Parent/Caregiver perspectives of specialist speech and language assessments for children and young people with Down's Syndrome



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Acknowledgents

This report is to illustrate the findings of the research I conducted for my MSc in Language and Communication Impairment in Children at the University of Sheffield.

I would like to thank all those who took part in this study, as well as the Down's Syndrome Association, for their assistance in advertising my study.

I would not have been able to complete this research without the tireless support of my tutor, Dr Chloë Bate, and the patience of Professor Jenny Thomson, both of the University of Sheffield.

Also, my thanks go out to Hannah Parkes, always a source of inspiration.

Purpose of Study

Down's Syndrome (DS) is the most common chromosomal cause of intellectual disability (Næss et al., 2021). The incidence of DS is approximately 1 in 700 live births in the UK (Hargreaves et al., 2021).

López-Riobóo and Martínez-Castilla (2019) found that speech, language and communication needs (SLCN) are present in 95% of the DS population. When compared to individuals with intellectual disability who do not have DS, individuals with DS are 2.6 times more likely to have moderate difficulties with communication and 1.9 times more likely to have a severe form of communication difficulty (Kent et al., 2021).

The UK Royal College of Speech Language Therapists (RCSLT) recommends that Speech and Language Therapy (SALT) provision should be established from the first year of life and that all individuals with DS will need SALT input to help reach their full potential (Burgoyne, 2020).



In addition, an All Party Parliamentary Group on Down's Syndrome (APPGDS) report (2012) states that those working with children and young people (CYP) with DS should understand DS as a condition.



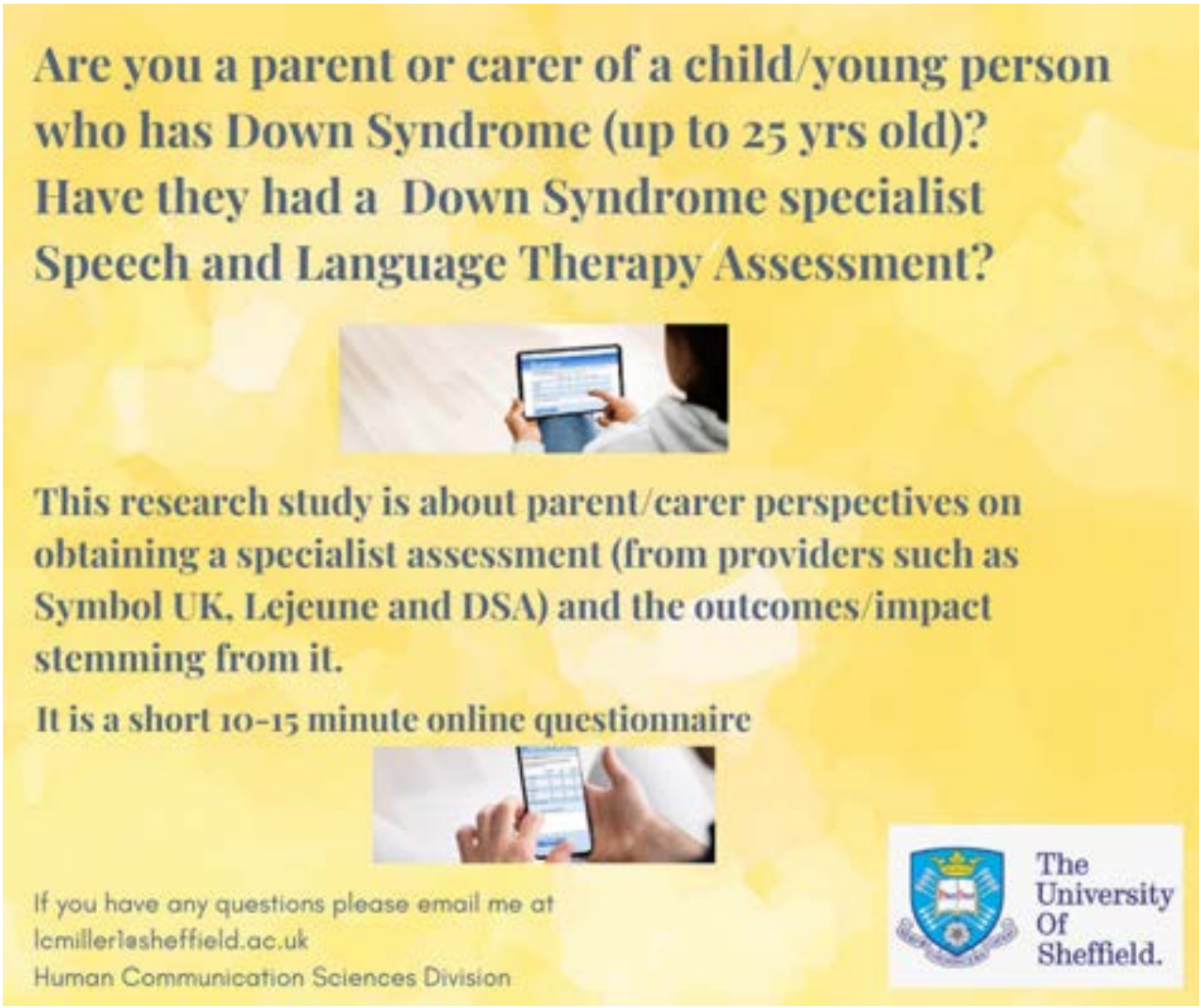
This is also recommended by the recent guidelines set out by the Down's Syndrome Association (DSA, 2021), stating that SALT professionals should demonstrate up-to-date knowledge and understanding of effective interventions for those with DS.

This study aimed to investigate parent/carer perspectives regarding DS-specialist SALT assessments. In terms of obtaining one; and the outcomes and impact stemming from it.

In terms of obtaining an assessment, it concentrated on how these were funded, where the knowledge of the assessments came from, and what triggered the parent/carer to investigate gaining a specialist assessment.

Regarding outcomes, it focused on any changes in the level of provision and/or the resources used that the parent/carer believed were a direct result of the specialist assessment.

For the impact, the questionnaire focused on where the parent/carer believed the biggest changes had occurred, or the largest effect on what was being done for their child. The key findings are presented here in summary.



Findings

The key findings of this study indicated that the majority of parents/caregivers funded the specialist assessment themselves. There were varying levels of difficulty reported in finding the funding, with quotes illustrating this stating '*very expensive'* and '*not cheap … but worth every penny!*'.

<u>Figure 1:</u> Percentage Ring illustrating sources of funding

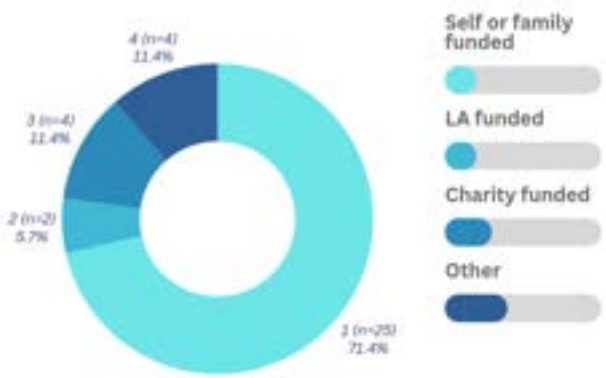
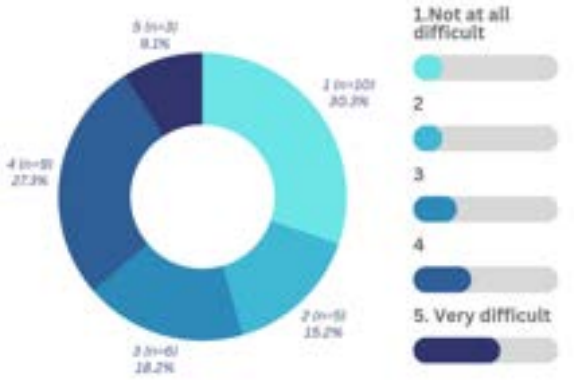


Figure 2: Percentage Ring illustrating levels of difficulty in sourcing funding

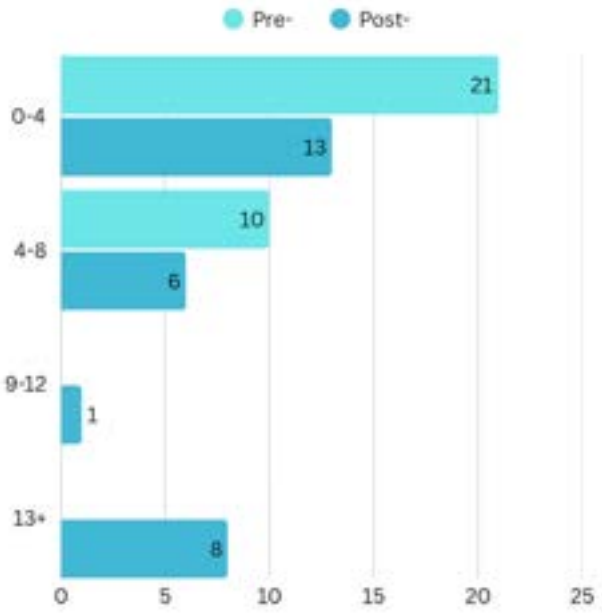


SALT provision before and after the assessment was measured, and greater provision was reported post-assessment.

However, it was noted that as neither individual case histories, nor the work management processes of different SALT teams, were taken into account, it was difficult to draw solid conclusions.

It should be reiterated that this survey purely measured parent/caregiver perspectives.

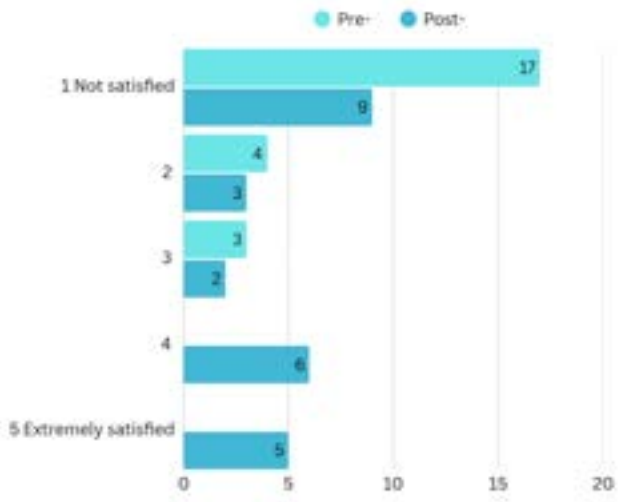
<u>Figure 3:</u> Graph illustrating provision pre- and post- assessment (times seen in a year)



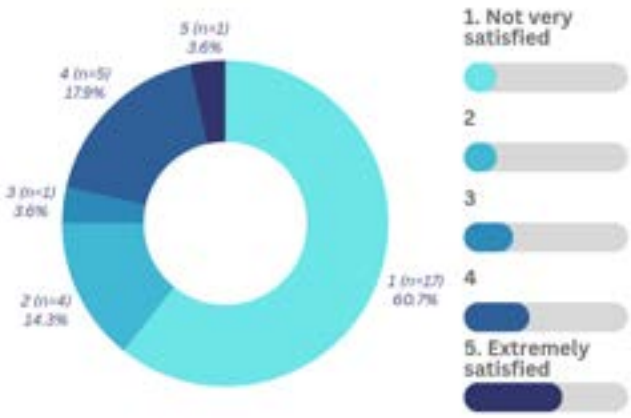
The satisfaction ratings of the SLCN contents of their child's Education, Health and Care Plan (EHCP), pre- and post-assessment were tested statistically. The responses given indicated a significant difference between the satisfaction ratings before the assessment compared with after. With higher satisfaction ratings of the content following the assessment.

A further question enquired about how satisfied parents/carers were with the process of incorporating the results of the assessment into the EHCP, and reported results for this can be seen below.

<u>Figure 4</u>: Graph illustrating satisfaction levels of the SLCN contents of EHCP pre- and post-assessment.



<u>Figure 5:</u> Graph illustrating satisfaction levels of ease of incoporating assessment into EHCP.



The question of whether the respondents would recommend the specialist assessment to other parents/carers produced a positive response, with 27 respondents out of the 34 that answered this question (79.4%) stating 'yes' and no one stating no. The remaining respondents stated 'other', for example:

'It can help parents to learn more about how to support their child's Speech and Language themselves at home.'

Discussion

Reasoning behind seeking a specialist assessment

Input into the EHCP was an important motivating factor mentioned by parents/carers. Castro et al. (2019) found that there was variation across Local Authorities (LA) on this very aspect of EHCPs, and results from this study indicate that this remains an issue.

Another aspect of the provision was reports of the child not being seen frequently, despite recommendations of a minimum of monthly sessions (Burgoyne, 2020), as previously indicated in Hargreaves et al. (2021).

The issues brought up by the respondents to the questionnaire are reflected in previous studies surrounding SLCN of CYP with DS. Studies involving broader aspects of educational experiences (for example, Hargreaves et al., 2021; Kendall, 2019) that cover SALT issues share parental/carer reports of perceived lack of provision, lack of DS specialism, and attempts at discharge.

Are There Tangible Outcomes that Parents/Carers Ascribe to the DS Specialist SALT Assessment?

The key outcomes emerging from the responses were a greater amount of provision and a greater emphasis on DS-specific interventions/resources following the specialist assessment. Some respondents, however, did not feel able or know how to push forward the recommendations from the specialist assessment to translate this into tangible benefits for their child.

They appear to reflect the findings of previous surveys, as mentioned above, that included SLCN of CYP with DS (Hargreaves et al., 2021; Kendall, 2019). This consistency of experience across studies highlights common problems in relation to perceptions of SALT among parents/caregivers.

Parent / Caregiver Perspectives on the Impact of the Specialist Assessment

The highest average score from the multiple-choice question about impact in different areas of the child's life was 'at home'. This indicates that most families felt in some way that the DS specialist SALT assessment had increased their knowledge and confidence in interventions/resources. This supports the findings of Law and Millward (2001), who found that parents/carergivers often take on a proactive role in the SLCN of their children.





Going Forward

As the questionnaire focused on the perceptions stemming from the DS specialist SALT assessment, it did not ask about other factors that may have influenced provision, such as progress made, different ages/stages, or the effects of different interventions influencing provision in any way.

Without a thorough understanding of the child about whom the questionnaire is being filled in, it is difficult to make firm conclusions about the effect of the DS specialist SALT assessment. No firm attribution to the specialist assessment can be made, as other factors locally or individually may also have brought about any change.

As this study concentrated solely on parent/carer perspectives, it did not involve any of the professionals from the local NHS SALT team, LA, or educational settings. Sales and Vincent (2018) have shown that it is possible to integrate all these different viewpoints, and replicating this regarding DS-specific issues relating to SLCN would provide a cohesive overview of the current situation. A chance to share best practices would be an additional bonus to this approach.

The parents/carers who had gone through the EHCP process in its totality reported a statistically significant difference in satisfaction with the SLCN contents of the EHCP following the specialist assessment. However, this is often in the context of having to go through tribunal procedures, which required further effort and produced negative responses within the questionnaire. There is also concern voiced around the involvement of the LA in determining levels of input from SALT professionals and whether staff and case workers at the LA have any specialist knowledge of DS.

The working relationships between SALT professionals, LAs, schools, and parent/carers involved in the SLCN provision for CYP with DS produce a complex picture. Future studies are warranted to see if the involvement of DS specialists has a positive impact on all sides, not just parents/carers.

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