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Speech and language therapy services for autistic children in Munster: An interpretative phenomenological analysis of parental experiences and expectations

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Abstract.

BACKGROUND: From a medical perspective, autism is characterised by a dyad of impairments in social communication and interaction, and restricted, repetitive behaviours. However, the neurodiversity movement sees autism as a difference and not as a disability. Autistic individuals account for 1–2% of the population and many autistic children and their families access Speech & Language Therapy (SLT). In Ireland, SLT is provided across primary care, childrens' disability network teams, as part of the progressing disability services for children and young people, and private providers. However, little is known about parents' experiences accessing SLT services for autistic children.

OBJECTIVE: This study aimed to investigate the parental experiences of SLT services for autistic children in the province of Munster, Ireland.

METHODS: Interpretative Phenomenological Analysis was used as a methodological framework. Semi-structured online interviews were carried out with six participants to identify their experiences of receiving SLT services for their autistic children. Data analysis followed a structured process, starting with in-depth explorations of individual datasets before cross-case analysis of the whole sample.

FINDINGS: Participants expressed a variety of experiences and expectations of SLT provision, which centred on three thematic journeys: 1) Parenting an autistic child, 2) Experiencing and navigating SLT services for autistic children and 3) Evolving expectations of SLT service changes.

CONCLUSIONS: Findings provide insight into parents' individual and shared experiences of SLT services for autistic children, which may enrich service providers' understanding of parents' perceptions of SLT services. Future research should focus on exploring the experiences of autistic individuals and Speech and Language Therapists providing services for autistic children.

Keywords: Interpretative phenomenological analysis, autism, parental experiences, expectations, speech and language therapy

1. Introduction

Autism refers to a heterogeneous neurodevelopmental disorder, characterised by a dyad of impairments in social communication and interaction, and restricted, repetitive behaviours (Lai, Lombardo & Baron-Cohen, 2014). Autism has steadily become one of the most widely researched neurodevelopmental disorders, yet despite multiple discussions regarding the possible causes of autism, current evidence continues to discuss the role of both genetic and environmental factors (Wiśniowiecka-Kowalnik & Nowakowska, 2019). Alongside medical advances in the understanding of autism, the util-

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isation of the social model of disability and the celebration of autism as a form of neurodivergence is at the forefront of autism research (den Houting, 2019).

1.1. The neurodiversity paradigm

Neurodiversity refers to the idea that differences in neurology should be recognized and respected as a social category, similar to ethnicity, socioeconomic status (SES), sexual orientation, gender, or disability (Chapman, 2019). Within the wider autistic community, the neurodiversity movement has gained ever increasing support, with autistic people, across all ranges of abilities and needs, leading discussions regarding the language used to describe their identities and the supports required (Botha, Hanlon & Williams, 2021). Supports which aim to eliminate autistic characteristics, are being replaced with neuroaffirmative, strength-based supports which ensure the unique culture of autism is understood, accepted and not pathologized (den Houting, 2019).

1.2. The prevalence of autism and accessing healthcare services

Estimates of the prevalence of autism are imperative for the prospective planning and funding of health services and guiding service reform for autistic individuals and their families (Ho, Kuluski & Im, 2017). Current epidemiological studies are reporting that prevalence rates for autism are between 1-2% (Fombonne, 2020). However, there are significant discrepancies in accessing healthcare services for autistic individuals internationally (Dew et al., 2012). In contrast to parents of children with other developmental differences, parents of autistic individuals experience heightened levels of stress and stigma and associated financial strain in their journeys to secure services (Ho et al., 2017; Woodgate, Ateah & Secco, 2008).

1.3. Speech and language therapy services for autistic children

While parents of autistic children are noted to engage in numerous therapeutic supports for their children, Speech and Language Therapy (SLT) is the most commonly sought-after service (DePape & Lindsay, 2015). Speech and Language Therapists (SLTs) are fundamental in identifying and providing therapeutic support to autistic individuals and their families (Irish Association of Speech and Language Therapists (IASLT), 2018). Despite advances in evidence-based practice for autism (Hume et al., 2021), large discrepancies between SLT provision are found (Pring, 2015). While there is research on the potential barriers to timely and accurate identification of autism (Abbott, Bernard & Forge, 2013), the causes of service inequality are not clearly defined (Pring, 2015). The lack of transparency on SLT resources between defined healthcare districts and the lack of appropriate referral to early intervention services may be further impacting autistic children and the future planning of equitable SLT services (Pring, 2015). In terms of geographical location, services for autistic individuals in rural and remote areas may be further impacted by a reduced prevalence of allied health professionals, resulting in possible preconceived expectations of SLT services by parents of autistic children (Dew et al., 2012).

From an Irish perspective, Public SLT for autistic children can be accessed at primary care level or via children's disability network teams (CDNTs), as part of the Progressing Disability Services for Children & Young People (PDS) model (HSE, 2020). The service in which each individual child can access is dependent on the complexity of their needs (HSE, 2020). The implementation of PDS and CDNTs aimed to facilitate a move towards interdisciplinary collaborative working and make services accessible and equitable for all children, regardless of the nature of disability and the geographical location of their home and school (HSE, 2020). However, services for autistic children in Ireland are challenged with limited resources and waiting lists. A significant proportion of autistic children (55%) have unmet needs arising from being on a waiting list for multidisciplinary team (MDT) services, including SLT (Roddy & O'Neill, 2020). The difficulties in accessing SLT services have also been noted in the final report by the Joint Committee on Autism, who published their findings in June 2023 (House of the Oireachtas, 2023). It is crucial to explore parents' experiences and expectations of SLT services for autistic children in Ireland. This new knowledge could provide valuable insights into parents' journeys and could identify useful information for service providers.

2. Aims and objectives

The primary aim of this study was to investigate the parental experiences and expectations of SLT services for autistic children and make recommendations for professionals. Additional objectives were to identify how parents' expectations change over time and collate their suggestions for improvements to SLT services.

3. Methods

3.1. Methodology

Interpretative Phenomenological Analysis (IPA) was chosen as the methodological approach for this study. Data were collected via online, semi-structured interviews (Smith, Flowers & Larkin, 2022). The first author, who is a male Speech and Language Therapist with a MSc by Research and BSc Speech and Language Therapy, undertook training on IPA and qualitative interviewing before the data collection, and completed all interviews. This paper follows COREQ reporting guidelines.

3.2. Sampling and recruitment

The province of Munster in Ireland was selected as the geographical area to conduct this study. While Munster was one of the first provinces to transition to the PDS model, it was also the location of the research team. Ethical approval for the study was granted in February 2021 by the Institute Research Ethics Committee in Munster Technological University (See Appendix A).

Participants were recruited using purposive sampling (Campbell et al., 2020). Invitation letters and information leaflets were disseminated via email to groups for parents of autistic children. A pre-arranged phone call with participants took place to explain the study, before informed consent was obtained.

3.3. Participants

The participants were parents of autistic children who:

1. Were living in the province of Munster.
2. Have attended SLT services, either public and/or private SLT services, with their child in the province of Munster. No limits in relation to the duration and frequency of attendance of SLT services were applied. The parent, who self-identified as the main parent attending SLT services with their child was eligible to partake.
3. Have children aged between 2–12 years old, with a formal, multidisciplinary autism diagnosis, which reflects the earliest diagnostic age for autism and allows for experiences to be captured across different ages groups.
4. Have proficient English (if not native speakers) and have access to the internet and an electronic device, compatible with Microsoft Teams.

3.4. Pilot and data collection

Prior to the data collection process, a pilot study was completed with one parent. This confirmed the suitability of the interview guide and the appropriateness of IPA as a methodological approach. Data from the pilot was not included in the final analysis. With regards to data collection, participants were interviewed with the camera on, but only audio was recorded (using an electronic voice recorder and the Microsoft teams recording feature as a backup). None of the participants refused to take part in the study.

3.5. Data analysis

The seven analytical steps of IPA were followed during data analysis to develop personal experiential themes (PETs) and group experiential themes (GETs) (Smith et al., 2022). All data were analysed initially by the first author before refining the analysis during meetings of all three authors. In line with IPA, data were analysed ideographically before the group level analysis took place. Member checking was facilitated via the repetition of the participant's answers, from field noted taken by the first author. Clarification of information was sought, if required, to ensure the accuracy of the data throughout all six interviews (Birt, Scott, Cavers, Campbell & Walter, 2016). Any follow up questions, regarding data provided, were confirmed with participants via email or phone.

4. Findings

Six participants (all mothers) were recruited and chose to be interviewed alone. The average length of interviews was 57 : 50 minutes, ranging from 46 : 09 minutes to 68 : 23 minutes. The ages of the participants ranged from between 25–34 years old and 35–44 years old (See Table 1 for demographic information).

This article will report the three GETs, which were identified across the whole sample: 1) The jour-

Table 1
Demographic information

Name*	Age range	Living area	Nationality	Education level	Employment status	Annual income	Relationship to child	Age and sex of child	Family type	Order of birth and other siblings
Ana	25–34	Rural area	Irish	Higher Certificate	Full-time carer	€20,000–29,999	Mother	10-male	One parent	First born – 2 siblings
Elsa	25–34	Urban area	Irish	Bachelor's degree with honours	Full-time employment and full-time carer	€40,000–€49,999	Mother	11-male	One parent	First born – 0 siblings
Grace	35–44	Rural area	Irish	Master's degree	Full-time employment and full-time carer	€30,000–€39,999	Mother	12-male	One parent	Second born – 1 sibling
Kate	25–34	Rural area	Irish	Higher Certificate	Part-time employment and full-time carer	€40,000–€49,999	Mother	4-male	Two parents	Second born – 2 siblings
Rose	35–44	Urban area	Irish	Bachelor's degree	Full-time carer	€30,000–€39,999	Mother	6-female	Two parents	Second born – 1 sibling
Tanya	35–44	Rural area	Irish	Master's degree	Part-time employment and full-time carer	€50,000–€59,999	Mother	9-male	Two parents	First born – 2 siblings

*pseudonym.

ney of parenting an autistic child, 2) The journey of experiencing and navigating SLT services for autistic children and 3) The journey of expectations of changes to SLT services.

Theme 1: The journey of parenting an autistic child: " *It is ok if they cannot say their name, they can do other things*"

For many participants, their journeys began with their children receiving an autism diagnosis, and it seemed to evolve from the feeling of loss and grief to acceptance of their new normal. Participants spoke about their fears and subsequent grief and loss. Guilt around leaving their old lives and sacrificing career goals to care for their children were echoed amongst participants. One participant, Elsa, stated that receiving her child's autism diagnosis was the "*day when you know your parenting experience will be different… I can remember that day as clear as day like. It was devastating in a way*!". The use of metaphor by Elsa suggests the realisation of the journey that lies before her as a parent of an autistic child. This sentiment was shared amongst all parents, especially Grace, who felt guilty for not recognising her son was autistic. Like to Grace, other parents also shared the fear and guilt that, at some level, they may have caused their child's autism, due to not engaging enough with their children at home. However, all participants spoke of their acceptance and hope of a new, but different normal, secondary to the initial loss of a neurotypical child. They experienced a sense of understanding their autistic children, how the diagnosis helped their family units to adjust and see their children's areas of strengths. One parent, Tanya, reported that her son "*was the most perfect child ever and when you are a first-time mom, you do not know any different anyway.* The use of positive adjectives by Tanya suggests that she understands that autism makes her son who he is and acknowledges how integral it is to his identity. However, participants spoke about the lack of understanding of their autistic children from the wider community. They reported difficulties with people "*listening to their concerns*" about their children and the perceived stigma associated with not being a good enough parent to their children. Elsa spoke about how "*the GP said straight out, 'if you are worried about autism, he is not an autistic child', those were his words*! This quote highlights the feeling of dismissal parents of autistic children often experience when meeting some healthcare professionals.

Theme 2: The journey of experiencing and navigating SLT services for autistic children: "*I did not have any understanding of that world. Sounds stupid but that's how the system works*"

Experiencing and navigating SLT services leads parents on an ever-evolving journey of searching for and understanding SLT services, as well as waiting and fighting for supports for their autistic children. Participants discussed having no prior knowledge of SLT services. However, participants' experiences quickly changed, with Ana stating that "*you learn very fast when you need to*". Ana's comments illuminate the sense of continuous evolving that she experienced as a parent of an autistic child. Participants also reported feeling like the responsibility to access supports was always placed upon them, with Elsa stating, "*When you are a parent of a child with autism, the responsibility is put on you a lot to, make him talk, if that makes sense? I remember a couple of comments being made actually that it is down to what the parent does at home.*" The use of the objective verb *put* shows the sense of burden experienced by Elsa. The reduced availability of access to information on services for autistic children was echoed by participants, particularly the recent reconfiguration of services, under the PDS model. Ana discussed that "*everything is after changing and I am trying to figure it out as I go along myself . . . . I just seem to be getting sent forms left, right and centre and just filling them in and sending them back and waiting.*" Peer support between parents of autistic children was a necessity and, without it, participants feared felt they would not have figured out how the services operate. Participants first spoke about their search for supports, prior to their child receiving their autism diagnosis. Participants shared contrasting experiences, with Ana stating that "*you are just kind of left waiting*". However, Elsa's experiences of her son's pre-diagnosis support, approximately nine years ago, led to her relief of having an older autistic child, stating "*I would be worried if I were trying to access services now, as at that time* (ten years ago), *maybe things were better?*". *One participant, Rose, spoke about how the reduced capacity of the public SLT system* "*was not the therapists' fault-it was more the system.*" Some participants observed the desire of some primary care SLTs to provide therapy services to their children, but they "*could not be seen*" as their children were on a list for an autism assessment. Kate's expressed her dismay at this barrier stating, "*I just thought it was a bit ridiculous really . . . the SLT was willing to offer her services, in our local town, but he was on a list. I could not see any harm in an hour a week there-it does not make any sense.*" Following their autistic children receiving their diagnoses, participants spoke about waiting for SLT services. Participants' hope for supports turned to dismay, as they reported not hearing anything from the public SLT services in their area. Ana reported that her son was "*probably four years of age, when we first saw SLTs . . . he got a six-week block of therapy and, after that, we had zero SLT through public services for six years*".

Participants' experiences of the reduced resources within public SLT services led some parents to engage in private, fee-paying SLT services. While some public SLTs understood participants' desires to engage private therapy providers, due to unfilled vacancies and reduced appointments, other participants felt the public SLT services questioned their motivation for private SLT services, which Elsa felt was ultimately "*not well received by them (public SLTs) that I was going private (SLT)*". Participants reported a variety of positive and negative experiences across public and private SLT services. Ana had "*doubts*" about whether her son would "*slip through the cracks*" of public SLT services, which led her to engaging in private SLT services, to ensure her son "*does not fall behind*". Elsa and Rose shared this experience, discussing that the sporadic public SLT services weren't working for their children. Some participants' experiences of private SLT services were described as incomparable to public SLT services, reporting that private SLT was focused on providing direct, goal-focused support. In contrast the public SLT service was reported as providing parent-training and consultative, indirect support. One participant, Tanya, reported that public SLT services "*appear to have no duty of care*" towards her autistic child, with no check ins, follow up appointments or reviews offered. The use of uncertain language shows the sense of confusion experienced by Tanya about her child's service entitlements. Another participant, Grace, stated that despite the lack of consistent public support, she was told that future public services "*would not be provided if we did not engage with the services being offered*". The nervous tone of voice used by Grace evoked a sense of fear that she previously experienced for trying to advocate for her autistic child.

Negative experiences of private SLT services included the unsuitable clinical experience of the private SLTs and the financial stress and commitment of access private services. Participants reported the higher expectations of value for money for a fee-paying service-Elsa stated that, "*it is definitely more positive when you are paying for it. They (private SLT), you know, are focused on the task at hand-less talking and getting down to the session. I would have found it more positive than the public system*". Some participants sought more suitable private SLT services for their child's individual needs or ceased private SLT services and started fighting for more public services. Kate experienced this sentiment with her autistic son when she had to move to a different private SLT, stating that "*You could tell that (new private SLT) was in it for him, you know?*" *(First private SLT) was not following his lead or maybe they did not have experience with autistic children*" The feeling of frustration associated with finding the most appropriate SLT service emerged across the whole sample. Participants initially spoke of being vocal of their childrens' needs, calling service providers regarding waiting times and holding them accountable. However, in time, participants reported being exasperated and ultimately giving up the continuous fighting. Instead, participants focused on practical and functional supports for their autistic children, such as creating inclusive tasks for their children at home and engaging with the local community in meaningful ways.

Theme 3: The journey of evolving expectations of SLT service changes: "*You learn very fast when you need to. It is a major battle for us*"

Participants expressed their desires for changes to the communication and engagement approaches of public service providers. This included the ability to access more frequent SLT supports and increased compassion and support for parents of autistic children accessing services. Participants discussed the long waiting times for public SLT services, the reduced resources available to support their autistic children and the inability to contact some service providers. Some participants reported that the COVID-19 pandemic was presented as a reason for increased waiting times, despite waiting lists being noted prior to this period. Participants detailed their frustration with the inability to contact their therapy providers, with Kate stating they "*do not need any more forms to fill in, we just need services*". Kate's experiences of no contact led to anger about not knowing a timeframe for getting the service in the future, leading to pessimistic expectations of the Public SLT services.

Participants reported differing ideas regarding their expectations of public SLT services; Ana expressed the need for a minimum of 12 weeks of public SLT sessions annually, in addition to the parent training. In contrast, Rose advocated for "*speech and language therapy to be in my child's house and their environment*", highlighting the need for more environment-specific supports across settings with access to fun, engaging equipment and home-based courses while awaiting direct support. However, participants noted that increased communication about when sessions and training would be accessible and on what frequency would be integral to its success. Participants, especially Elsa, called for increased recognition of the reality that "*raising an autistic child is not second nature and parents are vulnerable when they have autistic children*". The impact of an autism diagnosis " *directly affects your whole experience of services ... if you are feeling all these worries and guilt, it can impact on your ability to work with your child*". Compassionate support for parents of newly diagnosed autistic children and access to follow up supports were noted as integral for future successful experiences of SLT services. Without the ability to become an active member of the therapy process, participants may continue to negatively experience SLT services.

5. Discussion

This study illuminates the ever-evolving journey parents of autistic children experience when accessing SLT services. Parents' journeys often begin with noticing differences in their children's development, which may be attributable to early indicators of autism being present by 12 months to 18 months or even earlier (Johnson, Myers & American Academy of Pediatrics Council on Children with Disabilities, 2007). However, parents become cognizant of some professionals not listening to their concerns about their children, reinforcing the concept of autism often being invisible (Gentles, Nicholas, Jack, McKibbon & Szatmari, 2019; (Gentles, Nicholas, Jack, McKibbon & Szatmari, 2020). Therefore, some autistic children often cannot access early intervention MDT services offered to other children with visible additional needs (Abbott et al., 2013; Helkkula et al., 2020). While parents are fighting to figure out how SLT services are provided and facing barriers for timely access to diagnostic assessment and subsequent therapy services, some parents of autistic children are also trying to come to terms with the loss of a neurotypical child (Abbott et al., 2013; Woodgate et al., 2008).

5.1. Challenges accessing therapeutic supports

Participants of this current study relayed their dissatisfaction at the lack of information about recent reconfiguration of SLT services, as well as the reduction in the availability and frequency of direct, individual SLT sessions. Internationally, it has been recognised that uncertainty of how to navigate SLT services and negative experiences with some healthcare professionals has led to parents of autistic children facing significantly increased challenges accessing appropriate supports (Khanlou et al., 2017; Ho et al., 2017; Helkkula et al., 2020). Despite research calling for consistent development of services through evaluation of family and service access outcomes (Carroll, Murphy & Sixsmith, 2013), the lack of available information on service provision models for autistic children in Ireland can impact parents' experiences of SLT services (Dillenburger, Jordan, McKerr, Devine & Keenan, 2013). Parents' satisfaction or dissatisfaction with services for autistic children is also linked with how parents view themselves in SLT sessions and their own expectations of SLT (Robert, Leblanc & Boyer, 2015). In the current study, parents expressed dissatisfaction with the responsibility for implementing therapy plans being placed on them, further compounding their difficulties accessing SLT services and the reality of the unmet needs and negative experiences of SLT services for their autistic children (Buckley, Boland & Gowran, 2021; Roddy & O'Neill, 2020; House of the Oireachtas, 2023).

Internationally, parents also face significant challenges in acquiring services for their autistic children (Helkkula et al., 2020). Access to services, secondary to the availability of public healthcare services and financial ability to engage in private services, are noted as the major factors for parents (Helkkula et al., 2020; Woodgate et al., 2008). This observation is in line with participants' experiences in the current study, as some parents chose to make financial and personal sacrifices to access private SLT for their autistic children. It is noteworthy that despite significant ranges between participants' annual income, all but one parent engaged in private SLT services. This financial vulnerability of parents and their feelings of obligation to incur possible financial strain and debt to access private SLT services is in line with available research (Khanlou et al., 2017; Roddy & O'Neill, 2020). However, a report by the Joint Committee on Autism in Ireland has expressed commitment to ensuring autistic children and their families will no longer have to spend significant amounts of money to access services to which they are entitled (House of the Oireachtas, 2023). The report recommended financial supports for families of autistic children, who access private therapies. The report stated that the financial supports would be limited to families who, due to vacant positions within CDNTS, would be unable to acccess their publicly funded services via CDNTs. In contrast, the financial support, which was named the Children's disability service grant fund, was instead offered to community groups and services, who support children with a disability. However, this support was limited to autistic children who were on a waiting list for CDNTs and not those currently linked with CDNTS (House of the Oireachtas, 2023). With regards to the current study, participants reported that the significant waitlists for public SLT services and the provision of indirect parent training by public service providers has propelled them to engage in session based private SLT services. Participants placed value on the idea of private SLT equating to more direct, individualised, and focused therapy. This finding from the current study is in line with international research relating to other parents equating value for the financial difficulties endured accessing private therapy supports once positive impacts were noted for their autistic child (Helkkula et al., 2020).

5.2. Better integration of public and private SLT services

Despite the positive benefits of accessing private SLT for some autistic children, participants in the current study reported that some public SLTs noted their dissatisfaction of also attedning private SLT services. While there are guidelines on code of conduct and best practice amongst SLTs from different services in Ireland (IASLT, 2010), some participants expressed concerns about the appearance of a lack of established working relationships between public and private SLTs. The reduced communication between therapists further impacts professionals' decisions on whether to refer autistic children to private SLT while awaiting public SLT, further highlighting how the perceived demand for services does not reflect the actual need for services (Roddy & O'Neill, 2020). As a result, participants in the current study called for more integrated services, ensuring their autistic children are not missing out on necessary services across various providers.

5.3. Perceived lack of supports for families of autistic children

While parents of autistic children engage with more support services than other parents of children with additional needs (Gentles et al., 2019), they reported feeling more vulnerable, specifically due to the lack of supports for the impact of the diagnosis and the knock-on effect on their experience of services (Hall, 2012). Parents are required to amend many aspects of their daily lives, such as family lifestyles, work commitments and marital relationships (Ooi, Ong, Jacob & Khan, 2016). As a result, caring for an autistic child has been linked with negative outcomes for relationships (Hall, 2012). Participants in the current study reported that their relationship breakdown was linked with the additional healthcare needs and stressors of raising their autistic children, which is in line with the findings of available literature (Hall, 2012). 50% of participants in the current study were single mothers raising their autistic children with limited or no support from the children's father or other parent. In contrast to dual parent families, single mothers of autistic children are found to experience higher levels of stress, lower quality of life and risk of increased ill-health, secondary to the multiple demands of caring for the unique needs of their autistic children (Safe, Joosten & Molineux, 2012). It is important to note that some parents' readiness to engage in services for their child is linked to their perception of their child's neurodivergence (Gentles et al., 2020). Parents learn to understand their autistic children on their own terms, alongside support from professionals (Gentles et al., 2019). This phenomenon supports the idea of a transient grief, secondary to a loss of a neurotypical child, and subsequent reduced satisfaction and engagement with therapeutic services (Gentles et al., 2020). Parents in the current study desire services supporting their mental health, which are integral for parents to accept their neurodivergent child, and positively influence their perception of and engagement with therapeutic services. Access to mental health supports also have the potential to positively impact parental and family relationships, further increasing engagement and satisfaction with services (Langley, Totsika & Hastings, 2017; Gentles et al., 2020).

5.4. *Neurodiversity*

The concept of neurodiversity, and how the demands of a neurotypical focused world lead to imposed disability, has had an undeniable influence on our understanding of autism. Furthermore, the neurodiversity movement has informed SLTs how services for autistic individuals should be provided (den Houting, 2019). The traditional notion that autism is a disorder defined purely by deficits is being challenged (Happé & Frith, 2020). Central to neurodiversity is the concept of ableism, which refers to the beliefs and practices that discriminate and devalue individuals with disabilities, further promoting an ideology of fixing this deficit (Bottema-Beutel, Kapp, Lester, Sasson & Hand, 2021). Ableism is deeply embedded in therapy approaches and practices rooted in the deficit-based medical model of disability are negatively impacted autistic individuals (Crompton, Hallett, Ropar, Flynn & Fletcher-Watson, 2020). Previous neuronormative and diagnostic-driven interventions, such as social skills training, are being disregarded as research has shown that difficulties in autistic communication are apparent only when interacting with non-autistic people (Crompton et al., 2020). With regards to SLT service provision and neurodiversity, service providers should re-evaluate the criteria and outcome measures that aim to reduce or eliminate autistic traits as the goal of service provision (den Houting, 2019). This sentiment was shared by participants, who discussed their dissatisfaction with the lack of SLTs who understood and connected with their autistic children.

6. Limitations

Limitations of this study include the lack of cultural diversity amongst parents and the lack of fathers of autistic children. As parents were only recruited from the province of Munster, this further impacts the ability to generalise any findings relating to parents' experiences of SLT services for autistic children across the island of Ireland. This is secondary to the phased implementation of PDS across individual counties and other provinces of Ireland and large gaps in the historical provision of disability services in Ireland (HSE,2020). Furthermore, it was not possible to validate what SLT services the autistic children and their parents received, which may impact the parents' recall of their experiences.

7. Recommendations for future research

Qualitative research, which utilises a wider multi-site sample, could provide more comprehensive understanding of the experiences of parents of autistic children across Ireland. While the experiences of mothers of autistic children are commonly examined (Ekas, Lickenbrock & Whitman, 2010), there is a paucity of available studies on fathers' experiences of autistic children (Burrell, Ives & Unwin, 2017). In line with the neurodiversity movement and need for autistic voices, autistic individuals' experiences of SLT services need to be heard and compared with parents' experiences (Cummins, Pellicano & Crane, 2020). The additional information provided by autistic children, teenagers and adults about their experiences and expectations of SLT services would be paramount to any substantial changes to SLT supports for current and future autistic individuals. Finally, it would be meaningful to compare the experienced of parents and autistic individuals with the experiences of SLTs delivering services for autistic children. While there is available research on SLTs experiences of providing SLT support to children with developmental language disorder, there is limited research available on SLTs' experiences of SLT services for autistic children (Thomas, Schulz & Ryder, 2019).

Additionally, mixed-methods research exploring parents' experiences of SLT interventions they have received and what aspects were most and least beneficial would enable measurement of effectiveness of intervention, associated costs and the resources required. Parents of autistic children were more likely to experience unmet needs and financial hardship, which echoes finding from this study (Roddy & O'Neill, 2020; House of the Oireachtas, 2023). However, in the absence of quantitative data of parents' experiences of engaging in private, fee-paying SLT services in Munster, it is impossible to understand the additional supports required to support autistic children in Munster.

Acknowledgments

The authors wish to acknowledge the participants, who were parents of autistic children accessing SLT services.

Conflict of interest

The first and second author are involved in providing services for autistic children in a private speech and language therapy clinic. None of the parents recruited in this research 1) were known to either author, 2) have ever availed of the service in this clinic, 3) lived in the county where the clinic is situated.

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Appendix A- Ethical Approval

MTU
Ollscoil Teicneolaíochta na Mumhan
Munster Technological University

Institute Research Ethics Committee (IREC)
Munster Technological University - Kerry Campus

08/02/2021

David O'Shea
Postgraduate Student
Munster Technological University – Kerry Campus

Mr. O'Shea,

Re: **Parents' experiences and expectations of speech and language therapy services for children with Autism Spectrum Disorder in Munster**

Thank you for your ethics application in respect of the above research project. The application has been reviewed in accordance with the University's Research Ethics Policy. I can confirm your research has been granted ethical approval as a minimal risk project subject to the general conditions of approval outlined below:

1. The research is undertaken in accordance with University's Research Ethics Policy
2. If there is any planned substantive change in the research protocol, this detail is submitted to the Research Ethics Committee for review in advance.
3. If any ethical difficulties arise in the course of your project these are reported to the Chair of the Research Ethics Committee.

Please note, while IREC provides guidance on personal data management from an ethical perspective, compliance with data protection legislation, regulation and policy remains the responsibility of the research team.

The committee wishes you well in your research.