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#### **RESEARCH REPORT**

# Diagnostic procedures of paediatric speech and language therapists in the UK: Enabling and obstructive factors

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#### Abstract

**Background:** Extensive variation in the terminology used for paediatric diagnoses across the speech and language therapy research literature is an internationally recognized problem. Little is known, however, about how and how often diagnoses are given in a clinical context. In the UK, speech and language therapists (SLTs) identify and support children who have speech and language needs. To understand and address clinically rooted terminological issues that may directly impact clients and families, there is a need for exploration of how the diagnostic process is operationalized in practice.

**Aim:** To identify, from the perspective of SLTs, areas that present as enabling and obstructive factors to conducting diagnosis in clinical practice.

**Methods & Procedures:** Taking a phenomenological approach, 22 paediatric SLTs were interviewed using a semi-structured format. Thematic analysis revealed a number of factors that were either classified as 'enabling' or 'obstructive' to their diagnostic processes.

**Outcomes & Results:** Participants were often hesitant to provide a diagnosis to families and universally reported the need for targeted guidance, which accounts for the demands of current clinical practice, to guide their diagnostic process. Four enabling factors were identified from participant data: (1) working to a medical model, (2) the availability of collegiate support, (3) recognizing the benefits of diagnosis, and (4) relating to the needs of the family. Seven themes portrayed obstructive factors in practice: (1) the complex presentation of clients, (2) the risk of giving a 'wrong' diagnosis, (3) participants' uncertainty about diagnostic criteria, (4) insufficient training, (5) service models, (6) concerns about stigma and (7) not having enough clinical time. The obstructive factors created dilemmas for participants and resulted in hesitancy to give a diagnosis, potentially contributing to delays in diagnosis experienced by families as reported in previous literature. **Conclusions & Implications:** Of paramountcy to SLTs were the individual needs and preferences of their clients. Practical barriers and areas of uncertainty

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2023 The Authors. *International Journal of Language & Communication Disorders* published by John Wiley & Sons Ltd on behalf of Royal College of Speech and Language Therapists. increased hesitance to diagnose, which may inadvertently preclude families from accessing resources. Recommendations include more widely accessible training in diagnostic practice, guidelines to support clinical decision-making, and a greater understanding of client preferences with regard to terminology and its potential relationship with social stigma.

#### KEYWORDS

clinical practice, developmental language disorder, diagnosis, paediatric language, speech and language therapy, speech-sound disorder

#### What This Paper Adds

#### What is already known on the subject

Inconsistency in terminology for paediatric language diagnoses has been broadly discussed, mostly in reference to variation within research literature. The Royal College of Speech and Language Therapists' (RCSLT) position statement on developmental language disorder (DLD) and language disorder made recommendations for SLTs to use these terms in clinical practice. There is some evidence that SLTs face challenges in operationalizing diagnostic criteria in practice, particularly given financial and resource constraints.

What this paper adds to existing knowledge

SLTs disclosed several issues that either supported or were obstructive to the practice of diagnosing paediatric clients and delivering this information to families. Whilst most SLTs faced constraints related to the practicalities and demands of clinical practice, a number also held reservations about the impact of a lifelong diagnosis for young clients. These issues resulted in considerable avoidance of formal diagnostic terminology, in favour of description or informal terminology. *What are the potential or actual clinical implications of this work?* 

If diagnoses are not given, or if SLTs are using informal diagnostic terms as an alternative strategy, clients and families may experience reduced opportunities to yield benefits associated with a diagnosis. Clinical guidance that specifically addresses the prioritization of time and provides directives for clinical action in instances of uncertainty may support SLTs to feel confident in giving diagnoses.

#### INTRODUCTION

Diagnosis has been at the core of much discussion and debate in the field of paediatric speech and language therapy, particularly with regard to terminology (Bishop, 2017; Leonard, 2020; Walsh, 2005). Whilst literature reviews can demonstrate the use of terminology use across research (Bishop, 2014), there is limited evidence regarding its diagnostic application in clinical practice. Unlike typical research contexts, the clinical environment is embroiled with socially rooted issues and service constraints, and such issues may contribute to the terminology used by clinicians. Resources to guide diagnostic practice in the UK include policy statements and general practice recommendations, but these contain limited detail about processes (RCSLT, 2005). Most guidance prioritizes the application of clinical judgement which, whilst an essential tenet of evidence-based practice, is highly subjective and may be confounded by an array of factors. The development of a standardized approach to diagnostic practice is perhaps challenging, given that speech and language therapists (SLTs) work with highly heterogeneous clients across numerous settings including National Health Service (NHS) clinics, mainstream and specialist schools, and clients' homes (RCSLT, 2020), and the emphasis on diagnosis can vary depending on the nature of the setting.

The communication of a diagnosis to the client and their family has been recognized as a significant part of the process. Thomas et al. (2019) reported that, in focus groups, SLTs described clinical examples of parents expressing reluctance to acknowledge that their child may have a language difficulty, which adds to the issues that SLTs must handle. Reasons for parental reluctance are individual and multifactorial but may include resistance to spotlight areas that the child finds challenging (Dockrell et al., 2007). In contrast, there are also many documented examples of parents seeking a diagnosis, often due to the perception that it provides access to resources or serves as an explanation for the difficulties faced (Ebbels, 2014; Schuele & Hadley, 1999; Walsh, 2005). Navigating the competing paradigms, and potential constraints within a clinical setting, and practising sensitively to the anticipated preferences of families, presents a complicated picture for clinicians in administering a diagnosis (Cameron & Muskett, 2014). Quantitative studies with SLTs in the United States have suggested that this is not perceived to be adequately covered during initial training programmes (Plumb & Plexico, 2013). Whilst there is limited comparable evidence from the UK, Eadie (2005) has argued for skills in disclosing diagnoses to families to be more explicitly taught.

There is emerging evidence to suggest that children experience delays in accessing speech and language therapy services, and research has shown that parents perceive that attaining a diagnosis can take a long time (Hobson et al., 2022), if they receive one at all. Interviews with 12 mothers in the United States revealed that most children receiving speech and language therapy services did not receive a recognizable speech or language diagnosis, causing mothers to question whether the SLTs fully understood the nature of their child's needs (Ash et al., 2020). Without evidence of how SLTs conduct diagnosis in the UK, drives to address known issues, such as terminological inconsistency, are limited. This study, therefore, sought to attain a thorough understanding of the realities of current practice from the perspective of SLTs, and specifically identify areas that present as enabling and obstructive factors to diagnosis. This is in view to provide direction for how the profession can act meaningfully to address clinically rooted challenges.

## METHODS AND MATERIALS

## **Co-production**

Co-production events were conducted with a total of 43 SLTs to identify the research aims and formulate methods for the study. NIHR (2018) principles of co-production were upheld throughout, with sessions focused on sharing knowledge, skills and power. Clinicians were encouraged to share ideas about the research and challenge any assumptions of the lead researcher, both through discussion and anonymous Post-It note activities. To maximize the diversity of perspectives, sessions were conducted across four groups of SLTs attending clinical excellence networks (CENs) with specialist interests in the areas of fluency, and paediatric speech and language. CEN groups took part via face-to-face meetings (30–45 min) to discuss the study throughout its duration. Discussions often centred around the relevance of research issues within the context of a specific practice setting. Outcomes of discussions included an adjustment of the research aim, practical suggestions for increasing the reach of the research and refinement of the topics included in the interview guide.

## Design

The aim of this study was to explore participants' perspectives of conducting diagnosis in practice and develop an understanding of any enabling and obstructive factors. A phenomenological approach was taken, as this places emphasis on exploring people's lived experiences to understand a situation. Co-production work revealed that one-to-one interviews were an appropriate method for data collection, as SLTs felt that this would provide study participants with the optimal opportunity to talk openly about their practice. A semi-structured format was adopted to maintain focus, whilst allowing interviewees to discuss issues pertinent in their practice. The topic guide was informed by the literature review and refined in coproduction sessions. The interviewer (HH) is not an SLT, which created some distance from the topic as an 'outsider researcher', although this proved useful in engaging in critical dialogue, as participants assumed less knowledge and explained features of context in depth. One member of the core research team was an SLT, which supported the data analysis.

#### Participants and recruitment

Inclusion criteria for this study were SLTs (registered with the Health & Care Professions Council) practising in the UK with a paediatric caseload. Purposive sampling was used with the aim of achieving maximum variation (Palinkas et al., 2015). Information about the study was circulated on social media and through clinical networks. This study was part of a larger mixed-methods project, and all participants in the prior survey were invited to be interviewed (n = 19). Three additional participants were recruited through social media and word of mouth. All

#### **TABLE 1**Participant characteristics

Pseudonym	Setting(s) of practice	Clinical specialism(s)	Employment bod(ies)
Charlotte	Clients' homes	Speech and language	Independent
Nicole	Specialist school	Autism and language	Local authority
Jackie	Mainstream schools	Speech and language	NHS
Sheryllin	Community clinics	Language	NHS
Rebecca	Mainstream schools	Generalist	Local authority
Elle	Mainstream schools	Generalist	Local authority
Kitty	Mainstream schools	Language	NHS
Amanda	Mainstream schools	Language	NHS
Caitlin	Language unit	Generalist	Local authority
Dylan	Language unit	Generalist	Local authority
Heidi	Clinic	Speech and autism	NHS
Patricia	Mainstream schools	Language	NHS
Izzy	Community clinics	Generalist	NHS
Danielle	Mainstream schools	Language	NHS
James	Community clinics	Autism	NHS
Sandy	Clients' homes	Generalist	Independent
Grace	Specialist school	Autism	Local authority
Melissa	Specialist school	Generalist	Local authority
Sophie	Clinic	Speech	NHS
Laura	Mainstream schools	Language	Local authority
Harriet	Clinic	Generalist	University
Jessica	Clinic	Generalist	University

who expressed interest were sent an information sheet and consent form. Participant characteristics are listed in Table 1. Participants were asked their pronouns at the time of their interview: two used he/him and 19 used she/her. Each was offered the choice of having the interview via live virtual technology (n = 9), over the telephone (n = 2) or face to face (n = 11). Participants who selected face to face were offered the choice to have the interview on the university campus (n = 3), at their place of work (n = 5) or in a publicly accessible location (n = 3).

# Procedure

One-to-one interviews were conducted with 22 participants, lasting 35–65 min, and all were audio-recorded for transcription and analysis. During data collection, the project team held meetings to discuss the data, which functioned as reflexivity practices to help monitor biases and to conduct an initial review of the data. Whilst premeditation of sample size is not congruent with the principles of qualitative research (Bowen, 2008; Braun & Clarke, 2016), data saturation (where data collection no longer contributes significantly new themes) is generally considered a point at which recruitment could end (Francis et al., 2010). Whilst

the concept of true saturation is contentious, the principle offers a means to determine the sufficiency of a sample. As suggested by Francis et al. (2010), a '10+3' guide was used; a minimum of 10 interviews were conducted, and a further three underwent a brief analysis to check for substantially new themes. Surface analysis was conducted after each batch of three interviews and repeated until it was agreed by the core research team that data saturation had been achieved. This was deemed to be at the fourth cycle; resulting in a total of 22 interviews for full analysis.

## Analysis

Thematic analysis (TA), a descriptive method for systematically examining data (Clarke, Braun & Hayfield, 2015), was selected for its potential for studying the perspectives of each participant, whilst also exploring similarities and differences between them (King, 2004). The researcher plays an active role in identifying patterns within the data and generating representative 'themes'; in this case based on the salience of issues arising and areas of contrast and convergence across participants. The thematic structure facilitates interpretation and can provide comprehensive insight into the phenomena of interest (Braun & Clarke, 2019). The development of codes and synthesis of themes was regularly discussed with advisory paediatric SLTs who had not participated in the study and project supervisors. Agreement was reached through discussion, and the SLTs provided important clinical insight that supported the identification of patterns in the data. Qualitative researchers are encouraged to engage in continuous reflexivity throughout (Nowell et al., 2017), and examine how their positionality influences the research design and interpretation. This was implemented through reflexive journaling, including notes taken on reactions immediately after interviews and documenting considerations of potential themes during analysis.

## Ethics

Ethical approval was granted by the Health, Education and Life Sciences Faculty Academic Ethics Committee at Birmingham City University. Participants completed consent forms and were given full information about the study and their rights concerning participation. Personal data were stored on encrypted, password-protected devices. Pseudonyms are used for participants and references to identifiable information has been removed.

## Data availability

Research data are not shared for this study.

## RESULTS

The outcome of TA revealed a rich descriptive account of issues faced by SLTs in clinical practice when making diagnoses. Themes generated from the analysis were categorized either as enabling factors to diagnostic practice, or obstructive factors, as shown in Table 2. These themes are subsequently detailed with illustrative quotations from the raw data.

Overall, SLTs reported more obstructive than enabling factors when describing their experiences of conducting diagnosis, and this is reflected in the generation of themes. Most issues were complex, and across the dataset, were framed as both enabling and obstructive by various participants. A judgement was made to position a theme in either category based on the content of the data in the majority of cases. As an example, in relation to the theme 'Collegiate support', participants who typically worked within teams discussed the associated benefits; whilst those who had minimal contact with other SLTs framed this to be probInternational Journal of Communication

**TABLE 2** Themes constituting enabling or obstructive factors to diagnosis

1. Enabling factors	1a. Working to a medical model	
	1b. Collegiate support	
	1c. Recognizing the benefits of diagnosis	
	1d. Relating to the family's needs	
2. Obstructive factors	2a. Complex presentation	
	2b. Risk of getting it wrong	
	2c. Uncertainty around criteria	
	2d. Insufficient training	
	2e. Service models	
	2f. Concerns about stigma	
	2g. Not enough time	

lematic. Both issues are discussed under the same theme for continuity.

## **Enabling factors**

#### Working to a medical model

SLTs in the UK practice across medical and educational settings, and participants noted differences in how organizations incorporated the practice of diagnosis. It was posed that health settings, imbued with a medical model, heavily emphasized the need for ascribing a diagnosis and that this thereby supported its incorporation in their practice:

Laura: In the NHS service I worked in, provision was only given if children had a label.

Contrastively, it was observed that diagnosis was less essential in educational settings, and schools were generally focused on the functional impact of the child's difficulties. This resulted in some participants considering diagnosis to be unnecessary for some clients.

Elle: Schools don't understand the mass of diagnoses. If it won't impact what they're doing next term, they're not particularly bothered.

Participants also identified a disparity in how they were able to approach diagnosis based on their setting. Working in a school, Nicole felt that her diagnostic decisions were not respected in the same capacity as SLTs working in health, causing her to refer her own clients to SLTs working in the NHS: Nicole: I was told it wasn't my place to make diagnoses. [...] It's seen as an NHS thing to do [...] I always refer out. I feel that my clinical opinion won't be noted because I work in education.

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Generally, participants practising in the health sector talked about giving diagnoses as an integral feature of their practice. Whilst challenges remained, the expectations within organizations and systems worked to facilitate the process.

# Collegiate support

There were several instances across interviews when participants referred to their confidence in making diagnoses. Confidence could be enhanced through opportunities to discuss issues with other SLTs, both in informal conversations and structured events, such as supervision and CEN meetings. Those who were part of supportive teams spoke about the positive impact of being able to talk through difficult cases and resolve quandaries.

> Caitlin: Having the team to talk with helps. If I was working in isolation and didn't have a team to go back to, I might feel more unsure.

When discussing uncertainty in the interpretation of diagnostic guidance such as criteria, participants often expressed a desire to confer with specialist clinical colleagues. Those without the ease of access to collegiate support disclosed that this contributed to anxiety in the diagnostic process:

Nicole: I'm not part of a team. I have a supervisor, but that isn't an SLT—they're a headteacher—so I feel uncomfortable [diagnosing] because I wonder if it will be disputed.

Confidence appeared to be a key issue for participants, with most experiencing low confidence due to the presence of obstructive factors. Therefore, where available, support from colleagues was highly valued.

## Recognizing the benefits of diagnosis

A further area that made participants more inclined to give a diagnosis was the perception that clients and families could benefit from having a name for their difficulties. It was considered that it offered an explanation for observed challenges and the need for specialist support. Danielle: People want to be able to say 'my child has this, and that's why they're like that'—they want to name it.

James: It's very important to talk to them about their diagnosis so they have a good understanding of their differences and strengths.

Generally, there was a perception that it could be helpful and appropriate to share a diagnosis with a child if they had self-awareness of their difficulties or were noticing differences from peers. Some recognized that children were relieved to know their diagnosis, as it helped to contextualize their experience. This framed supportive conversations; for example, Jackie recalled a case in which talking about diagnosis had remediated negative comparison with peers, and Amanda observed that it could provide a helpful rationale for engaging in therapy:

> Jackie: I had a girl in floods of tears saying, 'I can't read as well as everybody else, I don't understand what the teacher's saying'. If you explain, 'it's because you've got a few difficulties [...] that's why you're finding it hard', they're like 'okay, I get it'.

> Amanda: Sometimes they begin to disengage, like 'I've had speech therapists since I was 4, why do I need this still?' We need [the diagnosis] to support them to understand what they're going through.

SLTs who worked with older children recognized that a diagnosis could be empowering. However, unless there were clear benefits to the child, most would only share a diagnosis with parents. Reasons for this included not wanting to:

Rebecca: put words into [their] mouth and concerns that: James: their awareness of it is maybe not quite as high.

# Relating to the family's needs

Participants approached disclosure of diagnoses to families in nuanced ways, depending on each family's circumstances.

> Charlotte: It's packaging information for parents in a way that they can cope with at a time.

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In addition to the individual needs of clients, their approach was also informed by personal views of the receipt of diagnoses. Many participants had empathy with parents and several disclosed that receiving diagnoses in their personal lives had increased their awareness of the needs of families. For some, this had informed their practice, increasing the inclination to share diagnoses with parents:

Jackie: The question 'Is she dyslexic?' [My daughter] was like 'I don't care if I am, but I want to know'. And you think about the kids you work with, and I thought 'yeah—you need to know'. They all need to know.

Patricia: For [my son], it was a relief to go, you're not stupid actually, there is something that is impacting on your ability.

Several talked about parents' sense of 'relief' following diagnosis, as it could support their understanding, and provide an explanation of their child's difficulties. Envisaging potential benefits for a family motivated participants to share a diagnosis, although few gave detail about how a judgement was made about a family's need. Some discussed the level of readiness for a diagnosis, often driven by explicit requests about the diagnosis. However, the:

Harriet: pressure from parents wanting diagnoses also required participants to develop approaches for managing expectations:

> Grace: People are seduced and flattered by labels. You say to parents, 'A label won't necessarily help.' And they come back with 'Yes, but I'd like to know what it is.'

> Rebecca: You get parents who say, 'what is it then?', in the first appointment when you're still exploring things. I tentatively say, 'it's feeling like disordered language'.

Anticipating the needs and preferences of families was framed as crucial in the decision to share a diagnosis. How participants related to the situation, and their views about the social impact of a diagnosis, appeared highly influential.

## **Obstructive factors**

### Complex presentation

The majority of participants reported challenges in conducting diagnosis, as diagnostic boundaries are often loosely defined to account for population-level heterogeneity. Many felt that the needs of their clients did not easily align with the criteria, leading some to question the extent that diagnoses are a useful tenet of practice.

Jessica: Things are always a bit woolly—it's not clear-cut as, 'we've diagnosed diabetes because the blood tests show it'. We don't fit into a medical model in that respect.

Elle: Children change—when they were little you think they might be on the spectrum. As they get older you realise that it's just lots of language difficulties.

When clients had prior diagnoses, some participants were reticent to give further diagnoses, especially if they had access to specialist support:

> Sophie: If there's no need to assign an extra label for service provision, you think about whether diagnoses are useful.

> Sandy: Sometimes [a diagnosis] doesn't make any difference, you just treat what's in front of you.

Some participants articulated the need for a strategy for cases where the needs of clients did not align with criteria, in order that they might still attain the benefits associated with having a diagnosis.

# Risk of getting it wrong

When giving a diagnosis, participants were greatly concerned with the need for accuracy, which was challenging given the complex presentation of clients. Additionally, their profiles of needs were dynamic over time, and therefore did not consistently fit the criteria for one diagnosis. There was sense of responsibility across participants in making diagnoses, and it was generally considered that it was better to withhold a diagnosis than to give one that might need to be changed.

> Elle: That's the reluctance—if you say for definite, you're going to be held accountable in five years' time: 'Well, the speech therapist said that's what it is.'

Participants were aware of being challenged by other professionals and discussed an element of risk involved in making a diagnosis, particularly for legal documents such as Education Health and Care Plans (EHCPs).<sup>1</sup>

Jackie: I'm scared to diagnose because I'm thinking 'What if I'm wrong? What if it isn't?' And then that's written down. Applying for an EHCP—having that go through—and what if I'm wrong?

Given the perceived negative consequences of giving an incorrect diagnosis, giving a description of the child's needs was perceived as 'safer', and less open to being queried or challenged by parents and professionals.

## Uncertainty around criteria

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Some participants described feeling unconfident to make diagnoses due to ambiguity in diagnostic criteria. This was particularly discussed in reference to the publication of new recommendations for diagnosing developmental language disorder (DLD), and many considered that there was insufficient clinically translatable guidance. There was concern that the lack of detail in the recommendations was resulting in inconsistent interpretation; both by clinicians and those determining service criteria. Participants also felt that functional assessments, which often relied on clinical judgement, were vulnerable to being challenged in an EHCP:

> Nicole: I feel uncomfortable putting DLD into reports because I could have interpreted it wrong. I don't think [my judgement] would stand up in a court of law.

Participants revealed specific uncertainties regarding DLD, particularly the age at which a child could be diagnosed, and whether there was a need for non-verbal IQ testing to be conducted to rule out severe learning difficulties. Many felt that these difficulties were shared across the profession and expressed a need for further guidance to improve confidence and provide clarity around criteria.

Amanda: I don't know if there's a cohort of us struggling or if it's across the board.

Nicole: I still find the whole situation really confusing and I would like clarification.

Due to their uncertainty, many disclosed feeling uncomfortable giving the diagnosis itself in reports and to parents. Most were keen for further support to have their queries resolved and gain a more confident understanding.

# Insufficient training

Participants talked about the value of training, including preregistration and opportunities for continuing professional development (CPD). Most perceived that their preregistration training had focused on theoretical domains and not prepared them to make diagnoses. Those who were newly qualified expressed frustration when reflecting on the need to learn about assessment and diagnostic strategies post-qualification:

> Melissa: None of us had experience of DLD, we only had theoretical knowledge. [...] I didn't realise there were so many different [assessment tools]. They didn't cover them in uni[versity].

Participants were highly critical of current guidance, and many felt that its inadequacies created difficulties in implementing an evidence-based model of practice, with overreliance on experience. Several expressed a need for more substantial professional guidelines to underpin diagnostic decisions:

> Nicole: They tell you to use clinical judgement, but you're pulling it out of thin air because there's no guidance.

> Jessica: That's the problem with our profession—it's experience and not concrete.

It was also raised across interviews that there was: Sheryllin: rarely any training around making a diagnosis.

Participants wanted more targeted guidance for understanding and implementing diagnostic criteria, and many considered that increased availability of high-quality support would be beneficial to their diagnostic confidence and skills.

## Service models

The nature of services and settings impacted the way that participants were able to conduct diagnosis. Whilst health-oriented (i.e., NHS) models generally align with making diagnoses, some reported nuances that presented as obstructive factors, such as dilemmas around caseload capacity. Participants generally reported that service criteria were stringent and conflicted with diagnostic criteria, which exacerbated practical challenges. Some disclosed withholding a diagnosis if the client did not meet the criteria for a care pathway to access intervention. This was partly due to concerns about the ethics of giving a diagnosis without the capacity to provide ongoing support:

> Grace: I think ethically if you're saying to someone 'you've got a problem', and you're not then able to help, I don't see the point.

A particular issue that was raised during interviews was related to the recent publications regarding the diagnosis of DLD, recommending the use of functional assessments in a move away from quantitative assessments. Participants felt that the need to comply with service criteria was unavoidable and put them in a challenging position.

> Amanda: In our borough, it's down to the scores, the evidence, the numbers. For the panel to agree support we need something more clear-cut, definitive, not wishy-washy and not able to be interpreted differently by anyone else.

Some were unsure of how to diagnose clients whose needs were not sufficiently severe to meet service criteria for intervention. In cases where clients had needs that did not qualify for service provision, participants were uncertain about whether to give a diagnosis.

> Danielle: The borderlines, those that might be on the edge of [service criteria], I worry about those.

> Kitty: If they don't meet criteria for our team, they could still have DLD. It's still having a significant impact, but they get no therapy.

This highlights the influence of capacity to provide intervention on the diagnostic practice of participants.

# Concerns about stigma

The process of sharing a diagnosis with families was revered as a highly important element of the process by the majority of participants. Guaging the parents' feelings was important in guiding their approach. Some described the diagnostic process as a 'journey', which involved the SLT making a judgement of the family's needs and modifying their approach in accordance. Izzy: I've had parents from cultures where it's seen as a negative thing to have a child with additional needs [...] with those families it's a journey to get to the stage where you talk about diagnosis.

Some had experienced working with parents who were fearful of diagnosis, particularly accepting that their child had difficulties:

> James: When families don't want a diagnosis, maybe that's a cultural reason. Maybe they just don't want to accept that their child has those needs.

> Patricia: The resistance is often parents struggling to accept it. Nobody wants their child to be different or set up to struggle in life.

Several participants talked about not sharing a diagnosis with families if it was deemed to be a difficult piece of information for the family to receive, and certain terms were considered to be particularly problematic. Some were hesitant to use the word 'disorder' in diagnoses due to the potential concern that it may cause:

> Dylan: To parents, I probably wouldn't say [DLD]. The word disorder is quite a medical term, and it can have a negative connotation. If a parent is told that their child has a disorder, it can cause worries that 'my child is inferior'.

Diagnostic terms were therefore often avoided if SLTs perceived that families were not ready for that information.

# Not enough time

Participants felt that, too often in practice, there was not sufficient opportunity to assess needs and talk to the family about a diagnosis. Insufficient time was deemed a barrier when it was not possible to conduct full assessments and observe the impact of intervention:

> Amanda: Part of DLD is that they respond to intervention. [...] If you just see a child for an assessment, it's difficult to diagnose because you need to then work with them to see the intervention to then diagnose it—that's not always practical.

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Given the limited time available, Heidi suggested that clinicians may need to take decisions about prioritizing clinical time, often at the expense of ascribing a diagnosis:

Heidi: If it's resource-driven, is that time better spent with intervention?

The need for more time was also related to the recognition of the emotional reaction of parents when receiving a diagnosis. Some described taking on a counselling role, guiding families through a difficult experience, which required empathetic discussion and the opportunity for follow up:

> Danielle: It's a big thing to tell parents that their child is going to have difficulties longterm, and we need that face-to-face meeting, we can't be just putting it on a report and sending it in the post.

Many referred to the need to build a rapport before a diagnosis was introduced, in order to gauge the likely reaction. Some were hesitant to share a diagnosis with families if there was limited opportunity to discuss potential anxieties.

Dylan: If I had time to talk to parents, I could introduce the term and talk about what it means and [...] that there shouldn't be a stigma and talk around it. But because I don't have that time, I'd rather send a report out with no diagnosis—just the percentiles and descriptors of the categories.

The complexity of diagnosis, in addition to the considerable impact on families, and the perceived risk associated with giving a diagnosis that may need to be changed, reduced confidence in their diagnostic practice. This is indicative of a need for professional guidance to support decision-making and clinical actions in such situations.

## DISCUSSION

This study explored the perspectives of paediatric SLTs in the UK regarding factors that enable or obstruct their diagnostic practice. TA of interviews highlighted numerous barriers that exist in practice, which contributed to widespread low confidence in this area and hesitance to share diagnoses with families. The diagnosis was considered to be a challenging aspect of practice, associated with insufficient guidance and training opportunities. Given the complex presentation of communication difficulties and the reliance on clinical judgement, participants perceived that there was considerable risk involved in ascribing a formal diagnostic term. Many were also highly concerned about the potential stigmatizing impact of diagnoses and questioned the ethics of giving a diagnosis if not required for intervention, or in the absence of capacity to provide it. Participants placed the needs of individual families at the heart of their practice and used clinical judgement and personal experience to guide their decision to disclose a diagnosis to families. Often it was deemed safer to provide parents with descriptions of their child's needs, as these were not associated with the same drawbacks as diagnostic terms.

Of particular concern to participants was the potential to cause harm by disclosing a diagnosis due to the potentially stigmatizing impact. Whilst research is needed to investigate the perspectives of those in receipt of speech and language therapy, there is limited evidence to indicate that the families of children with developmental disabilities consider diagnoses to be stigmatizing. By contrast, interviews with 43 parents of children with disabilities revealed that many find diagnostic labels to be helpful in challenging and deflecting stigma, using them in activist efforts, and as an important means to legitimize their child's difficulties (Manago et al., 2017). Additionally, participants in the current study reported that several parents came to them seeking a diagnosis, implying minimal concerns regarding stigma. From the perspective of young people, interviews with 54 adolescents with a speech or language diagnosis revealed that the majority felt positive about having their needs identified (Dockrell et al., 2007). However, most did not recognize diagnostic terms associated with their communication and were only aware of a description of their needs; suggesting that diagnoses had not been shared with them. Qualitative research has indicated that having a diagnosis can serve as a protective social factor (Bagatell, 2007; Silverman & Brosco, 2007), and for this reason, some young people choose to self-diagnose before formal assessment (Lewis, 2016). This suggests that SLTs' hesitance to diagnose due to concerns regarding stigma may be misaligned with the preferences of clients.

Participants regarded the act of sharing a diagnosis with a client and their family to be an important element of practice to be handled with a high degree of sensitivity, in order to address their concerns. Similarly, research with SLTs specializing in autism revealed that conversations around diagnosis were considered crucial in supporting the emotional needs of parents (Cameron & Muskett, 2014). As the reality of clinical practice did not always enable time for an in-depth conversation with follow up to address such needs, participants in the current study revealed that they were often reticent to share a diagnosis with parents. This reflects previous research with NHS-based SLTs which has shown that many perceive that insufficient clinical time limits their ability to provide a good standard of care (Loan-Clarke et al., 2010). Studies focusing on the family perspective also highlight the significance of the clinician taking time in the delivery of diagnosis. Interviews with 30 parents revealed that the attitude of clinicians and their ability to make time for the family were highly valued during the initial conversation around neonatal diagnoses (Davies et al., 2003). Whilst this indicates that the quality of care is important, withholding a diagnosis inevitably results in delay, which is a common frustration for parents of children with disabilities, as it can impede access to intervention (Stroebel & Swanepoel, 2014; Watson et al., 2011). This presents the profession with a dilemma, and arguably calls for a cohesive strategy to guide individual clinicians in their practice.

Participants reported that high demand for services meant that their caseload capacity was insufficient, and therefore some clients meeting diagnostic criteria would not receive any intervention. There was a perceived need for guidance to direct clinical action in such scenarios, and there were mixed views about whether it was ethical to give a diagnosis to families without intervention. Congruent with evidence identified across the literature regarding the views of SLTs (Fulcher-Rood et al., 2019; Selin et al., 2019; Thomas et al., 2019), this indicates that the profession openly perceives capacity to treat as a legitimate means to determine whether to give a diagnosis. Service capacity is not consistent across the UK (Hancock, 2019), and according to participants in this study, often not derived from research outcomes. This not only has consequences for diagnostic consistency, but also parity across clients.

The majority of participants expressed some degree of uncertainty with regard to diagnostic criteria, particularly for DLD. This was paired with a need for certainty, due to the perception of the high risk involved in giving a diagnosis that might need to be changed in the future, particularly in the context of writing statutory reports (e.g., EHCPs). In cases where EHCP support recommendations are disputed, it is typical for a tribunal to take place with involvement from all contributing professionals. Participants felt that the reliance on the clinical judgment rendered it difficult to justify diagnostic decisions, leaving them open to scrutiny if challenged. Even if found to be upheld, there are no tangible or legal consequences of a diagnosis being queried, but participants were concerned about their professional reputation. Previous research has shown that it is common for clinicians to take a cautious approach to avoid misdiagnosis, particularly given the complexity and fluctuating nature of communication difficulties over time (Cameron & Muskett, 2014; Goin-Kochel et al., 2006). In light of the challenges, Schuele and Hadley (1999) argued that SLTs should not be deterred from making diagnoses, as most parents are familiar with

risk models and can accept the potential for it to be changed. Although concerned with the needs of parents, participants in the current study were more focused on the potential professional and legal implications, highlighting a need for clarity in policy in this area.

Overwhelmingly, SLTs in this study expressed a desire for provision of training in diagnostic processes and opportunities for support. In particular, participants articulated difficulty in translating diagnostic criteria into practice, and expressed a need for clinically focused protocols to guide decision-making. Participants were critical of the lack of diagnostically focused content included in undergraduate programmes. Specific areas raised by participants included the identification of diagnoses in context and taking clinical decisions where there was ambiguity with regard to diagnostic or service criteria. Although there is limited research into satisfaction with preregistration training in the UK, previous surveys of SLTs in the United States have shown that many do not consider that training programmes provide adequate preparation for diagnostic practice (Brisk et al., 1997; Kelly et al., 1997; Plumb & Plexico, 2013). Given the low confidence across participants, future training development might specifically address the interpretation of diagnostic criteria in complex cases and strategies to disclose diagnoses to clients and familiesparticularly when there is a lack of time. It was widely acknowledged that the clients with whom SLTs work often have needs that are complex and prone to fluctuate; a phenomenon observed across developmental disabilities (Srebnicki et al., 2013). Whilst this arguably renders diagnosis inevitably challenging, there were a series of issues that confounded the process. Addressing the factors identified could potentially increase the low confidence of SLTs in this area.

### Limitations and strengths

This study has captured the perspectives of 22 SLTs working across the UK, however it is acknowledged that the nature of SLTs' roles can be highly varied across roles and settings (Pring et al., 2012). A detailed description of participants can be found in Table 1, so that readers can determine the degree of transferability of these findings to their own context. To date, and to the author's knowledge, this is the first study to qualitative explore the factors that enable and obstruct diagnostic practice from the perspective of paediatric SLTs in the UK.

## **Future directions**

From this study, some important and unresolved issues can be identified that would benefit from additional research. Diagnosis was considered to be a challenging aspect of practice, and future work might explore ways that SLTs could be supported to interpret and apply diagnostic criteria. It was clear that teamworking and access to clinical colleagues boosted the confidence of participants to give diagnoses. The setting of practice appeared to contribute to differences in the ways that diagnosis was approached, specifically that SLTs working in health were more likely to diagnose than those in other settings. Exploring the benefits of collaboration and increasing opportunities for mixed teams may be supportive of the diagnostic practice of SLTs. It would also be important to consider the different processes and barriers associated with differential diagnosis, for example in cases of DLD and autism, particularly as there is often involvement from a wider range of professionals (Cameron & Muskett, 2014).

Fundamental to the future of supporting SLTs is an understanding of the preferences of a diverse range of young people and their families, specifically with regard to diagnostic interactions with SLTs. The SLTs in this study emphasized the importance of incorporating the individual circumstances of families in their diagnostic practice. Capturing the views of young people and their families can contribute rich understandings to inform better practice (Roulstone & Lindsay, 2012) and may serve to reassure clinicians that they are acting on guidance underpinned by the preferences of clients. Future guidelines in this area might specifically address actions to be taken in cases where children have multiple diagnoses, or their needs do not meet the criteria for a service pathway. The training of SLTs might also benefit from a review to ensure that clinicians feel adequately prepared to approach diagnostic conversations with families.

## CONCLUSIONS

This study has shown that conducting diagnosis is a complicated area of practice and raises issues of parity for the field to reflect on. The reality of clinical practice, specifically the demands on time, large caseloads and minimal opportunities for training and clinical support, means that some SLTs are hesitant to make diagnoses. SLTs are not confident to share diagnoses where there is a chance of causing distress to families, where the diagnosis may not be required for intervention, or in cases where there is a risk of the diagnosis being challenged. Whether a diagnosis was given was ultimately determined through clinical judgement, and some participants considered that giving diagnosis is not appropriate in all cases. Conversations with families were considered to be a key opportunity to address issues pertaining to the stigmatization of developmental diagnoses, but time was rarely available for this.

Participants made it clear that support in this area is vital and that further targeted opportunities for training would be beneficial to develop confidence in their practice. In particular, the findings raised potential inconsistencies in diagnostic practice across settings (i.e., health versus education) and regions (i.e., if cases exceed the capacity to provide intervention, a diagnosis may not be given). The notion that children may have different experiences dependent on such factors raises an important ethical issue for the field. If families do not have a diagnosis, they may experience delays in finding or accessing services that are nominally associated with that diagnosis. Whilst the nuances are important to consider for each individual, addressing the barriers and capitalizing on the enabling factors may support clinicians in instances where giving a diagnosis is deemed useful. The diverse preferences of families should be incorporated into professional strategies in order that the delivery of this information is affirmative and supportive, moving towards a more inclusive environment for all in receipt of speech and language therapy services.

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**DATA AVAILABILITY STATEMENT** Research data are not shared for this study.

## ENDNOTE

<sup>1</sup>In England, EHCPs are personalized statutory documents that describe a child's areas of educational needs, the provision that must be made to meet those needs, and the child's strengths and interests (Department for Education/Department of Health, 2015).

#### REFERENCES

- Ash, A., Christopulos, T., & Redmond, S. (2020) "Tell me about your child": a grounded theory study of mothers' understanding of language disorder. *American Journal of Speech–Language Pathology*, 29(2), pp. 819–840.
- Bagatell, N. (2007) Orchestrating voices: autism, identity and the power of discourse. *Disability & Society*, 22(4), 413–426.
- Bishop, D. (2014) Ten questions about terminology for children with unexplained language problems. *International Journal of Language & Communication Disorders*, 49(4), 381–415.

- Bishop, D. (2017) Why is it so hard to reach agreement on terminology? The case of developmental language disorder (DLD). *International Journal of Language & Communication Disorders*, 52(6), 671–680.
- Bowen, G. (2008) Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research*, 8(1), 137–152.
- Braun, V. & Clarke, V. (2016) (Mis) conceptualising themes, thematic analysis, and other problems with Fugard and Potts'(2015) sample-size tool for thematic analysis. *International Journal of Social Research Methodology*, 19(6), 739–743.
- Braun, V. & Clarke, V. (2019) Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health, 11(4), 589–597.
- Brisk, D., Healey, E. & Hux, K. (1997) Clinicians' training and confidence associated with treating school-age children who stutter: a national survey. *Language, Speech, and Hearing Services in Schools*, 28(2), 164–176.
- Cameron, H. & Muskett, T. (2014) Recognising autism spectrum disorders in primary care: perspectives of speech and language therapists. *Child Care in Practice*, 20(3), 313–328.
- Clarke, V., Braun, V., & Hayfield, N. (2015) Thematic analysis. Qualitative Psychology: *A practical guide to research methods*. 3 222–248.
- Davies, R., Davis, B. & Sibert, J. (2003) Parents' stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child. *Child: Care, Health and Development*, 29(1), 77–82.
- Department for Education/Department of Health. (2015) Special educational needs and disability code of practice: 0 to 25 years. GOV.UK [online] Available at: https://www.gov.uk/government/ publications/send-code-of-practice-0-to-25 (Accessed: 13 December 2022)
- Dockrell, J., Lindsay, G., Palikara, O. & Cullen, M. (2007) Raising the achievements of children and young people with specific speech and language difficulties and other special educational needs through school to work and college. London: Department for Education [online] Available at: https://discovery.ucl.ac.uk/id/eprint/ 10000771/1/Dockrell2007raising.pdf (Accessed 15 September 2022)
- Eadie, P. (2005) The case for public speech pathology terminology: recognizing Dianthus caryophyllus. *Advances in Speech Language Pathology*, 7(2), 91–93.
- Ebbels, S. (2014) Introducing the SLI debate. *International Journal of Language & Communication Disorders*, 49(4), 377–380.
- Francis, J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. et al. (2010) What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology and Health*, 25(10), 1229–1245.
- Fulcher-Rood, K., Castilla-Earls, A. & Higginbotham, J. (2019) Diagnostic decisions in child language assessment: findings from a case review assessment task. *Language, Speech, and Hearing Services in Schools*, 50(3), 385–398.
- Goin-Kochel, R., Mackintosh, V. & Myers, B. (2006) How many doctors does it take to make an autism spectrum diagnosis? *Autism*, 10(5), 439–451.
- Hancock, D. (2019) What has been achieved a year since Bercow: ten years on? *Journal of Health Visiting*, 7(7), 336–340.
- Hobson, H., Kalsi, M., Cotton, L., Forster, M. & Toseeb, U. (2022) Supporting the mental health of children with speech, language and communication needs: the views and experiences

of parents. Autism & Developmental Language Impairments, 7, 23969415221101137.

- Kelly, E., Martin, J., Baker, K., Rivera, N., Bishop, J., Krizizke, C. et al. (1997) Academic and clinical preparation and practices of school speech-language pathologists with people who stutter. *Language, Speech, and Hearing Services in Schools*, 28(3), 195–212.
- King, N. (2004) Using templates in the thematic analysis of text. Essential Guide to Qualitative Methods in Organizational Research, 2, 256–270.
- Leonard, L. (2020) A 200-year history of the study of childhood language disorders of unknown origin: changes in terminology. *Perspectives of the ASHA Special Interest Groups*, 5(1), 6–11.
- Lewis, L. (2016) Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of Psychiatric Nursing*, 30(5), 575–580.
- Loan-Clarke, J., Arnold, J., Coombs, C., Hartley, R. & Bosley, S. (2010) Retention, turnover and return-a longitudinal study of allied health professionals in Britain. *Human Resource Management Journal*, 20(4), 391–406.
- Manago, B., Davis, J.L. & Goar, C. (2017) Discourse in action: parents' use of medical and social models to resist disability stigma. *Social Science & Medicine*, 184, 169–177.
- NIHR. (2018) Guidance on co-producing a research project. Available from: https://www.invo.org.uk/wp-content/uploads/2019/ 04/Copro\_Guidance\_Feb19.pdf:
- Nowell, L., Norris, J., White, D. & Moules, N. (2017) Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1609406917733847.
- Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N. & Hoagwood, K. (2015) Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533–544.
- Plumb, A. & Plexico, L. (2013) Autism spectrum disorders: experience, training, and confidence levels of school-based speechlanguage pathologists. *Language, Speech, and Hearing Services in Schools*, 44(1), 89–104.
- Pring, T., Flood, E., Dodd, B. & Joffe, V. (2012) The working practices and clinical experiences of paediatric speech and language therapists: a national UK survey. *International Journal of Language & Communication Disorders*, 47(6), 696–708.
- RCSLT. (2005) *Clinical Guidelines*. Bicester, UK: Speechmark Publishing Ltd,.
- RCSLT. (2020) Where do speech and language therapists work? RCSLT [online] Available at: https://www.rcslt.org/speech-andlanguage-therapy/#section-6 (Accessed 5 October 2022)
- Roulstone, S. & Lindsay, G. (2012) The perspectives of children and young people who have speech, language and communication needs, and their parents. London: Department for Education. [online] Available at: https://assets.publishing.service.gov. uk/government/uploads/system/uploads/attachment\_data/ file/219633/DFE-RR247-BCRP7.pdf (Accessed 18 September 2022)
- Schuele, C. & Hadley, P. (1999) Potential advantages of introducing specific language impairment to families. *American Journal of Speech–Language Pathology*, 8(1), 11–22.
- Selin, C.M., Rice, M.L., Girolamo, T. & Wang, C.J. (2019) Speechlanguage pathologists' clinical decision making for children with

specific language impairment. Language, Speech, and Hearing Services in Schools, 50(2), 283–307.

Disorders

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- Silverman, C. & Brosco, J. (2007) Understanding autism: parents and pediatricians in historical perspective. Archives of Pediatrics & Adolescent Medicine, 161(4), 392–398.
- Srebnicki, T., Kołakowski, A. & Wolańczyk, T. (2013) Adolescent outcome of child ADHD in primary care setting: stability of diagnosis. *Journal of Attention Disorders*, 17(8), 655–659.
- Stroebel, D. & Swanepoel, D. (2014) Does parental experience of the diagnosis and intervention process differ for children with auditory neuropathy? *International Journal of Pediatric Otorhinolaryngology*, 78(12), 2210–2215.
- Thomas, S., Schulz, J. & Ryder, N. (2019) Assessment and diagnosis of developmental language disorder: the experiences of speech and language therapists. *Autism & Developmental Language Impairments*, 4, 2396941519842812.

- Walsh, R. (2005) Meaning and purpose: a conceptual model for speech pathology terminology. *Advances in Speech Language Pathology*, 7(2), 65–76.
- Watson, J.B., Byrd, C.T. & Moore, B.J. (2011) Ethics in stuttering treatment in the schools: issues and intersections. *Seminars in Speech* & Language, 32(4), 319–329. https://doi.org/10.1055/s-0031-1292757

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