

Paediatric dysphagia: workforce review and training needs analysis



First published in 2023

by the Royal College of Speech and Language Therapists

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Reference: Royal College of Speech and Language Therapists. Paediatric dysphagia: workforce review and training needs analysis. London: RCSLT, 2023

Supported by:



Health Education England



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1. Background

The purpose of this project is to understand the gaps and challenges in the speech and language therapy workforce that work with infants, children and young people with eating, drinking, and swallowing needs. There is a huge risk to this population without a workforce to meet their needs in primary and secondary healthcare settings including community clinics, district general hospitals and special schools. This project has been made possible by the support and funding of Health Education England (HEE) and is an extension from the significant work that is already taking place and impacting on the neonatal speech and language therapy workforce.

The key recommendations identified following this RCSLT / HEE collaboration project can be found in section 5.

The term paediatric dysphagia or 'paediatric feeding disorder' (PFD, Goday et al, 2019) encompasses a broad spectrum of eating, drinking and swallowing difficulties that may be congenital, acquired, or iatrogenic in origin (Mayerl et al, 2023). From the neonatal period to adolescence and into adulthood, typical eating, drinking, and swallowing skills navigate complex developmental and pathophysiological changes that are vulnerable to disruption (Gosa et al, 2020; LaMantia et al, 2016; Dodrill and Gosa, 2015).

Prevalence data is limited and variable, for example, between 31-99% of children with neurological issues such as cerebral palsy are reported to have eating, drinking, and swallowing issues (Pagnamenta et al, 2020; van den Engel-Hoek et al, 2017), whilst Lawlor and Choi (2020) suggest up to 50% of typically developing children and up to 80% with neurodevelopmental issues have feeding issues. Kovacic et al (2021), although acknowledging the limitations of the USA study, found a prevalence rate of PFD in 25 – 44 in every 1000 children under 5 years. They highlight that this exceeds the rate of diagnosis of autism in the USA, currently 16.8 per 1000 8-year-old children.

PFD can impact both short-term and long-term physical, social, emotional, and nutritional outcomes for children and young people (Taylor and Taylor, 2021) as well increase parent / carer burden (Pagnamenta et al, 2020; Goday, et al, 2019) and impact on healthcare costs and quality of life (Simione et al, 2020).

In the UK, like colleagues in USA, Australia and New Zealand, the role of the speech and language therapist (SLT) in assessing, diagnosing, and providing intervention for infants, children and young people with PFDs is well recognised and they are considered an integral part of the multidisciplinary teams (Gosa et al, 2020; Pagnamenta et al, 2020). The Royal College of Speech and Language Therapists (RCSLT) dysphagia competency documentation highlights the breadth of skills and experience required by SLTs and the importance of working within an MDT framework (RCSLT, 2014).

With increasing survivability and medical complexity, the prevalence of PFD in children and young people is increasing (Kovacic et al, 2021; Lawlor and Choi, 2020). With a focus on supporting patients, including children, in local communities, as highlighted in the NHS Long Term plan (NHS,



2019) and more recently in 2022 with the development of Integrated Care Boards (ICB) and systems (ICS) (Dunn et al, 2022), the need for a collaborative workforce capable of delivering safe, effective, and timely services across healthcare is emphasised.

The provision of care for PFD is complex, involving integration of clinical history, parent report, observational and instrumental assessment (Balest et al, 2021; Duncan et al, 2018). This informs family-centred intervention in often emotionally challenging situations. Highly developed "soft skills" (Abraham et al, 2021; Dal Mas, et al, 2021) are required alongside the subject specific knowledge in order that care provision is effective and compassionate. Without these skills, clinicians may be exposed and vulnerable in often complex and ethical decision-making discussions (Mahurin-Smith and Beck, 2021; Rosen et al, 2020).

2. Methods

A total of 28 questions, including demographic detail, were agreed for inclusion in the survey following consultation and consensus opinion from a working party in paediatric dysphagia, convened by RCSLT. The survey was shared nationally in January 2023, aimed at UK based speech and language therapists (SLTs) working with infants, children, and young people PFD. The survey, shared via social media and the working group's contacts, was made available for two weeks. The survey included questions exploring current workforce staffing, gaps, and training needs. Please see Appendix II for details of the survey questions.

Consent to partake in the study was confirmed and anonymity clarified.

To confirm, for the purposes of this project, infants, children, and young people are defined, in accordance with the United Nations Convention on the Rights of the Child (UNCRC, 1989) and in accordance with legislation in England and Wales (UK Government, 1989), as persons that have not reached their 18th birthday. It is recognised however, in health, social and education systems in the UK that paediatric services may be accessible to individuals up to 19 years or beyond.

3. Results

183 clinicians responded to the survey from across the UK representing nearly all healthcare regions in England, Scotland, Wales, and Northern Ireland (see figure 1). There was no response from clinicians in the Channel Islands or Isle of Man. Representation was confirmed from Scotland, Wales, Northern Ireland and 23 of the 42 ICBs in England, with 44 clinicians unsure of which ICS they were aligned.



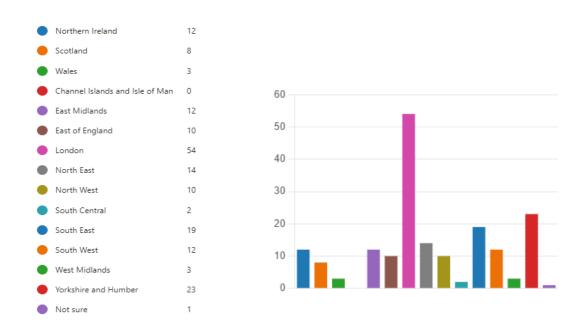


Figure 1: Clinicians by UK region

Most clinicians reported their primary employer as the NHS, however independent, education, and third sector organisations were also represented (figure 2).



Figure 2: Clinicians' employer

Demographic detail from the survey is presented, followed by the four main themes identified through thematic analysis and reviewed by the project manager and lead author.

¹ Multiple choices were possible



3.1 Demographics

The following information highlights the demographic profile of the clinicians. Less than half of the clinicians reported being a team lead or service manager (n=79, 43%) and over 46% reporting over 10 years' experience in paediatric dysphagia.

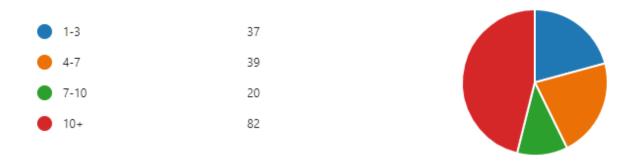


Figure 3: Years' experience in paediatric dysphagia (n = 178)

Clinicians reported a range of job titles; however, a limitation of the study was that the banding and job title were not correlated. It is recognised in the UK that job titles such as 'Advanced', 'Senior', 'Clinical Specialist' and 'Highly Specialist' have been used interchangeably to reference a band 7 role. This highlights the lack of clarity on role definition in paediatric dysphagia and may have implications for expectations and skill mix at each level. Additionally, banding may reflect broader skills and not competency in PFD.

3.1.1 Clinical setting

Most clinicians (63%) identified their clinical base as being in a community clinic setting (figure 4). It is important to highlight clinicians were able to choose multiple settings, e.g., some services may offer Tertiary and community SLT services.



Figure 4: Clinician base (Question: What setting is your team based in?)



Exploring SLT service delivery with this cohort, the clinicians were asked to identify how the service is delivered. Once again, the option to select multiple locations was possible (figure 5).

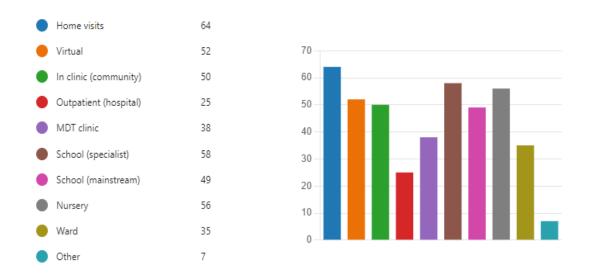


Figure 5: How is the paediatric dysphagia service delivered?

The locality of service delivery is an important consideration when working with children with eating, drinking and swallowing problems. Some environments may be considered higher risk or more isolating, for example home setting, nursery, where access to other medical services or MDT may be lacking. As noted earlier and below, clinical decision making within an MDT framework is preferable in managing complex conditions.

Although not specifically discussed, reference was made to the challenges of working in rural services, which led to increased isolation and barriers to support, including MDT support, and supervision. This is further discussed below.

3.1.2 Multidisciplinary teams

As discussed, it is recognised that working in paediatric dysphagia needs to be in collaboration with a multidisciplinary team (Gosa et al, 2020; Pagnamenta et al, 2020; RCSLT, 2014). 58 (32%) clinicians responded to the question around MDT support (figure 6).



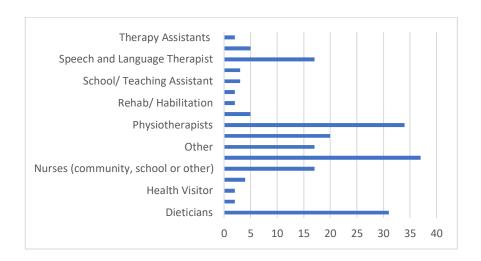


Figure 6: Members of the MDT

Clinicians reported they had access most commonly to the following MDT members: physiotherapists (59%), occupation therapists (64%) and dietitians (53%). However, clinicians also identified challenges in accessing members of the MDT, including lack of colocation, lack of response or joint working.

"Many of us within the MDT share a large office space but part time working, home working, lack of knowledge about who people are... Others within the MDT are hard to reach or it can be hard to coordinate visits/meetings."

As discussed, and highlighted by Raatz et al (2023), there is a broad range of health, social and education colleagues that a speech and language therapist may collaborate with to improve outcomes for children and young people living with PFD. Without access to these teams, the quality of intervention and outcomes may be affected.

3.1.3 Roles and banding

The banding and whole-time equivalents (WTE) for clinicians working with PFD was noted by 78 clinicians and described to range from band 3 to band 8b (figure 7a and 7b).

As noted, most clinicians noted roles with paediatric dysphagia responsibilities, were primarily banded at 6 (31%) and 7 (50%), perhaps highlighting the expectation of early paediatric clinical experience in developmental and typically developing populations. Supportive roles, band 3 and 4, were noted to represent 1.7% of the workforce reported in this survey.



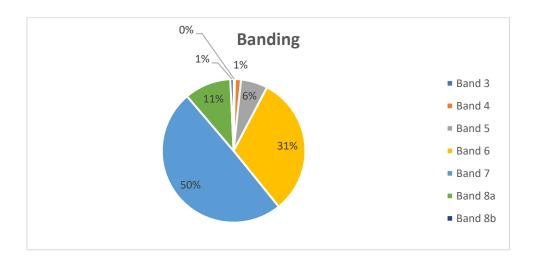


Figure 7a: Banding

The range of allocation of WTEs in PFD ranged from 0.1 - 5.0, with most services describing smaller, piecemeal allocations (1.0 wte or less). Reported isolation and limited capacity remains a concern, with several clinicians describing themselves as being lone clinicians covering all the PFD needs of the service.

"I am the only paediatric SLT working with post graduate dysphagia training and delivering paed dysphagia assessment and intervention. It is part of my clinical remit of approximately 0.1 dependent on need"

"...lack of peer support, lack of sharing knowledge and team working, very isolated working."

As noted in figure 7b, 70% of roles were reported to be 1.0 wte or less, with 56.5% of these being less than 1.0 wte, across all bandings. A further 16.2% of roles were between 1.1-2.0 wte, with only 13.8% of roles over 2.1 wte. It is recognised that further exploration of this data is valuable in understanding the workforce further, however this is beyond the scope of this report.



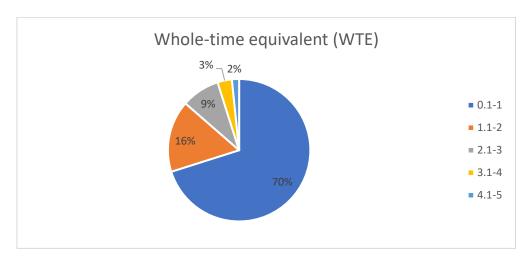


Figure 7b: WTE

It is recognised that community paediatric SLT services have not been meeting clinical needs of children and young people (ICAN/RCSLT, 2018). Furthermore, the COVID-19 pandemic impacted and changed the way community and therefore PFD services were delivered, with 81% of children and young people reportedly receiving less SLT input during this period (RCSLT, 2021a).

Of note, many clinicians were unable to provide a workforce structure, noting this was due to paediatric dysphagia being either included in a wider clinical role, e.g., communication focused, or not designated and although clinicians were trained in dysphagia it was not their primary role.

"...time is not protected for dysphagia and there is wider communication caseload pressure so there aren't allocated dysphagia sessions..."

"...these are not allocated / protected sessions and are often 'eaten' by communication caseloads..."

"We have no designated time allocated for dysphagia, we just absorb the demands as part of our speech and language clinical commitment."

Additionally, where more senior roles were identified, for example bands 7 or 8a, these included wider service responsibilities, such as operational, service, or managerial duties. Two services report band 8b roles, one at 0.1 wte and the other at 1.4 wte, however these roles were reported as strategic or professional lead roles and not specifically allocated to PFD.

3.2 THEME: Recruitment and retention

Clinicians that were managers were asked to describe the challenges in relation to recruitment and identify what the gaps and limitations of their service. This generated considerable narrative.

Clinicians reported specific recruitment issues with most reporting at least a 4–6-month vacancy period (64%), with over 43% of these being vacant for over 10 months. However, it is important to highlight that these questions referred to currently funded posts that have been unsuccessful in



recruitment. Therefore, this does not necessarily highlight the paucity of service available in some services or regions.

When asked about current challenges to recruitment issues such as needing to downgrade posts, location, recruitment process issues and lack of interest to upskill were noted.

"Difficulties getting more staff dysphagia trained - due to lack of interest and funding."

As shown in figure 8 below, overwhelming the main issues with recruitment related to:

- Lack of applicants
- Lack of skill mix, training, or experience
- Funding and capacity issues, i.e., no funding to recruit



Figure 8: Main issues with recruitment

Gaps in service lead to increased waiting times, limitations to, or scarcity of service provision and increased reliance on GP services to manage care. Additionally, as noted by a clinician from an acute setting, the backflow to tertiary settings may increase the pressures on acute care services and indeed in some instances leave children and young people without any services. The access to speech and language therapy services for a vulnerable population of children and young people with PFD then becomes a postcode lottery and raises concerns about health inequalities.

The challenges around recruitment highlight the lack of skill mix amongst the profession and the subsequent risks to individuals and organisations, but most importantly to the service user.

"Seems impossible to find staff for community with infant experience"

"Recruiting to B7 with necessary paediatric dysphagia skills and experiences is a challenge. We have previously advertised with no applicants."

The burden of care alongside the duty of care becomes a moral and emotive concern with this cohort. However, highlighting service need, gaps and risk is essential in supporting commissioning



and prioritising of services to vulnerable children and young people. As demonstrated in one region, where community services are absent, passing the duty of care back to the GP on discharge to community services should be a standard response to highlight lack of service provision. Furthermore, lack of service provision should be stressed to the Clinical Commissioning Groups (CCG), with local services documenting service gaps on risk registers as well as recording critical incidents. As an example, a child requiring on-going assessment and intervention for swallowing issues is referred to a local community service from a tertiary setting. The referral is rejected due to lack of qualified SLTs to provide services for PFD. The tertiary setting then hands over the duty of care to the primary care physician, in this case a GP. It is the responsibility of the primary care team to identify and commission support.

3.2.1 Applicants and vacancies

As noted, at least 50% of clinicians reported vacancies in their services of more than 1.0 wte, i.e., multiple posts. Of these responses, recruitment to bands 6, 7, and maternity leave cover were often cited as the most challenging to fill. This emphasises the challenges of recruiting to roles that require experience and filling temporary or fixed term posts.

"We have had difficulties recruiting to b7 post in special school, put advert out several times with no applicants, decided to down-grade to b6 and make it development post. Only 2 applicants, so very small group to select from. Have been having significant difficulties covering maternity leave / fixed term contracts at b7."

Some clinicians described vacancies between 0.2 – 0.8 wte which may pose further recruitment issues, particularly in recruiting to smaller roles. The impact on the wider team is acknowledged, regardless of the role size, whereby time to supervise and support completion of competencies is emphasised.

The challenges around maternity cover are of relevance in a predominantly female workforce, with over 76% of NHS employees being female (NHS England, 2021). In the Speech and Language Therapy profession this impact is exacerbated, with 96.5% of the workforce being female (HCPC, 2021).

As noted, these questions did not explore unfunded gaps in service or unmet service needs. Some clinicians however described wider issues with staffing, for example one clinician reported a 5.6 wte vacancy rate within their service, which likely reflects the wider recruitment and retention issues in SLT.

For some services, where prolonged vacancies existed, for example in one area where a band 7 post remained vacant for 18 months, subsequent upgrading of the post to band 8a resulted in successful recruitment to the post. However, for some services where prolonged vacancies have existed, as shown in the example above, successful recruitment may require down-grading of posts and focusing on upskilling.



3.2.2 Skills, training, and experience

For the clinician working in PFD, knowledge and skills across the age range are required, along with an ability to transfer skills from diagnoses and presentations.

Where some services (as identified in section 3.2.3 below) closed services where skill mix was not available, such as services to under 1s, others absorbed the workload, acknowledging limited skills or knowledge. Professionally this raises concern and risk around liability and professional scope of practice.

"It is very difficult to develop our competence with children with traches as we see so few."

"Inconsistencies in community SALTs confidence in working with super specialist patients eg tracheostomy/upper airway/complex neonates/surgical/neurosurgical."

"Our team is well-trained but overall, there are glaring gaps in depth of knowledge/clinical experience/understanding of and application of research/evidence-based practice, difficulties with flexible thinking/approaches to case management and use of outdated practices..."

When it comes to recruitment and development of teams, the lack of staff and skills creates a perfect storm. Incentives to improve recruitment, for example 'golden handshake' and relocation packages, do not necessarily guarantee resolution to recruitment issues.

The commitment to innovative thinking, training and support is clear in some services, however lack of staff, skills or resources may impact on the potential to apply innovative strategies and interventions.

"[We] lost 3 very experienced therapists in one go. The band 6's were not ready to step up at that point. Thanks to training and good support the team skills mix is much healthier now."

3.2.3 Funding and capacity

From the responses in this survey and from clinical reporting, services are designed to reflect the available budget and funding priorities. This results in limitations to service provision, for example by diagnosis, age and type of intervention offered.

"We do not accept referrals for ARFID. We have a huge number of new referrals and large caseload sizes so opportunity for reviews are limited."

"Service demands mean we are limited to assess and review only model..."

"We have long waiting lists and therefore have had to shorten our package of care for most children to assessment + reducing risks of aspiration or first / next steps advice for maximising potential."

"Too many referrals and not enough time to complete all assessments and interventions for dysphagia."



Some clinicians noted that services for PFD were sometimes offered across settings as 'good will' without allocated funding or not offered at all, for example to local acute paediatric services, or where services had not been reviewed, despite increasing prevalence of PFD. Again, as noted in 3.2 above, this highlights the risk of postcode lottery and health inequalities, as well as increasing risks to services.

"No funding from acute paediatrics therefore SLT intervention for neonates / inpatients / acute is delivered as a "good-will" and is allocated from community budget/resource."

"Service very pressurised, capacity does not meet demand."

"Service contract has not been reviewed for 10 yrs so service under-commissioned in relation to size of [the county] – not able to be as responsive as need to be..."

There remain disparities in service accessibility to children across the age range where funding may be allocated to one cohort but not to other children and young people accessing SLT services in the same setting.

"At present our paediatric wards have no access to SLT because the time is ring fenced for neonates. This means no MDT clinics or onward referrals to community."

Almost 20% of clinicians reported current work on business cases, primarily focused on development of neonatal roles, input to acute wards and development of ARFID/SOS clinics and support. Reference to the recent Independent Maternity Review (Ockenden Report, 2022) to fund acute neonatal posts and other evidence are noted as factors in supporting increased funding and establishment of specific clinical posts. Lack of dedicated time to complete business cases was cited as a barrier to accessing funding and service development. It is important to consider that to truly understand the needs of children and young people with PFD and the clinicians that support them, development of a minimal data set is needed to enable identification of nationwide standards and service development.

Children under 1 remain a vulnerable group highlighted throughout the responses in the survey, and the challenges of managing expectations between acute and community services.

"No current Community service for under 1s."

"We closed our 0-6 months service for 7 months while we recruited."

"...service for under 6mth olds was closed for approx 9 mths..."

With the focus and work of neonatal colleagues, successful funding and support has enabled improved access to acute neonatal SLT services within secondary settings, however, as noted, there remains a perceived disparity and potential inequity to the availability of SLT services to paediatrics where funding is not accessible.

"We have an acute hospital locally – [secondary acute setting]. They have just purchased a small amount of provision on NICU but no other SALT provision."



"At present our paediatric wards have no access to SLT because the time is ring fenced for neonates."

Lack of capacity, large caseloads, and waiting lists presented an overarching view of service pressures. The importance of reporting on risk, capacity, and demand needs within services to support change is emphasised. It is acknowledged, as reported above, that time and skill impact on development of business cases and risk reporting.

"Constantly dealing with high priority patients and therefore find it difficult to get to lower priority cases."

"We are struggling with capacity and waiting lists for initial appointments are increasing."

"Resources are stretched. This in a rural county where travel and administration time eat into clinical time."

As demonstrated in figure 9 below, the most notable service gap identified was services for children and young people with sensory, behavioural, or psychologically related PFD, including ARFID. Several clinicians reported a complete absence of services to this cohort of children and young people, with redirection of referrals to the wider MDT such as Occupational Therapists (OTs) or health visitors. Again, this reflects the point highlighted above around service design reflecting funding rather than needs or available skills.

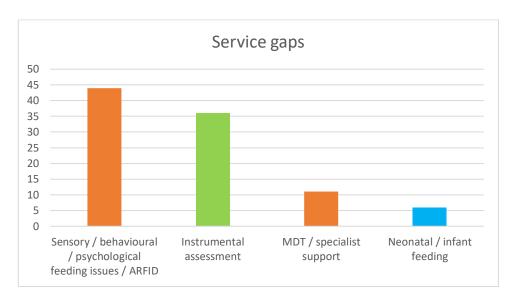


Figure 9: Identified service needs and gaps

Lack of access to instrumental assessment was highlighted, both locally and at tertiary level. Furthermore, access to colleagues from the wider MDT, including OTs, Psychologists and paediatricians was noted. Although less frequently, as discussed, lack of services to neonates / infants was reported as a service gap.



3.3 THEME: Supervision

Nearly every clinician reported that they received supervision, and this was delivered by an SLT (98%). However, this question lacked clarification on the specificity of paediatric dysphagia supervision. This was highlighted in the responses to the later question around on-going support that clinicians needed and the training needs. Over 36% of the clinicians to the question around support highlighted the need for peer support, joint working, individual, group or external supervision.

It is emphasised that clinical supervision is an essential part and expectation of clinical practice and to maintain professional standards and demonstrate continuing professional development (HCPC, 2014; RCSLT, 2017). In paediatric feeding disorders, where risk management and clinical skill are highlighted, access to appropriate clinical supervision and implementation of appropriate evidence-based clinical practice is essential to optimise safety and outcomes.

3.4 THEME: Education and training

Compared to our colleagues in countries such as South Africa and USA where paediatric dysphagia skills training are embedded in pre-registration curriculum, this has not previously been a requirement of UK pre-registration SLT courses. However, in 2023, all SLT pre-registration university programmes across the UK will have around 10 hours of paediatric eating, drinking and swallowing competencies added to the curriculum, in some part to address the knowledge gap and workforce needs (RCSLT, 2021b). However, a significant gap will remain, and it may be years before the impact of training will address issues in clinical practice. Additionally, it is important to acknowledge that even in countries where paediatric dysphagia is embedded at pre-registration level, lack of resources and wider clinical issues are noted to have on-going impact on delivery of care (Schie et al, 2020).

There is a need to further explore the challenges and opportunities of training provided in the UK. A thorough examination of the types, nature and impact of courses aimed at supporting those clinicians working with PFD is paramount. This analysis may facilitate understanding in the gaps and needs of clinicians across the career journey with these cohorts.

Clearly courses that include focused paediatric dysphagia pedagogy and embedded supervision are integral to support current and on-going learning. However, from responses whilst formal courses are favoured and highly valued, they and indeed shorter, one-off courses without practical elements or supervision, may not address the on-going, long-term, and continuous need for learning and clinical skill development.

Figure 10 highlights the formal and post graduate training clinicians advised they had received.





Figure 10: Training received

Of note, whilst some clinicians reported in a later question wanting further training and support in infant feeding / neonates, 46% of clinicians reported attending neonatal / infant focused courses. The type and nature of these courses may highlight challenges in transferability, clinical application, and relevance.

Whilst clinicians' reference RCSLT competency frameworks, including the neonatal dysphagia competency framework (RCSLT, 2018), aimed at SLTs working in neonatal units, it is unclear if these are embedded, for example as learning objectives, in the courses described. Additionally, this perceived gap in training may demonstrate a need for alternative and innovative approaches to training for this and other vulnerable and complex cohorts.

With the recent collaborative work of the neonatal SLT Clinical Excellence Network (CEN) and neonatal clinicians, supported by HEE funding and assistance, changes in access to neonatal training and education is evolving. The SLT Neonatal CEN, continue to work innovatively, for example, running 'hot topic' series webinars and virtual research café, to optimise access to training for clinicians working across the pathway for neonates, including those in community clinical practice.

Competency documents form an important part of learning and assessment of skills and knowledge. The RCSLT paediatric dysphagia competencies (RCSLT, 2014) provide a framework to support learning and application of theoretical knowledge. However, completion is reliant on access to resources to support completion and development of confidence, including access to supervisors and training.

Whilst access to training was acknowledged, clinicians described barriers to accessing training including lack of permission to attend courses and associated costs. They noted that events such as CENs were valuable opportunities for supervision, training, and networking. However, it was noted that management often limited numbers and frequency of clinicians attending such events, even if attendance could be virtual.



"Currently our service doesn't like too many SLTs to attend CENS at a time, so if someone is down as attending a particular CEN then we rely on info being cascaded and it restricts our networking."

Training in neonatal / infant feeding including breastfeeding was highlighted as an area of most need by clinicians (35%)², despite as noted above, a considerable cohort reporting attending at least one neonatal focused training event. It is hoped that signposting clinicians to the breadth of current resources, for example the Health Education England (HEE) Introduction to Allied Health Professionals in the Neonatal Unit module, developed in collaboration by members of the RCSLT Neonatal CEN and advisory group, and the work of the UK-wide neonatal Operational Delivery Networks (ODN) may increase collaboration and confidence particularly in supporting infants in community settings. Four clinicians reported having already accessed the HEE training, however these are modules aimed at clinicians working in neonatal units where learning can be fully embedded.

Furthermore, the following training needs were emphasised, including respiratory and airway needs (e.g., tracheostomy, airway anomalies, long-term ventilation), behavioural / sensory feeding and instrumental assessment. This highlights the potential challenges of developing skills and knowledge when working with a highly heterogenous population, across the age range, that are otherwise low incidence but highly complex.

Across the UK and indeed globally, education solutions are being explored and form an important part of improving safety and outcomes in healthcare settings and indeed explore 'soft skills' as referenced above (Schutt et al, 2017). Marshall et al (2023) investigated the use of telesimulation to support infant dysphagia management training for Speech-Language Pathologists in Australia. This and other innovative approaches may offer some solutions to the time, financial and on-going clinical training needs that clinicians in this survey have identified.

Innovative practice has also extended to role development to meet the on-going clinical and training needs of paediatric dysphagia clinicians. As an example, the recently advertised, Birmingham Community Healthcare NHS Foundation Trust role for a Clinical Education Lead Paediatric Dysphagia (appendix III).

Whilst cervical auscultation (CA) training was noted to be one of the most common training events accessed, it remained a gap for some clinicians. It is recognised that there is a paucity of research in use of CA with children (Frakking et al, 2019). However, the importance of structured training to optimise use of CA is highlighted in the literature (Bergström and Cichero, 2022) and stresses the importance of clinicians having access to a range of tools to support clinical swallowing examinations (CSE).

Whilst the breadth of formal education and learning opportunities have been described, there remains a hunger in the profession for on-going clinical training and support and indeed broader

² Clinicians could offer multiple responses.



consideration of 'diverse assessment' methods that otherwise informs pedagogy (O'Neill and Padden, 2022).

3.4.1 Sensory / behavioural / psychological associated feeding issues

It is noted that around 67% of parents of autistic children report strong feeding preferences (Zhu et al, 2019). Furthermore, Sanchez-Cerezo et al. (2023) clarifies that prevalence of Avoidant / Restrictive Feeding Intake Disorder (ARFID) is unclear. The authors note from their review that studies in clinical settings reported a 32 – 64% prevalence rate, whereas studies including non-clinical settings reported a 0.3 – 15.5% prevalence. The authors go on to advise that research reflects a heterogenous population, which may make access to clinically relevant support, research, and clinical evidence difficult.

Sensory, behavioural, or psychological feeding issues are highlighted throughout the survey responses. Specifically, lack of skills, experience, MDT support or clinical capacity to work with children and young people with complex sensory, behavioural, or psychologically related eating disorders was reported.

"For feeding disorders/ARFID there is a lack of psychology support."

"We do not have any input to MDT feeding clinics and would like to support the local ARFID team to help with sensory feeding issues."

Clinicians recognise the role and value of SLTs alongside MDT colleagues in supporting these issues, however the clinical challenges with this cohort and the long-term impacts are acknowledged.

"Training around ARFID – diagnosis process and SLT role."

The role of the SLT in supporting children and young people with a range of sensory, behavioural, and psychological feeding needs, including ARFID and those related to Autism requires further exploration and beyond the limitations of this report. It is recognised that for some children, an organic origin, such as reflux or limited oral diet during critical periods may impact on their ability to access an oral route for nutrition and so may benefit from the support of an SLT. However, with wider issues, beyond organic origins may raise queries and debate about how the SLT role is positioned in the MDT and vitally, how these needs can be balanced with the pressures from other eating, drinking and swallowing diagnoses.

3.4.2 Instrumental assessment

There is reference to clinicians having accessed Videofluoroscopy Swallow Study (VFSS) and Fibreoptic Endoscopic Evaluation of Swallowing (FEES) training. However, of note was considerable reporting of lack of access to instrumental assessment particularly in community (vs. tertiary) settings.



Long waiting lists for tertiary services were reported and noted to impact on care. Some services described no service or lack of input or support following a VFS carried out in another setting.

"Access to community VFSS takes very long and not always supportive for types of complexities of caseload"

"We have no access within our trust to VFSS and have to refer elsewhere. Vacancies and other pressures at [a tertiary centre site] mean that these services are often paused/halted as eligibility criteria changes which impacts on our referrals and creates longer waiting lists."

Where VFSS may be available in community settings, those children perceived with more complex needs may need assessment within a tertiary setting, which may lead to longer waits as tertiary services serve a large often regional population. Although not explicitly discussed, given the concerns raised around skill mix, capacity and staffing, there may be more information needed to understand the skill mix and competencies around those carrying out instrumental assessment, particularly where this is a less frequently offered service.

3.5 THEME: Clinician vulnerability and support

The participants were asked what support they would like to receive that they weren't already receiving. Of the 139 clinicians that responded to this question, 83% confirmed they required further support to that they don't already have access.

As shown in figure 11, clinicians suggested further support included joint working (29%), development of and access to guidelines and current evidence base (7%), access to MDTs (7%) and forums/ groups (10%) to offer both formal and informal support. However, overwhelmingly clinicians wanted access to clinical supervision (47%), both internal and external, suggesting current supervision requirements were not addressing clinical needs.

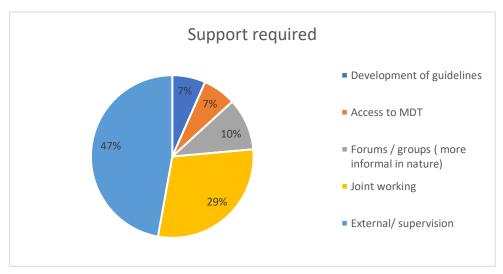


Figure 11: Support required



When exploring the clinicians that described the need for joint working, lack of designated time and geographical distance were noted as barriers to accessing this support. Clinicians noted the value of building links, particularly with tertiary settings and specifically with neonatal units to enable seamless transfer of care whilst optimising care planning:

"...better links with NICUs referring babies to community on discharge, e.g. visiting them on the unit prior to discharge to meet parents and for clinical planning..."

"The pressure from the acute team is affecting the team's health and wellbeing as they are being blamed for delayed discharge..."

There was an acknowledgement of the need for managerial and local authority support, particularly when considering allocation of funds and priorities. It was noted that for some, lack of managerial experience, clinical role or understanding of paediatric dysphagia impacted on allocation of resources and understanding of the SLT role.

"...more managers being dysphagia trained and not forgetting about dysphagia..."

"Local authority recognition of the needs of children with eating and drinking difficulties in schools."

"Always struggling to offer what patients and families need. Managers do not appear to recognise the critical nature of paediatric dysphagia."

Throughout the responses to the survey issues around lone working, lack of skills and experience or supervision were prominent. Working with paediatric dysphagia requires a high level of clinical skill and knowledge and access to appropriately trained and with a range of experience is invaluable.

"Lone SLT working at present."

"Face to face supervision and face to face support in my assessments and reviews - those more experienced only work virtually."

"I would find it incredibly valuable and reassuring to have to a more experienced colleague who was available for joint visit and joint working, particularly when it comes to younger and/or more medically complex children."

4. Discussion

The survey indicates a workforce eager for change and support. Clinicians offered examples and recommendations of ways to support children and young people with eating and drinking difficulties.

Reference is made to our RCSLT neonatal SLT colleagues and the services they have changed and supported over the last decade (RCSLT, 2018) along with the development of nationwide Neonatal



ODNs. The challenges around the heterogeneity and breadth of paediatric cohorts, not so easily defined by age, diagnosis, and locality, and therefore not meeting a single funding criterion or source is noted.

The survey provided rich data to further analyse and draw on responses. Additionally, correlating responses to workforce, training and service needs to service specification and availability may further inform our understanding of training needs and opportunities.

The three main areas for further prioritisation and exploration, recruitment and retention, supervision and support, and training are detailed in the recommendations (section 5).

4.1 Limitations

Clarity around the role of the person completing the survey may have further informed the responses. Additionally, responses were possible from clinicians in the same institution, which may lead to duplication or contradicting information, depending on the perspective of the clinician.

5. Recommendations

The following recommendations and priorities are suggested following analysis and discussion of the survey and reference to the evidence base. It is important to highlight that overarching issues around capacity and health inequalities are key to address in improving services for those with PFDs.

5.1 Training

Clinicians were able to identify a range of competencies and training to access to support clinical knowledge and skill in PFD, however, there remains a prominent clinical need for on-going support and training. This survey has offered an overview of the training needs and gaps; however, it is recognised that a deeper exploration will better inform understanding of the breadth and type of training that is needed.

There is a lack of formal, accredited training, as highlighted in the training needs analysis. Even where accredited courses exist, there is no requirement to complete these to work with PFD. Also, whilst competency documents provide a framework for learning, as clinicians have highlighted throughout the survey, completing, and importantly maintaining skills is difficult.

There is a need to explore innovative approaches to education and support clinicians from preregistration throughout their clinical career. Additionally, formalising qualifications in PFD, such as the board-certified accreditation required by American Speech-Language-Hearing-Association (ASHA), may support training and improve clinical skill.



Access and contribution to the evidence-base is highlighted, emphasising a workforce that is striving to offer clinically relevant and evidence-based care, however lack of capacity, access, or skill to explore the research gaps is prominent.

- Deeper dive into the exact training needs and gaps for clinicians working in PFD.
- Further exploration of accredited training courses available and needs within the workforce.
- Development of an updated tool / resource of current courses, broad learning objectives and expectations to support clinical skills in PFD.
- Exploration of a minimal standard of training, skill and supervision for clinicians working in PFD.
- Development of novel and inspiring pedagogy to meet the on-going needs of clinicians training and continuing clinical practice in paediatric dysphagia. For example, use of clinical simulation and virtual reality.
- Further development of clinical application of the EDS competencies (for students graduating in 2026), including supporting practice educators and exploring online resources, case scenarios, case studies, etc.
- Access current resources, forums, and funding to support development of training resources, for example, Health Education England.

5.2 Supervision and support

As noted, whilst almost all clinicians (98%) reported access to supervision including some reference to external supervision, there remained a high reporting of need for further peer support, shadowing, and clinical supervision. It is recognised that professional supervision vs. dysphagia supervision needs is not clearly defined and warrants further exploration.

- Development of a minimum expectation for working in PFD, or 'safe skills mix', facilitated by RCSLT, including accreditation and criteria to confirm competency and ensure on-going competency and safety.
- Promotion of local paediatric dysphagia communities of practice (COP) and clinical networks to facilitate cross-setting working, supervision and support.
- Improvement of paediatric dysphagia clinical guidelines and evidence base summaries to support clinical practice reflective of current evidence-based practice and supervision.



- Development of clinical tools to support business case development and signposting, for example, letter templates for GP / CCGs where services are not available or commissioned.
- Dissemination of current examples of good clinical practice and training approaches.
- Review and update RCSLT paediatric dysphagia research priorities.

5.3 Recruitment and retention

Understanding the full extent of recruitment and retention issues may inform how services can improve access to PFD services. However, responses focused on service gaps where funding had been allocated, rather than exploring service need. There is no current reference to minimal staffing requirements for services to PFD.

- Exploration of current innovative clinical practices that support access to services for PFD and methods to improve recruitment and retention.
- Leveraging the recent changes to healthcare provision, for example with the expansion of ICSs to address recruitment and service needs.
- Benchmarking of service delivery across service models.
- Addressing training, experience and supervision needs of clinicians to support career development and retention.
- Identify funding routes for PFD services within tertiary, secondary and primary care settings, including leveraging the current goals and focus of ICS' and promoting cross-service skill mix, supervision, and training.
- Implementation of a *minimal data set* to ultimately improve understanding of gaps, needs and service provision.



6. Acknowledgements

We are grateful to the paediatric dysphagia working group (see Appendix I] that informed the project, development of the survey and review of the report.

We are also very grateful to all the clinicians that gave up their valuable time to complete the survey and share their voice. We recognise the limitations of the survey but hope this will lead to more indepth look at the needs of children and young people with dysphagia across the life journey and the experiences of clinicians supporting them in all settings.

Louise Edwards CertMRCSLT, MHCPC Consultant Paediatric Speech and Language Therapist



7. Appendices

Appendix I: Acknowledgements

With thanks to the paediatric dysphagia working group that supported, developed, and reviewed the project.

Tahiyat Rashid, Project Manager

Judith Broll, Director of Professional Development

Special thanks to:

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Jo Marks, Lead SLT NWNODN, Professional Lead Paediatric SLT

Kate Hutton, Highly Specialist SLT

Thanks to the advisory and working group clinicians:

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Kristy O'Connor, SLT

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Jane Shaw, Clinical Lead

Lauren Harwood, Clinical Lead

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Marina Sloan, Highly Specialist SLT

Shirley While, Paediatric Team Manager, Highly Specialist SLT

Daniella Tora, Highly Specialist SLT



Appendix II: Survey questions

- 1. What is your job title?
- 2. What geographical hub is your team in?
- 3. Who is your employer? You may tick multiple options.
- 4. What setting is your team based in? You may tick multiple options
- 5. Are you a Service Lead/ Team Lead/ Manager? If you tick yes, it will direct you question 6
- 6. What Integrated Care System (ICS) is your team in? Please write not known if unsure.
- 7. How is the service delivered? You may tick multiple options
- 8. Is your team: Multidisciplinary / uni-disciplinary / transdisciplinary
- 9. If multi-disciplinary, who are the members of the multi-disciplinary team (MDT)?
- 10. If there are gaps or limitations in accessing MDT, please describe below.
- 11. In your paediatric dysphagia service, what WTE do you have at each of the following grades: 8b, 8a, 7, 6, 5 (or any other not listed). Please write in the text box below.
- 12. Are there currently vacancies within your team and if so, how many?
- 13. How long have these roles been vacant for?
- 14. Can you describe any current challenges in relation to recruitment?
- 15. Do you feel there are gaps or limitations in your service provision? E.g. no service under one's, no access to instrumental assessment, sensory feeding, assess and review only.
- 16. Do you have a business case ready and what for?



- 17. What age range does your service cover?
- 18. Is your team able to take paediatric referrals from NICU or tertiary setting?
- 19. How many years of experience do you have in paediatric dysphagia?
- 20. Please indicate what formal training you have accessed, if any
- 21. Please list what additional training you feel is needed within your team to work in community paediatric dysphagia?
- 22. What, if any, post graduate courses do you have access to or are aware of?
- 23. Which competency frameworks have you worked through? E.g. including RCSLT, local, national and international frameworks.
- 24. What type of clinical supervision do you receive? You may tick multiple options.
- 25. How frequent is your supervision?
- 26. What is your supervisor(s) profession?
- 27. What support do you feel would be helpful that you don't currently have access to?
- 28. Please use the text box to provide any additional comments.



Appendix III: Birmingham Community Healthcare NHS Foundation Trust Clinical Education Lead role (advertised January 2023)

Birmingham
Community Healthcare
NHS Foundation Trust

A4C Banding No: P3428

Job Description

TITLE: Clinical Education Lead SLT Paediatric

Dysphagia

DEPARTMENT:C. Gren's Speech and Language Therapy

LOCATION: Community settings

PROFESSIONALLY CCC JN TABLE TO: Children's SLT Leadership and Management

Team

CLINICAL .Y A COUNTABLE TO: Clinical Expert S'21 Paediatric Dysphagia

PAND:

HC JRS: 37.5 hc urs \er woek

Job Purpose

To provide Speech and Langua to There by a ca highly specialist level, functioning in partnership with other agenties and uncipilines to support in the holistic asset sment, diagnosis and intervention for the great and young people known to the service.

To work as part of multi-disc plinary and multi-agency teams to deliver highly specialist interventions according to the agreed service packages of core and pathways.

To develop and maintain effective working relationship. with place its / carers and other stakeholders, using highly developed negotiation, clambial nicetion and interpersonal skills

To maintain, develop and promote excellent in clinical practice within the specialist area of the service, with reference 's current escarch and evidence-based practice, contributing to safe effective practice in the specialist clinical area

Demonstrate clinical leadership and rep. esent the local team/service area in all appropriate meetings to support the planning and development of quality services across the city

To contribute to the identification of training needs of team members, other professionals and deliver training in the highly specialist area

 As requested, to take delegated responsibility for ensuring equity of service delivery and management of waiting list and active caseloads across the city in conjunction with the Service Operational Manager

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