confidentiality: The data collected below is confidential and used for research purposes only.

8. Gender of parent/carer
*

- ◯ Woman
- ◯ Man
- ◯ Non-binary
- ◯ Prefer not to say

9. Age of parent/carer
*

- ◯ 18–24
- ◯ 25-34
- ◯ 35-44
- ◯ 45-54
- ◯ 55+

10. Parent/Carer level of education completed
*

- ◯ No education
- ◯ High School
- ◯ College
- ◯ University
- ◯ Prefer not to say

11. Age of child
*

- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ 10
- ◯ 11
- ◯ 12

Section 3 (Service Experience):

Age of First Support or Intervention

12. How old was your child when they first received support for **communication** from **NHS SLT services**?
    *

- ◯ 0-3 months
- ◯ 3-6 months
- ◯ 6-12 months
- ◯ 1-2 years
- ◯ 2-3 years
- ◯ 3-4 years
- ◯ 4-5 years
- ◯ 5+ years

Section 4 (Intervention Details):

NHS SLT Provision at Primary school age

Below are some examples of SLT interventions grouped into four key areas - communication, vocabulary, grammar and speech work.

Please read through the examples and consider whether your child has had support in all or some of these areas.

Please remember that you should not expect your child to have received all of the therapy interventions listed, as selection would be based on assessment and the individual needs of your child.

Communication

- Working on *social communication skills* e.g. shared attention, turn taking during a game.
- Using *visual supports* such as photos, symbols, objects or visual schedules to aid understanding (e.g. now and next boards to support with transitions, boards for requesting during meal times etc)
- Using *gesture or sign* to support communication (e.g. Makaton)
- Use of *AAC* (Augmentative and Alternative Communication) e.g. communication book with symbols or iPad with communication software. Click here if you are unsure what AAC is
- Development of *attention and listening* skills thorough shared activities
- Emphasis on teaching *functional words or short phrases* through modelling, prompting and repetition
- Working on understanding *instructions* containing several key pieces of information (Information Carrying Words) E.g. "Put the **big car** in the **box**"
- Focus on parent interaction and environment e.g. modelling predictable communication such as 'hello', using songs to introduce words or sounds and provide repetition, providing extra time to respond by using the 'wait and see' strategy.

Vocabulary

- Working on *expanding vocabulary* and generalising it e.g. introducing a new word and demonstrating all the ways it could be used (including within a sentence), providing real life images, associated Makaton signing and other variations of the word in context.
- Use of 'word walls' to learn and retain new vocab

Grammar

- Working on encouraging the use of *functional* language e.g. using sentences such as 'I want....' often supported by visual boards using symbols or real life pictures. Phrase building to support expression of comments or opinions.
- Working on *sentence structure* e.g. through the use of colourful semantics (breaking down a sentence into sections such as 'who/did what' = 'the girl/is sitting.

Speech work

- Working on *oral motor skills* through fun, interactive games e.g. blowing bubbles, sucking straws, use of chewy tubes. Tongue and lip exercises such as Freddy Frog (moving tongue side to side, up and down) or Miss Lips. Tactile input such as vibrating toothbrushes.
- Encouraging *imitation* and *repetition* of speech sounds e.g. *auditory bombardment* (listening to the sound repeatedly). This could be through play e.g. Pop up Pirate - target sound pictures under each sword. The child must say the target word/sound 5 times before placing the sword in.
- Working on *speech sounds* and articulation to improve clarity of speech e.g. looking at how your child is making the sounds and providing prompts for correct positioning of tongue, lips etc
- *Auditory discrimination* tasks e.g. asking the child to differentiate between similar words (minimal pairs) such as "cat" vs. "bat") and practicing with rhyming games.
- Supporting *phonological awareness* by breaking down sounds in words and/or blending to create words e.g. using jigsaws with words cut up into syllables, or syllable clapping to help segment the words
- Working on a set of key words and improving their intelligibility (*Core vocabulary* approach)

With this in mind, please answer the following questions:

13. In which of the following areas has your child received **NHS SLT** intervention? **Please select all that apply (see examples above)**
*

- [ ] Communication
- [ ] Vocabularly
- [ ] Grammar
- [ ] Speechwork

14. On **average**, how often is your child seen by NHS SLT services for communication?
*

- ◯ Twice a week
- ◯ Weekly
- ◯ Every 2-4 weeks
- ◯ Every 4-6 weeks
- ◯ Every 6-12 weeks
- ◯ Every 3-6 months
- ◯ Every 6-9 months
- ◯ Every 9-12 months
- ◯ 12 months +

15. **At any point**, have you been offered **parent training** for any of the following? **(please select all that apply)**
*

- [ ] Makaton/signing
- [ ] Total Communication Approach e.g. accepting all methods of communication (speech, sign, gesture, text or symbols)
- [ ] AAC partner training e.g. training parent/carer in modelling and/or incorporating the use of communication boards, switches or devices (Proloquo2Go, Grid software etc) in day to day life and conversations
- [ ] Parent-child Interaction e.g. parent group sessions looking at using clear, simple language and supporting with gesture to provide visual clues
- [ ] No
- [ ] Other

16. How would you rate your child's **speech and communication** progress?
*

- ◯ My child has made little or no progress
- ◯ My child has made expected progress
- ◯ My child has made good progress
- ◯ My child has made progress beyond my expectations

17. Why do you think your child made this level of progress? **Select all that apply.**
*

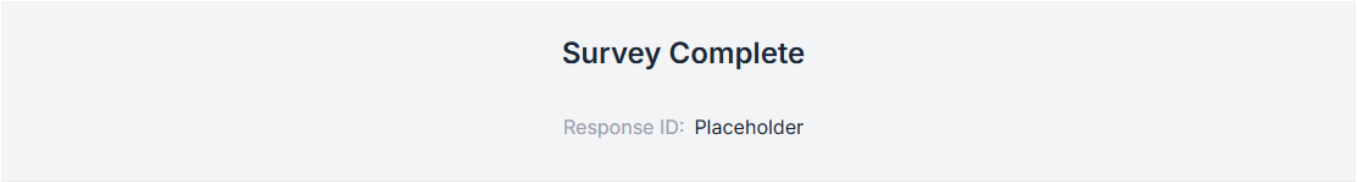
- [ ] As expected for a child with DS
- [ ] Due to illness
- [ ] Due to other factors e.g. impact of Covid
- [ ] Due to quantity of NHS SLT support received
- [ ] Due to quality of NHS SLT support received
- [ ] Due to additional input from private SLT
- [ ] Due to parental/carer input
- [ ] Due to support from school setting

18. How would you describe your **overall level of satisfaction** regarding the support that your child has recieved from **NHS SLT services for speech and communication**?
*



Very Unsatisfied Very Satisfied

Survey Completion Page:



Thank you for completing this survey

Your time is greatly appreciated. Findings of the study will be shared with the Future of Down's Facebook group and DSCEN.

Some useful links:

- **If you would like to know more about SLT recommendations for children with Down's Syndrome based on current best evidence, please click here**
- **Resources demonstrating some of the SLT activities mentioned in the survey can be found by clicking here**
- **Positive about Down syndrome (PADS) provide support, info and resources for new and preschool parents**
- **Future of Down's Facebook Group is a Facebook page run by parents of children with Down's syndrome for parents of children with Down's syndrome**
- **For a map of local DS support groups, click here**
- **To find out more about the DSCEN or about joining the The Friends of the Down Syndrome CEN, which was set up for parents and non-SLT professionals, please click here**

Links from completion page (last accessed 27.06.26):

- https://www.down-syndrome.org/en-gb/library/news-update/02/2/speech-language-therapy-down-syndrome/
- https://www.downs-syndrome.org.uk/speech-and-language-activities/
- https://downsyndromeuk.co.uk/about-dsuk/pads/
- https://www.facebook.com/groups/futureofdowns
- https://www.downs-syndrome.org.uk/about-dsa/our-network/local-support-groups/
- https://www.ds-cen.co.uk/
- https://www.ds-cen.co.uk/friendsdscen

Screening message:

We're sorry, but the answers you have chosen mean that your response does not meet the criteria for this survey.

Please consider answering the questions on this link to provide data on why you were unable to complete the survey: **https://app.onlinesurveys.jisc.ac.uk/s/mmu/reasons-for-not-completing**

Alternatively contact Holly Shevlin 14022942@stu.mmu.ac.uk if you need assistance with completing

Thank you for taking the time to participate.

Supplementary Exit Survey

Reasons for not completing the survey on 'Parent/Carer Satisfaction of NHS SLT provision for primary school aged children with Down's Syndrome'

1. This question has been created in addition to the original survey to establish reasons that parent/carers were unable to complete it.
   The survey: https://app.onlinesurveys.jisc.ac.uk/s/mmu/parent-carer-satisfaction-of-nhs-slt-provision-ds

   If you have been unable to complete the survey on parent/carer experience, please select why from the below options:

   Select all that apply
   *

- [ ] My child has been discharged from NHS SLT services
- [ ] My child has no active involvement from NHS SLT services
- [ ] My child has never been seen by NHS SLT services
- [ ] My child sees a private SLT instead of NHS SLT due to lack of service
- [ ] My child sees a private SLT instead of NHS SLT due to lack of specialist knowledge
- [ ] My child has a dual-diagnosis of ASD (autism)
- [ ] My child has a co-occurring neurological condition that is not ASD
- [ ] My child has a co-occurring structural diagnosis (e.g. cleft palate)
- [ ] My child has not lived in the UK from birth
- [ ] I was unable to complete the survey due to not being the primary parent/carer
- [ ] I was unable to complete the survey as I have not always been the primary parent/carer and do not have knowledge of service
- [ ] Other

2. What is the age of your child?
   *

- ◯ 4
- ◯ 5
- ◯ 6
- ◯ 7
- ◯ 8
- ◯ 9
- ◯ 10
- ◯ 11
- ◯ 12

Survey Insights

Initial stats (before survey amendments):

Survey progress

Responses	Response rate	Running days
177	177%	55

Engagement analytics

Views	Starts	Completion rate	Av. completion time	Screened out
701	417	42%	0 hr 3 m 41 s	122

Drop-out analysis

Page	Drop-out
1. Participant Information and Invitation to Research	28 (24%)
2. Demographic Information	8 (7%)
3. Age of First Support or Intervention	7 (6%)
4. NHS SLT Provision at Primary school age	27 (23%)
5. Thank you for completing this survey	48 (41%)

Final stats (after survey amendments):

Survey progress

Responses	Response rate	Running days
199	40%	61

Engagement analytics

Views	Starts	Completion rate	Av. completion time	Screened out
795	460	43%	0 hr 3 m 40 s	139

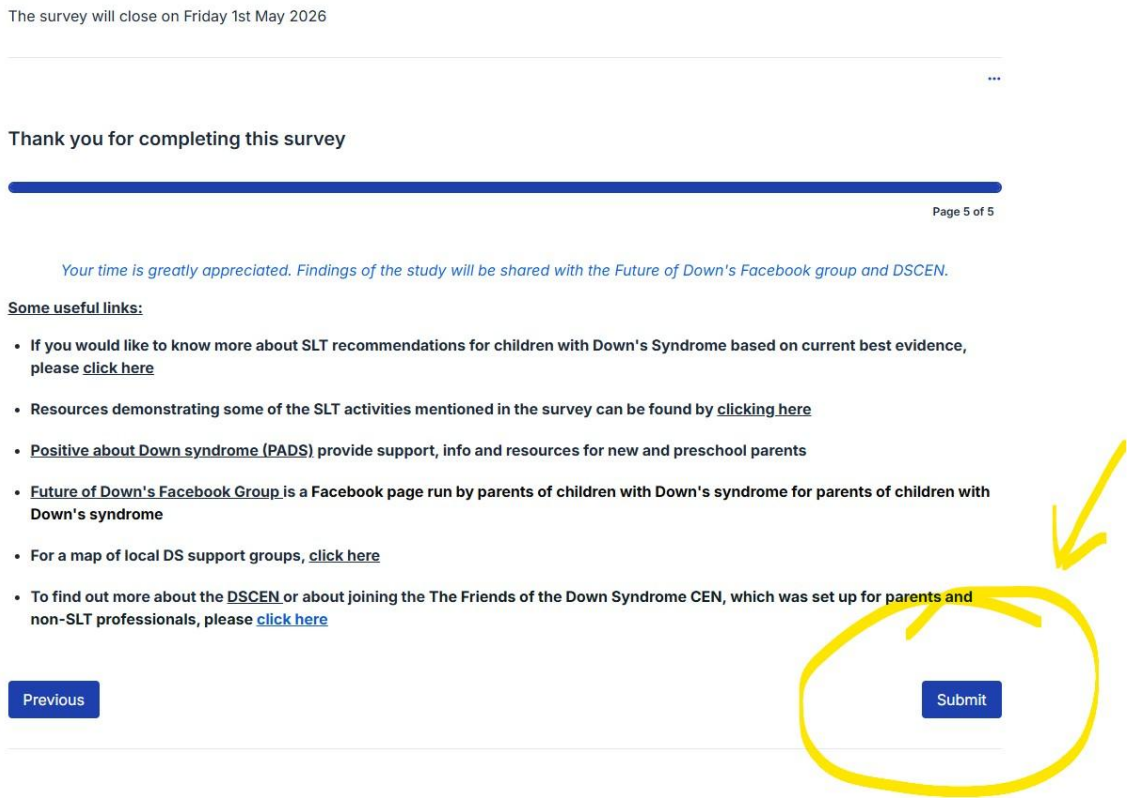
Drop-out analysis

Page	Drop-out
1. Participant Information and Invitation to Research	31 (42%)
2. Demographic Information	8 (11%)
3. Age of First Support or Intervention	7 (10%)
4. NHS SLT Provision at Primary school age	27 (37%)

Survey Design - layout issue:

Submit button is below ‘Thank you’ message, meaning that 48 participants likely saw the ‘Thank you’ and closed the browser thinking the survey was complete.

Amendment: ‘Thank you’ page was moved to be after the submit button, and recruitment window extended by seven days.



Raw Data Sample

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T
1	Response ID	1. I am a parent or carer of a primary school aged child with Down's Syndrome (4-12 years)	2. Please confirm that you are at least 18 years of age and that you understand the information above	3. Does your child have any additional, non-DS related conditions that have substantially impacted communication? For example, any co-occurring neurological conditions such as Autism Spectrum Disorder (ASD) or additional structural diagnosis to the mouth e.g. cleft palate, apart from those expected with Down's Syndrome (DS) that have impacted communication.Expected conditions include: Hypotonia (low muscle tone), high palate, small mouth, enlarged tongue or tonsils. Conductive hear loss, including glue ear. Developmental delay or delayed speech, slower processing times, difficulties with memory, speech sound challenges (e.g. they are harder to understand when speaking, they struggle to use the right sounds).	4. I can confirm that my child has had input from NHS Speech and Language Therapy (SLT) services for speech and communication.	5. I can complete this survey with full knowledge of the input my child has received from NHS Speech and Language Therapy services.	6. I can confirm that the child has lived in the UK from birth	7. I am comfortable with completing this survey in English.	8. Gender of parent/carer	9. Age of parent/carer	10. Parent/Carer level of education completed	11. Age of child	12. How old was your child when they first received support for communication from NHS SLT services?	13. In which of the following areas has your child received NHS SLT intervention? Please select all that apply (see examples above)	14. On average, how often is your child seen by NHS SLT services for communication?	15. At any point, have you been offered parent training for any of the following? (please select all that apply)	16. How would you rate your child's speech and communication progress?	17. Why do you think your child made this level of progress? Select all that apply.	18. How would you describe your overall level of satisfaction regarding the support that your child has recieved from NHS SLT services for speech and communication? (1-4	Start Date
2	cmn31g88x00gt02l8r26byd06	Yes	I confirm I understand and are happy to proceed	No	Yes	Yes	Yes	Yes	Woman	35-44	University	9	1-2 years	Communication,Grammar,Speechwork	Every 3-6 months	Makaton/signing,AAC partner training e.g. training parent/carer in modelling and/or incorporating the use of communication boards, switches or	My child has made expected progress	As expected for a child with DS,Due to quality of NHS SLT support received,Due to additional input from private	3	2026-03-23 10:13:48 UTC
3	cmn5t1us9001l02ihtraybluu	Yes	I confirm I understand and are happy to proceed	No	Yes	Yes	Yes	Yes	Woman	35-44	University	9	4-5 years	Communication,Vocabularly,Grammar,Speechwork	Every 2-4 weeks	Makaton/signing	My child has made expected progress	Due to quantity of NHS SLT support received ,Due	2	2026-03-25 08:34:27 UTC
4	cmn9ze5q0004s02lba5fat7pe	Yes	I confirm I understand and are happy to proceed	No	Yes	Yes	Yes	Yes	Woman	35-44	University	9	3-6 months	Communication,Vocabularly,Speechwork	Every 3-6 months	Makaton/signing,Parent-child Interaction e.g. parent group sessions looking at using clear, simple language and	My child has made progress beyond my expectations	Due to additional input from private SLT,Due to parental/carer	2	2026-03-28 06:59:27 UTC
5	cmnacowyi008l02l4dfwefm1x	Yes	I confirm I understand and are happy	No	Yes	Yes	Yes	Yes	Woman	35-44	University	7	2-3 years	Communication	Every 6-9 months	No	My child has made good progress	Due to additional input from	1	2026-03-28 13:10:06
6	cmnaiitx100ek02k2b381qxhp	Yes	I confirm I understand and are happy	No	Yes	Yes	Yes	Yes	Woman	35-44	University	7	1-2 years	Communication,Vocabularly	Every 6-9 months	Makaton/signing	My child has made expected progress	Due to additional input from	2	2026-03-28 15:50:52

Data sample after preparation and cleaning

	A	B	C	D	E	F	G	H	I	J	K	M	N	O	P	Q
1	ID	Child_Age	Timing	IC_Comm	IC_Vocab	IC_Gram	IC_Speech	Content_Sum	Dosage	Training	Progress	Ext_Private	Ext_Parental	Ext_School	External_Sum	Satisfaction
2	1	9	4	1	0	1	1	3	4	1	2	1	1	1	2	3
3	2	9	7	1	1	1	1	4	7	1	2	0	1	0	2	2
4	3	9	2	1	1	0	1	3	4	1	4	1	1	1	3	2
5	4	7	5	1	0	0	0	1	3	0	3	1	1	0	2	1
6	5	7	4	1	1	0	0	2	3	1	2	1	0	1	1	2
7	6	8	5	1	0	0	0	1	4	1	1	0	0	0	1	1
	7	8	4	1	0	0	1	2	5	0	3	0	0	0	1	3

Key:

Column	*Row*	*Coding*
A	ID	Participant number from 1 to 199
B	Child_Age	The child's exact age in years (4 to 12)
C	Timing	**Question 12:** Age bands coded as follows: 1 = 0–3 months, 2 = 3–6 months, 3 = 6–12 months, 4 = 1–2 years, 5 = 2–3 years, 6 = 3–4 years, 7 = 4–5 years, 8 = 5+ years
D	IC_Comm	**Question 13 (Communication checkbox):** 1 if checked, 0 if blank
E	IC_Vocab	**Question 13 (Vocabulary checkbox):** 1 if checked, 0 if blank
F	IC_Gram	**Question 13 (Grammar checkbox):** 1 if checked, 0 if blank
G	IC_Speech	**Question 13 (Speechwork checkbox):** 1 if checked, 0 if blank
H	Content_Sum	**Formula Column:** Sum of D-G (0 to 4 score for intervention comprehensiveness)
I	Dosage	**Question 14:** Frequencies coded sequentially as follows: 1 = 12 months+, 2 = Every 9–12 months, 3 = Every 6–9 months, 4 = Every 3–6 months, 5 = Every 6–12 weeks, 6 = Every 4–6 weeks, 7 = Every 2–4 weeks, 8 = Weekly, 9 = Twice a week.
J	Training	**Question 15:** 0 if selected "No". 1 if any of the training strategy boxes were ticked (Makaton, Total Comm, AAC, or PCI).
K	Progress	**Question 16:** 4-point progress scale as follows: 1 = Little or no progress, 2 = Expected progress, 3 = Good progress, 4 = Progress beyond my expectations.
L	Ext_Private	**Question 17 (Private SLT checkbox):** 1 if checked, 0 if blank
M	Ext_Parent	**Question 17 (Parental Input checkbox):** 1 if checked, 0 if blank
N	Ext_School	**Question 17 (School support checkbox):** 1 if checked, 0 if blank
O	External_Sum	**Formula Column (Moderator):** Sum of external supports (max 3)
P	Satisfaction	**Question 18 (Dependent Variable):** Coded sequentially as follows: 1 = Very Unsatisfied, 2 = Unsatisfied, 3 = Satisfied, 4 = Very Satisfied

Data Analysis - SPSS output

Primary Hypothesis Testing:

Explore

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Progress	199	100.0%	0	0.0%	199	100.0%
Satisfaction	199	100.0%	0	0.0%	199	100.0%

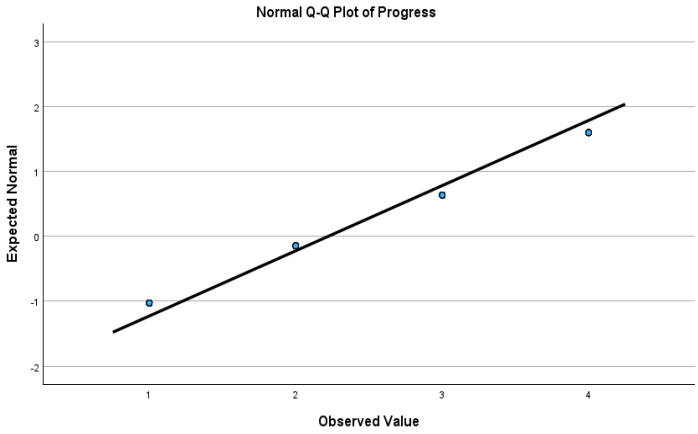
Descriptives

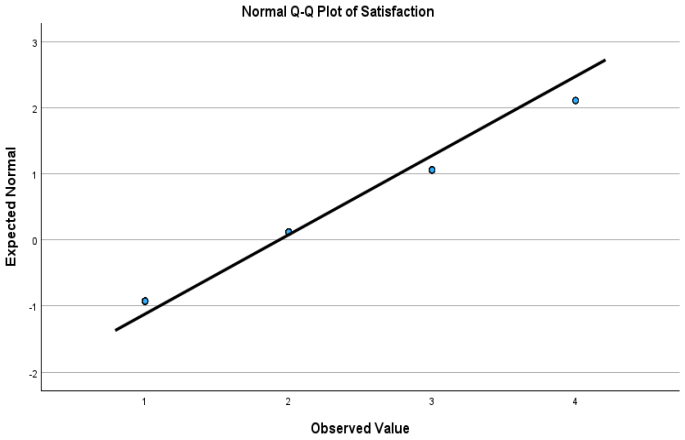
			Statistic	Std. Error
Progress	Mean		2.22	.071
	95% Confidence Interval for Mean	Lower Bound	2.08	
		Upper Bound	2.36	
	5% Trimmed Mean		2.19	
	Median		2.00	
	Variance		.991	
	Std. Deviation		.996	
	Minimum		1	
	Maximum		4	
	Range		3	
	Interquartile Range		2	
	Skewness		.195	.172
	Kurtosis		-1.104	.343
Satisfaction	Mean		1.93	.059
	95% Confidence Interval for Mean	Lower Bound	1.82	
		Upper Bound	2.05	
	5% Trimmed Mean		1.89	
	Median		2.00	
	Variance		.698	
	Std. Deviation		.835	
	Minimum		1	
	Maximum		4	
	Range		3	
	Interquartile Range		2	
	Skewness		.439	.172
	Kurtosis		-.687	.343

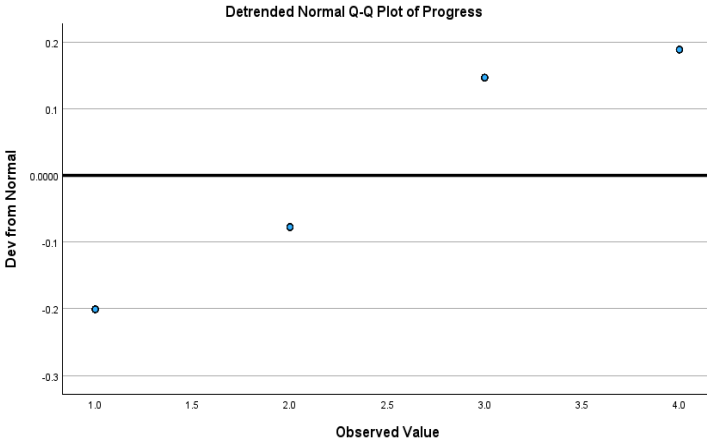
Tests of Normality

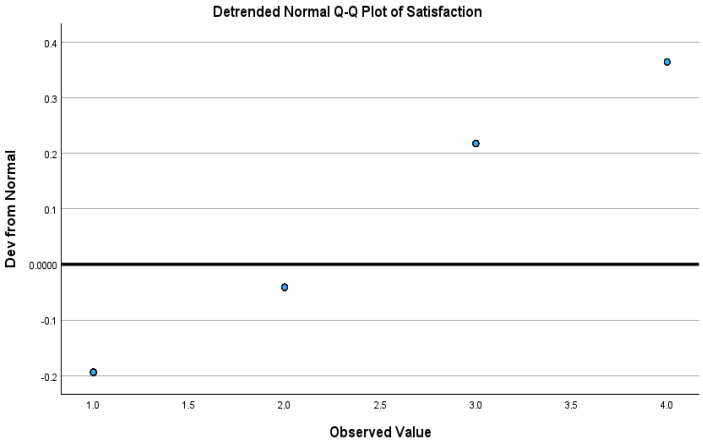
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Progress	.200	199	<.001	.860	199	<.001
Satisfaction	.220	199	<.001	.835	199	<.001

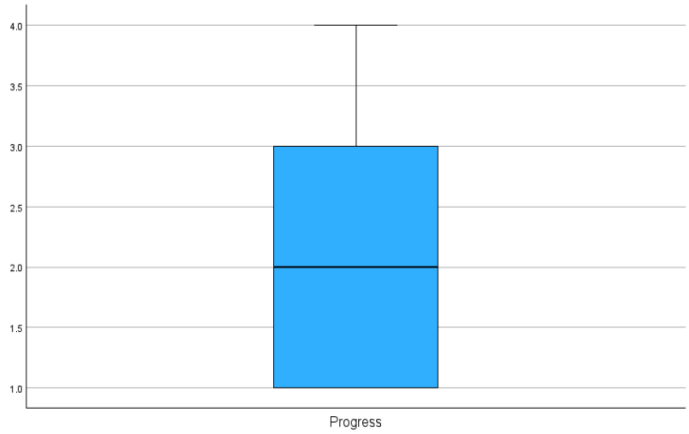
a. Lilliefors Significance Correction

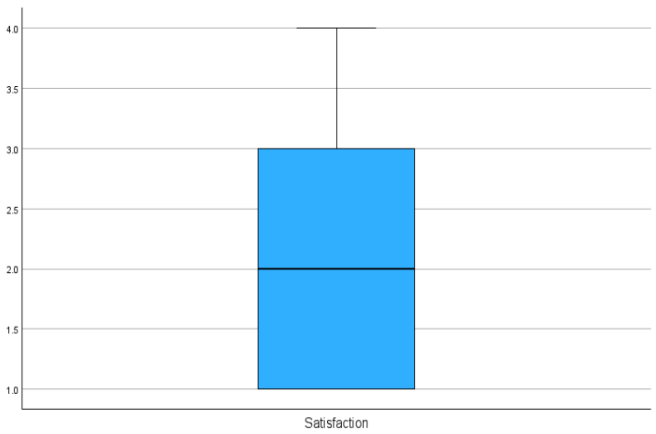

Normal Q-Q Plot of Progress
Expected Normal
Observed Value

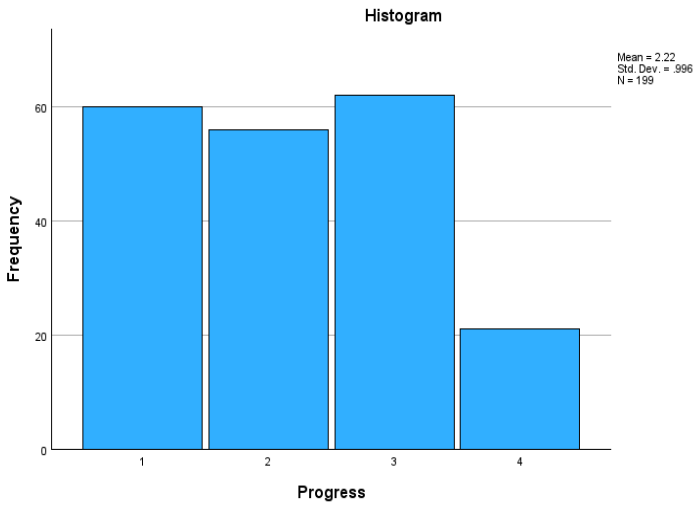

Normal Q-Q Plot of Satisfaction
Expected Normal
Observed Value

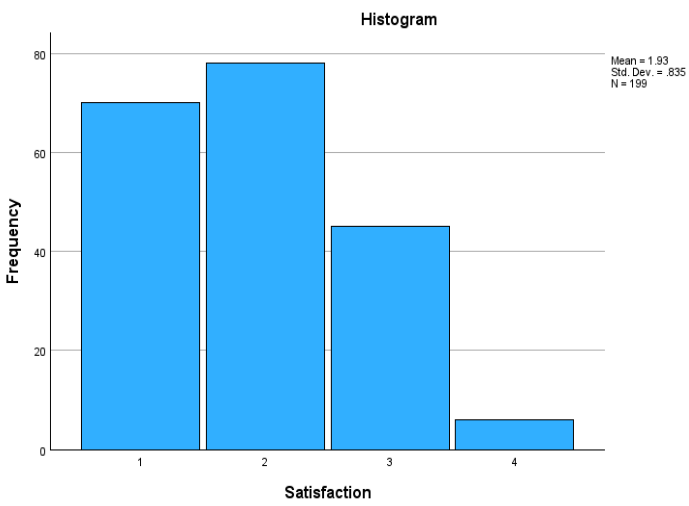

Detrended Normal Q-Q Plot of Progress
Dev from Normal
Observed Value


Detrended Normal Q-Q Plot of Satisfaction
Dev from Normal
Observed Value


Progress


Satisfaction


Histogram
Mean = 2.22
Std. Dev. = .996
N = 199
Frequency
Progress


Histogram
Mean = 1.93
Std. Dev. = .835
N = 199
Frequency
Satisfaction

Regression

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	Dosage, Timing, Training, Content_Sum[b]	.	Enter

a. Dependent Variable: Satisfaction

b. All requested variables entered.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.484[a]	.235	.219	.738	.235	14.873	4	194	<.001

a. Predictors: (Constant), Dosage, Timing, Training, Content_Sum

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	32.423	4	8.106	14.873	<.001[b]
	Residual	105.727	194	.545		
	Total	138.151	198			

a. Dependent Variable: Satisfaction

b. Predictors: (Constant), Dosage, Timing, Training, Content_Sum

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
1	(Constant)	1.281	.196		6.522	<.001	.894	1.669		
	Timing	-.055	.031	-.112	-1.746	.082	-.116	.007	.965	1.036
	Content_Sum	.170	.050	.229	3.383	<.001	.071	.270	.861	1.161
	Training	.355	.107	.213	3.330	.001	.145	.566	.967	1.034
	Dosage	.092	.025	.243	3.638	<.001	.042	.141	.887	1.127

a. Dependent Variable: Satisfaction

Collinearity Diagnostics[a]

Model	Dimension	Eigenvalue	Condition Index	Variance Proportions				
				(Constant)	Timing	Content_Sum	Training	Dosage
1	1	4.133	1.000	.00	.01	.01	.02	.01
	2	.418	3.144	.00	.02	.00	.88	.06
	3	.237	4.173	.03	.21	.02	.00	.60
	4	.163	5.041	.00	.10	.67	.06	.33
	5	.049	9.190	.97	.67	.30	.04	.00

a. Dependent Variable: Satisfaction

Correlations

Correlations

		Progress	Satisfaction
Progress	Pearson Correlation	1	.279**
	Sig. (2-tailed)		<.001
	N	199	199
Satisfaction	Pearson Correlation	.279**	1
	Sig. (2-tailed)	<.001	
	N	199	199

**. Correlation is significant at the 0.01 level (2-tailed).

Nonparametric Correlations

Correlations

			Progress	Satisfaction
Spearman's rho	Progress	Correlation Coefficient	1.000	.252**
		Sig. (2-tailed)	.	<.001
		N	199	199
	Satisfaction	Correlation Coefficient	.252**	1.000
		Sig. (2-tailed)	<.001	.
		N	199	199

**. Correlation is significant at the 0.01 level (2-tailed).

Exploratory Analysis

Matrix

```
Run MATRIX procedure:

***************** PROCESS Procedure for SPSS Version 5.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************

PROCESS is now ready for use.

Copyright 2013-2025 by Andrew F. Hayes. ALL RIGHTS RESERVED.
This version of PROCESS requires SPSS version 26 or later
Workshop schedule available at haskayne.ucalgary.ca/CCRAM
In SPSS 29 and later, change default output font to Courier New for tidier
output. More information about PROCESS at processmacro.org/faq.html.

------ END MATRIX -----

Run MATRIX procedure:

Copyright 2013-2025 by Andrew F. Hayes. ALL RIGHTS RESERVED.
This version of PROCESS requires SPSS version 26 or later
Workshop schedule available at haskayne.ucalgary.ca/CCRAM
In SPSS 29 and later, change default output font to Courier New for tidier
output. More information about PROCESS at processmacro.org/faq.html.
This beta release has not been completely tested. Use at your own risk.



***************** PROCESS Procedure for SPSS Version 5.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************
  Model: 1
      Y: Progress
      X: Satisfac
      W: Ext_Sum

Sample
Size:  199

**************************************************************************
```

```
**************************************************************************

OUTCOME VARIABLE:
 Progress

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .4005      .1604      .8451    12.4175     3.0000   195.0000      .0000

Model
              coeff         se          t          p       LLCI       ULCI
constant     1.1381      .2438     4.6679      .0000      .6572     1.6189
Satisfac      .4129      .1185     3.4836      .0006      .1792      .6467
Ext_Sum       .5010      .2046     2.4482      .0152      .0974      .9046
Int_1        -.0808      .1032     -.7829      .4346     -.2842      .1227

Product terms key:
 Int_1    :        Satisfac x        Ext_Sum

Test(s) of highest order unconditional interaction(s):
       R2-chng          F        df1        df2          p
X*W      .0026      .6130     1.0000   195.0000      .4346
----------
    Focal predict: Satisfac (X)
          Mod var: Ext_Sum  (W)

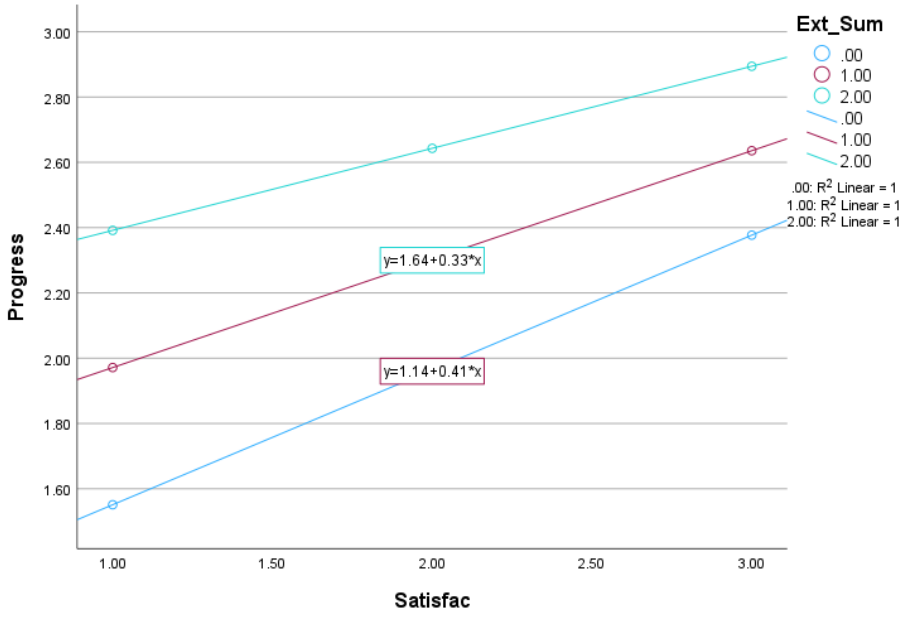
Data for visualizing the conditional effect of the focal predictor:
Paste text below into a SPSS syntax window and execute to produce plot.

DATA LIST FREE/
   Satisfac   Ext_Sum    Progress   .
BEGIN DATA.
     1.0000      .0000     1.5510
     2.0000      .0000     1.9639
     3.0000      .0000     2.3769
     1.0000     1.0000     1.9713
     2.0000     1.0000     2.3034
     3.0000     1.0000     2.6356
     1.0000     2.0000     2.3915
     2.0000     2.0000     2.6429
     3.0000     2.0000     2.8943
END DATA.
GRAPH/SCATTERPLOT=
 Satisfac WITH     Progress BY       Ext_Sum  .

*********************** ANALYSIS NOTES AND ERRORS ************************

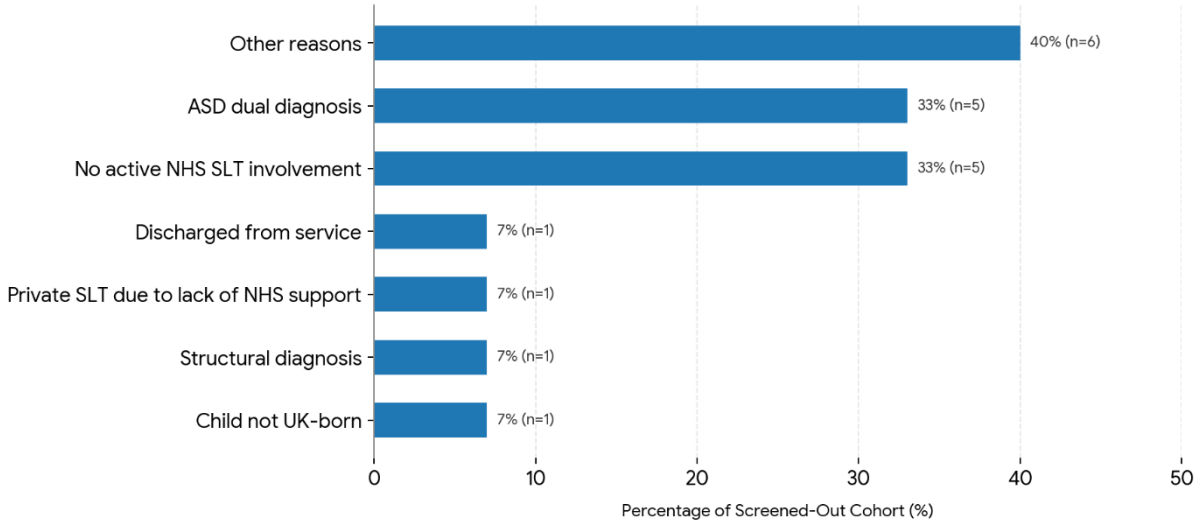
Level of confidence for all confidence intervals in output:
  95.0000

------ END MATRIX -----
```



Supplementary Results Data

Figure 10: *Categorial breakdown of ineligibility and non-completion reasons from Supplementary Survey (n =15)*



Unsolicited Comments

Note: These comments from consenting participants were made on public Facebook posts advertising the survey, during the recruitment window.

1. “My 5 year old daughter has been attending speech, language and communication sessions run by a local charity since she was 9 weeks old. We have used Makaton with her since birth and have tried to give her lots of opportunities to encourage her speech and language. We have attended charity run workshops and seminars in order to support her too. Through the NHS, she received a couple of sessions between 2-3 years old, where we were taught some very basic Sign Along (far below the level my daughter was already understanding and attempting to use) and I was treated like someone with no knowledge of my child’s condition. I was also told we shouldn’t use anymore Makaton, despite my having completed Levels 1&2 in order to help her.”
2. “Hi Holly, I’ve completed the survey, but I’m not sure it reflects the true (non)impact of NHS input. We had a couple of NHS SLT sessions between age 2 - 3, and were “taught” simple sign-along signs when we’ve been using Makaton since birth. I felt like we were not listened to (I also complained that we should have had input much earlier than age 2). We have been attending a charity run speech and language group since age 9 weeks, and my daughter has made amazing progress through these sessions (she is now 5 years old). As such, I put down she has made good progress through extra private sessions and parental input, but worry that the lack of NHS support will be missed.”
3. “Hi Holly, just to say I’ve completed the form. I’d be happy to be interviewed if needed to expand on my answers. It would be great to hear what ‘as expected’ for a child with DS looks like! So often therapies use this to dismiss any need for input, but what actually are the expectations of children with DS with speech delay? Every child is SO different!! You’ve probably had loads of feedback, so good luck with the dissertation and thank you for choosing this as your topic, it is so needed.”
4. “NHS SALT has been truly shocking for us so just wanted that to come across”
5. “Hello, I just wanted to explain my situation. Knowing exactly how poor the NHS SLT was in our area (my daughter saw someone a couple of times in a year) and we paid for a private SLT until she reached school age. We purposely picked a school with a speech unit and an on site NHS SLT and my daughter has absolutely thrived. So whilst we have had a positive NHS experience since school age, that's only because of the school provisional and not via the availability of NHS SLT outside and we would have struggled to have her ehcp needs met. Good luck with your studies , we need you!”
6. “Happy to support your research & have filled in the survey. The frequency question didn’t take into account count that the SLT was delivered in 6 session batches by a

practitioner rather than directly by SLT. Very little support for sensory & motivation issues. Perhaps an 'Any other information' section could capture qualitative info. I would like to receive results of survey finding. This is important work. Thank you"

7. "Completed! My main gripe is none of the NHS salt have specific training to work with children with DS and so just use general strategies that aren't suitable. No working on how to form speech sounds and oro motor exercises which is his main area of need. We do now have an AAC device through NHS SALT as I pushed for that. I am really grateful for their support with that. He is a prolific Makaton user but that is solely down to me and school. At 9 years old he remains non verbal x"
8. "Submitted. X did very well with signing but not speech due to low muscle tone in her throat and neck. Speech therapy sent me on 2 sign language courses which were mega helpful. I've wrote this as I didn't see any comment spaces."
9. "Hi Holly, I've completed the survey but no option to explain views to give more insight. Seen a couple of times and discharged. Given core boards which were not at all appropriate. Because he has speech sounds no input with speech given and then discharged. Hope it helps. 😊"
10. "Would be great if SALT actually functioned effectively. We were approved for SALT 2 years ago had our initial appointment via video call and still havent had anything more. Eventhough it has been said we should have a SALT plan. Ive called multiple times and just get told about the wait list being 18-24months.... however we are now passed that. Its a postcode lottery as always and where we live its insufficient and unsupportive. A group of parents have even asked for group sessions to be held so we can have something but this hasnt happened. I am very fortunate I found a volunteer led group funded by a charity who helped with early speech activities. I am.also a teacher in a SEND school so have access to private salt team who i have asked for advice and used my own experiences from years of teaching. Without that his speech would be much further back especially as he has moderate hearing loss too. Most people are amazed at how clear his speech is and that is with no thanks to nhs salt."
11. "NHS SLT? What a joke"
12. "It would be good to have a survey for secondary aged children. Support is few and far between after transition. It's just not consistent and doesn't provide support that our son needs and deserves."

Electronic Storage Form

Permission to make work available granted

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Date: 30.06.26