

Suffering in Silence:

Access to specialist services for
children who stammer

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Foreword

At Action for Stammering Children, we are dedicated to ensuring children and young people who stammer receive the specialist support they need to reach their potential. Now in our 30th year, we continue to advocate for those children and their families affected by stammering through commissioning specialist assessment and therapy, funding research activity to enhance the evidence-base, and provide training to Speech and Language Therapists across the UK.

Core to our work is funding specialist assessment and intervention for children and young people who stammer, who otherwise may not receive support in their local area. We are delighted that, in the last year, we have been able to reach over 5,900 children who stammer across the UK through the funding of specialist support provided by our partner, the Michael Palin Centre (MPC), and by delivering specialist training to hundreds of Speech and Language Therapists¹. However, it is clear from our work, and from what we hear from families, that much more needs to be done.

This report evaluates the availability of specialist stammering services across the UK, based on data gathered from Freedom of Information requests sent to health providers. The data indicates that a specialist dysfluency service is available in only half of local government areas across England, and offered by half of health boards across Scotland and Wales.

The fact that there are such differences in the level of provision (generalist versus specialist) available to children who stammer across the UK, suggests that many children are not receiving the support they need. A graduate from a four-year generalist speech and language course will typically have spent only four or five days working specifically on stammering. Generalist Speech and Language Therapists, without additional post-graduate training, simply do not have the experience, specialist skills and confidence required to support a substantial proportion of children and young people who stammer.

We know that stammering can have a significant impact on social and emotional development, employment opportunities, economic status, and mental health outcomes. Stammering has been shown to have strong links with how well children do at school, their levels of anxiety and depression, and the sort of jobs that they get when they grow up. We also know, through our work with the Michael Palin Centre, that the most effective way of supporting children who stammer is to ensure they have access to Speech and Language Therapists who have the specialist clinical skills in stammering assessment and intervention.

Our research has shown that there is a postcode lottery in the level of support that children who stammer receive. Where a child happens to live should not determine whether they are given the opportunity to access the specialist support that can help to offset the adverse outcomes that can be associated with stammering.



Steven Gauge
Chief Executive

¹ Our Trustees' Report and Financial Statements (2018-19) can be found on our website.
https://actionforstammeringchildren.org/wp-content/uploads/2019/10/ASC-AR-2019_online-interactive.pdf

Executive Summary

- Approximately 8% of children stammer at some point².
- Early intervention is crucial to ensuring children can access timely, evidence-based support for their speech fluency and accompanying social, emotional or mental health difficulties.
- The goal of our research was to investigate the extent to which children who stammer have access to specialist stammering services in their local area.
- Between November 2018 and August 2019, Freedom of Information Requests (FOIs) were sent to healthcare providers and commissioners across England, Scotland, Wales and Northern Ireland.
- Based on information gathered from FOI requests, we ranked services according to level of provision:
 1. *Specialist stammering centre or stammering service (highest ranking)*
 2. *Clinical Lead/highly specialist Dysfluency Speech and Language Therapist*
 3. *Speech and Language Therapists who have additional post-graduate training in stammering*
 4. *Generalist Speech and Language Therapists (SLTs) as part of the Speech and Language Therapy service (lowest ranking)*

Key findings

We found Speech and Language Therapy services ranged from provision of generic services to specialist dysfluency clinics.

- Across the UK, 45% of health providers offer a specialist stammering service
- Specialist stammering services are not available in around half of local authority areas in England.
- Around half of Local Health Boards in Wales do not offer specialist stammering services to children.
- In Scotland, almost two thirds of Health Boards do not provide specialist services, and only offer Speech and Language Therapists (SLTs) with some postgraduate training, to work with children who stammer.
- Most services in England and Wales report employing at least one Specialist Speech and Language Therapist in dysfluency as part of their team.
- Over three quarters of Health and Social Care Trusts in Northern Ireland offer a specialist stammering service.

Our data highlights two concerns relating to access to specialist provision for children who stammer across the UK:

- **Uneven access** to specialist provision across the UK.
- **Demand is likely to outweigh the supply** of specialist provision for children who stammer.

While many services report that they employ a highly specialist Speech and Language Therapist (SLT) who can provide intervention to children, the therapist often needs to divide their time between

² Yairi, E., and Ambrose, N., 2013. *Epidemiology of stuttering: 21st Century Advances*. Journal of Fluency Disorders, 38: 66 – 87

offering advice and training to the wider Speech and Language Therapy team, coordinating care pathways and consequently can work with only a small number of children who stammer.

According to figures from April 2019, the UK has only 16,637 registered SLTs³, and the NHS employs 6,261 full-time SLTs⁴. We are concerned as to how far these specialist services can stretch. Many of the responses that stated they employed a clinical lead or specialist dysfluency SLT as part of this specialist service, allocated only part of their weekly contact time to this clinical group.

Policy Recommendations

We believe every child who stammers in the UK should have access to a local specialist stammering service during childhood. The recommendations made in this report would ensure the needs of children who stammer, which are so often overlooked, are addressed equitably across the country.

Policy Recommendations

- Local access to a specialist stammering service for every child who stammers across England, Scotland and Wales.
- Priority given to early intervention.
- A national awareness raising campaign.
- Increased training for education and healthcare professionals.
- Closer working between Health and Education Authorities.

³ Health and Care Professions Council (HCPC) snapshot of professionals registered across the UK. The HCPC is the regulator of health, psychological and social work professionals and it is not possible to practise as one of these registered professions without registration with the HCPC: <https://www.hcpc-uk.org/globalassets/resources/data/2019/registant-snapshot---april-2019.pdf>

⁴ NHS Digital (2019). NHS Hospitals and Community Health Service (HCHS) monthly workforce statistics. Accessed

online: <https://files.digital.nhs.uk/0C/7512E4/NHS%20Workforce%20Statistics%2C%20April%202019%20Staff%20Group%2C%20Care%20Setting%20and%20Level.xlsx>

Introduction

As children across the UK start primary school this September, approximately 48,720 of them will stammer at some point⁵.

Stammering is a speech disorder that disrupts spoken fluency and is often recognised by repetitions, hesitations and prolonged sounds in words. Stammering is a form of speech, language and communication need, which affects approximately 8% of children at some point⁶. Typically, developmental stammering begins between two and five years of age and affects more boys than girls⁷.

Stammering – or stuttering as it is also known – can have a significant impact on a child socially and emotionally, as well as longer-term implications for educational progression, economic and employment opportunities^{8,9}. Children who stammer are more likely to be bullied than their non-stammering peers¹⁰, and we know that bullying has been associated with poorer mental health outcomes in young people¹¹. Adults who stammer are more likely to experience anxiety¹², which has been associated with onset of depression later in life¹³.

While research has not consistently shown stammering to be more prevalent amongst particular socio-economic groups, adults who stammer are more likely to hold lower status jobs than their non-stammering colleagues¹⁴. Recent research has shown that adults who stammer in the United States earn significantly less annually, and that men who stammer are less likely to participate in the labour force, while women who stammer are more likely to be underemployed in comparison to

⁵ This figure is based on calculations using data from the Department for Education statistical release, [‘The Secondary and Primary Schools applications and offers: March and April 2019’](#). This publication states that 609,000 applications for primary school places were received in 2019. It is estimated that stammering incidence is higher amongst younger children and reduces with age (Yairi and Ambrose, 2013) and so we have focused on the primary school entry age. Our calculations have estimated that 48,720 children of primary school age will stammer based on applying the 8% incidence rate cited to the number of primary school applications.

⁶ Yairi, E., and Ambrose, N., 2013. *Epidemiology of stuttering: 21st Century Advances*. Journal of Fluency Disorders, 38: 66 – 87.

⁷ Guitar, B., 2014. *Stuttering: An integrated approach to its nature and treatment*. Philadelphia: Lippincott Williams and Wilkins.

⁸ Hayhow, R., Cray, A. M., and Enderby, P., 2002. *Stammering and therapy views of people who stammer*. Journal of Fluency Disorders, 27: 1 – 17.

⁹ Klein, J. F., and Hood, S. B., 2004. *The impact of stuttering on employment opportunities and job performance*. Journal of Fluency Disorders, 29: 255 – 273.

¹⁰ Blood, G. W., and Blood, I. M., 2007. *Preliminary study of self-reported physical aggression and bullying of boys who stutter: relation to increased anxiety*. Perceptual and Motor Skills, 104: 1060 – 1066.

¹¹ Schoeler, T., Duncan, L., Cecil, C. M., Ploubidis, G. B., and Pingault, J., 2018. *Quasi-Experimental Evidence on Short- and Long-Term Consequences of Bullying Victimization: A Meta-Analysis*. American Psychological Association, 144: 1229 – 1246.

¹² Craig, A., and Tran, Y., 2014. *Trait and social anxiety in adults with chronic stuttering: conclusions following meta-analysis*. Journal of Fluency Disorders, 40: 35 – 43.

¹³ Stein, M. B., Fuetsch, M., Muller, N., Hofler, M., Lieb, R., and Wittchen, H., 2001. *Social anxiety disorder and the risk of depression: a prospective community study of adolescents and young adults*. Arch Gen Psychiatry, 58.

¹⁴ McAllister, J., Collier, J., and Shepstone, L., 2012. *The impact of adolescent stuttering on educational and employment outcomes: evidence from a birth cohort study*. Journal of Fluency Disorders, 37: 106 -121.

their fluent counterparts¹⁵. Furthermore, children from lower socio-economic backgrounds may have more difficulty accessing support due to their parent's work responsibilities and availability of local services. It has been suggested that those in higher socio-economic groups may be more informed or able to access support¹⁶.

Children who stammer are also at risk of co-occurring disorders, with approximately 60% of children who stammer presenting with another speech, language or non-speech-language disorder¹⁷.

Stigma and negative connotations surrounding stammering remain a persistent challenge to participation in wider society. From being bullied and teased directly as a result of their stammer in school, to facing belittling and discriminatory reactions from others on the telephone, at work and in the community. The media continues to portray stammering for comic effect and negative connotations around levels of intelligence and assumed low self-esteem can result in fewer opportunities being offered to people who stammer.

There is still a long way to go in order to change societal attitudes towards people who stammer and ensure individuals are accepted on the basis of who they are rather than defined by their stammer. In addition to offering children who stammer the therapeutic support to rise to their potential, we advocate campaigning to challenge the stigma around stammering in wider society.

Speech and Language Therapy and Stammering

Recent legislation change in England

The introduction of the Children and Families Act (2014) in England required Education, Health and Social Care to work together to support children and young people with Special Education Needs and/or Disabilities (SEND). As part of this, local authorities were required to make arrangements for joint commissioning of services between Local Authorities and Clinical Commissioning Groups (CCGs), as well as work with NHS England where required¹⁸. It has recently been revealed that only 50% of areas in England report joint commissioning of Speech and Language Therapy services by health and local authorities¹⁹.

Speech, language and communication needs (SLCN) are the most common type of primary need, accounting for 22% of children with SEND in England²⁰. It has been acknowledged that SLCN falls under SEND provision but that SLTs are often employed by the NHS, therefore The Communication Trust has advocated for Education and Health to work closely together to offer effective provision for children with a broad range of needs that fall under the SLCN umbrella²¹.

¹⁵ Gerlach, H., Totty, E., Subramanian, A., and Zebrowski, P., 2018. *Stuttering and labor market outcomes in the United States*. Journal of Speech, Language and Hearing Research, 61: 1649 – 1663.

¹⁶ Manning, W. H., 2010. Clinical decision making in fluency disorders. Vancouver: Cengage.

¹⁷ Blood, G. W., Ridenour Jr., V. J., Qualls, C. D., and Hammer, C. S., 2003. *Co-occurring disorders in children who stutter*. Journal of Communication Disorders, 36: 427 – 488.

¹⁸ The Communication Trust, *Communicating the Code: A resource to enable implementation of the code of practice*. <https://www.thecommunicationtrust.org.uk/media/362440/ctc-9-jointcommissioning.pdf>

¹⁹ Children's Commissioner. *We Need to Talk: Access to Speech and Language Therapy* (2019).

²⁰ Department for Education, 2019. Special Educational Needs in England: January 2019. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814244/SEN_2019_Text.docx.pdf

²¹ The Communication Trust, *Communicating the Code: A resource to enable implementation of the code of practice*. <https://www.thecommunicationtrust.org.uk/media/362440/ctc-9-jointcommissioning.pdf>

Although stammering is a type of SLCN, children who stammer who have no additional needs are typically not categorised as SEND²², and therefore they are unlikely to qualify for an Education Health and Care Plan (EHCP). This puts them at greater risk of receiving inadequate support as funding constraints result in those with EHCPs being prioritised for intervention. Additionally, SLCN is a broad category, of which dysfluency is one disorder, and consequently these children may fall through the net or are not prioritised.

Speech and Language Therapy in the UK

Speech and Language Therapists (SLTs) are the specialists qualified to work with children with a range of speech, language and communication needs. All generalist SLTs have the training to work with children who stammer but SLTs can access further training once qualified that enables them to specialise in this clinical area. While some children who stammer will benefit from access to a SLT with some additional postgraduate training, many require access to a Specialist SLT who has the experience, training and expert knowledge of working with this disorder.

The association between the type of provision offered and treatment outcomes is beyond the scope of this report. Yet we know that targeted intervention delivered by a trained SLT for pre-school and school-aged children is effective in improving fluency and managing the broader emotional and psychological aspects of stammering²³.

Access to SLTs with a clinical specialism in dysfluency maximises the effectiveness of intervention, particularly in the most complex cases, leading to greater cost benefit for children, families and commissioners. In spite of this, recent research has shown that there have been significant cuts to spending on Speech and Language Therapy services²⁴, resulting in demand outstripping capacity for children with a range of speech, language and communication needs.

Demand outstrips supply

We know that there is increasing demand on Speech and Language Therapy services across the UK, with high levels of need and limited capacity to support these children adequately. The *Bercow: Ten Years On (2018)* report showed that a third of children are waiting over a year for support from Speech and Language Therapy services. Furthermore, just 15% of people reported that Speech and Language Therapy was available as required in their local area and 52% of families reported their experience of speech, language and communication support was poor²⁵.

The recent report by the Children's Commissioner, *We Need to Talk*, found that children with speech, language and communication needs are facing a postcode lottery for intervention. Their investigation into spending on Speech and Language Therapy services revealed that while 23% of areas across England had seen an increase in spending, 57% had seen a reduction between 2016/17 and 2018/19. In 2018/19, the top 25% of areas were spending £16.45 compared with the bottom 25% who spend £0.42 per child²⁶.

²² Hayhow, R., Roulstone, S., White, P., and Lindsay, G., 2012. *Prospective cohort study of speech and language therapy service for young children who stammer*. Department of Education.

²³ Royal College of Speech and Language Therapists (RCSLT), Resource Manual for Commissioning and Planning Services for SLCN – fluency (2012). Accessed online [7.10.19]:

<https://www.evidence.nhs.uk/search?pa=1andq=stammering+therapy>

²⁴ Royal College of Speech and Language Therapists (RCSLT), cuts to speech and language therapy services factsheet (2014). Accessed online: <https://www.rcslt.org/speech-and-language-therapy#section-7>

²⁵ RCSLT and ICAN (2018), *Bercow: Ten Years On*. Accessed online [18.10.19]:

<https://www.bercow10yearson.com/wp-content/uploads/2018/03/337644-ICAN-Bercow-Report-WEB.pdf>

²⁶ Children's Commissioner. *We Need to Talk: Access to Speech and Language Therapy* (2019).

Given the limitations on capacity across Speech and Language Therapy services, we are concerned that many children who stammer are falling through the gaps and therefore failing to receive the necessary support to offset the longer-term consequences of living with this disorder.

What was our objective?

In this report, we share the findings of our investigation into the availability and accessibility of specialist intervention for children who stammer across the UK. Between November 2018 and August 2019, we sent Freedom of Information (FOI) requests to commissioners and providers of Speech and Language Therapy services across the UK, requesting information about the structure of provision available to children who stammer. Due to differences in commissioning, data has been summarised separately for each nation of the UK. We have complemented our quantitative data analysis with responses gathered from an online survey completed by young people who stammer and their families about their experiences of Speech and Language Therapy.

Currently, children and young people who seek support for their stammer are referred to Speech and Language Therapy services, which are provided by the NHS but may also be offered by private service providers. Stammering is a complex speech disorder that requires prolonged professional intervention to address both speech fluency and possible emotional and psychological needs. Children who stammer benefit from early intervention shortly after onset, which involves monitoring the child for no longer than one year and ensuring treatment begins by five years of age²⁷. Until recently, many services have followed a watch-and-wait approach following referral meaning that children do not receive access to direct intervention immediately and are placed under review. However, this is now changing with increasing recognition of the importance of providing necessary support upon referral – something we welcome.

Prior attempts have been made to investigate access to specialist provision for children who stammer. A 2011 study found that 70% of SLT services offered group therapy for children who stammer, although levels of provision was noted to be very variable²⁸. Eight of the 11 services involved in the Better Communication Research Programme study (2012) comprised an SLT with a specific role as a stammering specialist, who had completed some postgraduate training, worked extensively with children who stammer and designated part of their caseload time to this clinical population. The other services did not have a highly specialist SLT or had little or no time designated to stammering referrals²⁹.

While Speech and Language Therapy services accept referrals for suspected stammering, there are differences in the levels of provision offered by these services. For instance, some services may offer a distinct dysfluency service comprising a team of specialist SLTs who dedicate part or all of their clinical time to this caseload. Others may employ clinical specialists in stammering or have a highly specialist SLT as part of their team. Some may provide additional postgraduate training to their generalist SLTs or provide a dysfluency pathway as part of the overall Speech and Language Therapy

²⁷ Onslow, M., and O'Brian, S., 2013. *Management of childhood stuttering*. Journal of Paediatrics and Child Health, 49: E112 – E115.

²⁸ Liddle, H., James, S., and Hardman, M., 2011. *Group therapy for school-aged children who stutter: A survey of current practises*. Journal of Fluency Disorders, 36: 274 – 279.

²⁹ Hayhow, R., Roulstone, S., White, P., and Lindsay, G., 2012. *Prospective cohort study of speech and language therapy services for young people who stammer in England*. Department of Education, accessed online [18.10.19]:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/219629/DFE-RR247-BCRP16.pdf

service that guides the management process of these children. Other services may not employ an SLT who specialises in stammering or dedicate any time specifically to this client group.

The Michael Palin Centre in London is a national specialist centre for children who stammer³⁰. The Centre provides support to children from across the UK, and receives referrals from community Speech and Language Therapy services, as well as offering training and advice to SLTs working with children in their local areas.

We believe that all children who stammer should have the opportunity to access a local specialist service comprising Speech and Language Therapists who have specialist clinical skills in working with this disorder. Sadly, our report suggests this is not currently the case.

³⁰ The Michael Palin Centre for Stammering. <https://www.whittington.nhs.uk/default.asp?c=26669>

A note on methodology

Freedom of Information (FOI) requests were sent out to Local Authorities, NHS Foundation Trusts and Clinical Commissioning Groups (CCGs) in England, as well as a small number of independent providers.

The way that Speech and Language Therapy services are commissioned in Wales, Scotland and Northern Ireland means that data has been sought predominantly from the local health boards (Wales and Scotland) or health and social care trusts (Northern Ireland). However, some information was sourced from local authorities, which was integrated with information from local health boards where necessary.

Information gathered from local authorities in the UK, NHS Trusts and CCGs in England, Health Boards in Scotland and Wales, and Health and Social Care Trusts in Northern Ireland have been collated. Where we received information from both commissioner and provider for the same area, particularly with regards to England, data was integrated to provide more insight into the local provision available. Please refer to appendices for further information.

There have been changes in who provides paediatric Speech and Language Therapy services in the UK. As of April 2019, there were 6,261 full-time SLTs employed by the NHS in England³¹. Due to limitations in the resources available to us for data collection, including the fact that FOI requests can only be made to public bodies, we have focused predominantly on services available through NHS Trusts. The increasing number of different schools types, such as Academies, Free Schools, and Independent Schools, all of which do not come under the control of the Local Authority³², posed a challenge in collecting information from non-NHS providers. However, we recognise that there has been an increase in schools directly commissioning Speech and Language Therapy services.

Given this, the data collated in this report does not take into consideration any services commissioned by individual schools through private sector organisations, social enterprises, third sector collaborations or independent Speech and Language Therapy practises who may have separate service level agreements with schools or colleges.

In summary, it should be recognised that the conclusions drawn in this report are not based on the complete set of data available from all commissioners or providers of Speech and Language Therapy services, however they do offer an insight into the variation in resources available to support children who stammer.

³¹ NHS Digital (2019). NHS Hospitals and Community Health Service (HCHS) monthly workforce statistics. Accessed online:

<https://files.digital.nhs.uk/0C/7512E4/NHS%20Workforce%20Statistics%2C%20April%202019%20Staff%20Group%2C%20Care%20Setting%20and%20Level.xlsx>

³² GOV.UK. Types of school [accessed 19.8.19]: <https://www.gov.uk/types-of-school>

Stammering Provision by Nation:

England

We sent FOIs to commissioners across England, including Local Authorities – chiefly County Councils, Unitary Authorities, Metropolitan Districts and the London Boroughs – and Clinical Commissioning Groups (CCGs). Additionally, we contacted healthcare providers who were often able to provide more detailed information about the structure of the service offered to children who stammer in the local area. The majority of providers comprised NHS Foundation Trusts, although we also contacted some social enterprises and independent providers.

The data detailed here begins by providing an overview of the information reported by Healthcare Providers, which was then combined with information sourced from CCGs and Local Authorities, to map health service provision onto local government areas.

The information provided by public bodies and some independent organisations was used to generate a ranking of the support available to children who stammer in the local area:

1. Response referred to availability of a specialist stammering centre or stammering service
2. Response indicated availability of a Clinical Lead/Highly Specialist Dysfluency SLT or Specialist Dysfluency SLT within the Speech and Language Therapy service
3. Response reported that SLTs within the Speech and Language Therapy service have additional post-graduate training in stammering
4. Response referred to support offered by generalist SLTs as part of the Speech and Language Therapy service

Note: 'dysfluency' and 'stammering' are used interchangeably and do not reflect a difference in meaning

Supporting children who stammer

In order to adequately support children who stammer, every child should have access to a specialist stammering service in their local area (ranking [1]). We consider access to a Specialist Dysfluency SLT (ranking [2]) to be a minimum requirement to secure meaningful treatment outcomes. Those local areas that received a ranking of [3] or [4] do not appear to offer specialist support that would optimise treatment outcomes.

Key findings

Overall, approximately half of health providers in England report availability of a dedicated specialist dysfluency service.

After analysing the data organised by healthcare provider (pg. 15) and by local authority areas (pg16-19), it appears that around half of local authority areas in England offer access to a specialist stammering service comprising a team of Speech and Language Therapists who specialise in dysfluency.

If we collapse data for rankings [1] and [2], then the majority of local authority areas appear to provide a specialist stammering service or employ a highly specialist stammering SLT.



Health Providers in England

We contacted 145 Healthcare Providers across England, which mainly comprised NHS Foundation Trusts. We received responses from 135 NHS providers in total (including one social enterprise), and gathered information about the paediatric Speech and Language Therapy services available from 84 providers. The other providers we contacted either did not respond (10) or were not responsible for paediatric speech and language therapy services (51).

As the geographical areas covered by an NHS Trust and defined within Local Authorities do not necessarily overlap, we began by analysing the responses from individual providers to find out more information about the provision of specialist support available from NHS providers.

Of the providers that responded, 84 stated they provided paediatric Speech and Language Therapy. We have displayed the number of NHS providers and the one social enterprise that provide generalist versus specialist input below:

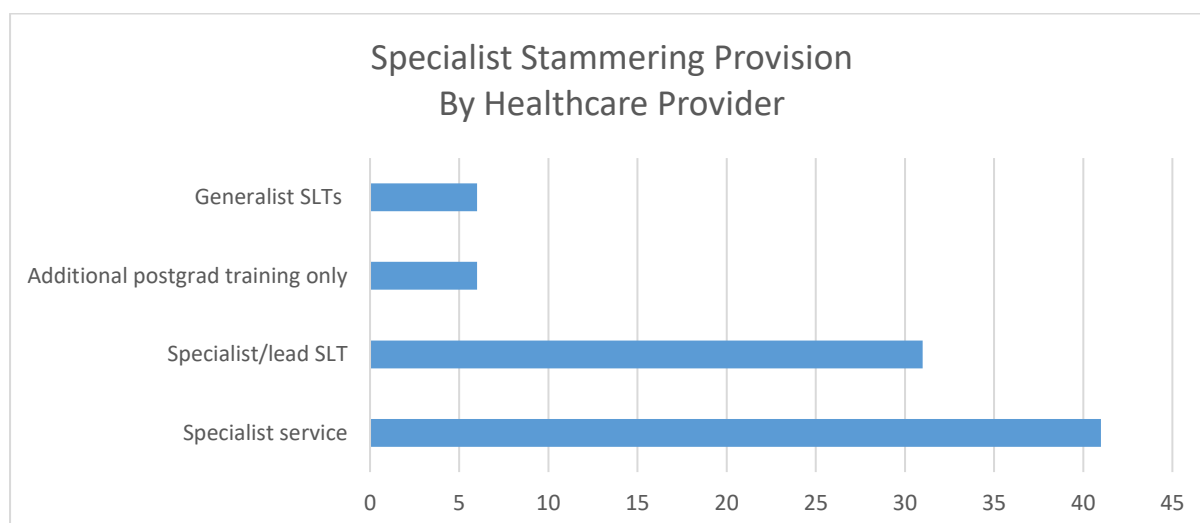


Figure 1: Breakdown of levels of specialist provision offered across the 84 providers who responded to our FOI request

As indicated in the graph, out of the total number of providers who responded [84], a 'specialist service' for children who stammer was most commonly reported [41]. Yet crucially, the total proportion of healthcare providers who offer a specialist service still stands at around half.

It is also worth noting that according to the figures published in April 2019, only 6,261 full-time SLTs are employed by the NHS in England³³. Although not directly comparable, there are 13,275 registered SLTs in England³⁴, potentially offering some insight into the number of practising SLTs working outside the NHS³⁵. SLTs may be employed by Local Authorities, social enterprises, directly by

³³ NHS Digital (2019). NHS Hospitals and Community Health Service (HCHS) monthly workforce statistics. Accessed

online: <https://files.digital.nhs.uk/0C/7512E4/NHS%20Workforce%20Statistics%2C%20April%202019%20Staff%20Group%2C%20Care%20Setting%20and%20Level.xlsx>

³⁴ Health and Care Professions Council (HCPC) snapshot of professionals registered across the UK: <https://www.hcpc-uk.org/globalassets/resources/data/2019/registant-snapshot---april-2019.pdf>

³⁵ Figures showing the number of SLTs working across different sectors was beyond the scope of this report and we acknowledge the differences in NHS Digital and HCPC data that mean these figures are not directly comparable.

schools or the independent sector, which affects access to specialist service structures. Independent SLTs who may be employed directly by schools are less likely to reflect the service structures common to NHS models. For instance, independent providers (or schools directly) may employ one generalist SLT to work with all the children with SLCN in that school, and therefore there is little scope for a specialist dysfluency service.

The next section summarises information by local authority area by attempting to map health areas onto local government areas through culmination of data received from local councils, CCGs and healthcare providers.

County Councils

Of the 25 County Council areas that we gathered information for, the majority offered access to either a clinical lead in dysfluency or a specialist stammering service, compared with areas that offer access to generalist SLTs with or without additional postgraduate training. It should be acknowledged that NHS Trusts do not often directly map to a local authority region. Therefore, the service available from one provider may differ depending on the part of the county in which the child lives.

Although at first glance, this data looks promising, it is important to note that just over half of them report offering specialist stammering services. Moreover, there needs to be some evaluation of the broader context. The qualitative information provided by some Trusts indicated that these 'specialist services' often comprised only a handful of specialist SLTs working part-time. And in some counties, there was only one clinical lead for dysfluency who was responsible for the entire county.

Considering the reasonably high prevalence of stammering during childhood and that there are a mere 13,275 SLTs registered in England – this figure includes those who may not be practicing clinically full-time – it is likely that the level of need will outstrip service capacity. It is also important to acknowledge that approximately 60% of SLTs work with children³⁶. Recent figures show 97% of the workforce is female³⁷, which has implications for higher rates of part-time working and maternity leave. This is important to consider as those on maternity leave would still be included in the Health and Care Professions Council (HCPC) register, but would not be working clinically.

Furthermore, the extent to which an unbalanced demand-capacity ratio exists may vary significantly across different areas of the country, as a consequence of the number of SLTs employed in local area. For example, according to recent data there are 326 registered SLTs in the county of Essex alone compared to a total of 460 registered SLTs across the three counties of Cambridgeshire, Norfolk and Suffolk, and 352 SLTs in the counties of Cumbria and Lancashire³⁸. Again, it is worth noting that not all those registered in a local area may be practicing clinically nor working within that area.

³⁶ Royal College of Speech and Language Therapists (RCSLT), Children's Service Overview. Webpage [accessed: 18.10.19]: <https://www.rcslt.org/speech-and-language-therapy/where-slt-work/childrens-services>

³⁷ Health and Care Professions Council (HCPC), Registrant snapshot – 1 September 2019. Accessed online [18.10.19]: <http://www.hcpc-uk.co.uk/about-us/insights-and-data/the-register/registrant-snapshot-1-september-2019/>

³⁸ Health and Care Professions Council (HCPC) response to FOI request submitted jointly by the Royal College of Speech and Language Therapists (RCSLT) and Action for Stammering Children: 'Age brackets and percentage of men and women in each profession across all areas on 30/08/2019. Available here: <https://www.hcpc-uk.org/resources/freedom-of-information-requests/2019/speech-and-language-therapists-data---august-2019/>

While it is not possible to determine whether those registered in a particular area work there, these figures suggest significant variation in the ratio of clinicians to children requiring specialist support in different areas of England.

Overall, around half of the county councils we have collected data about provide specialist services.

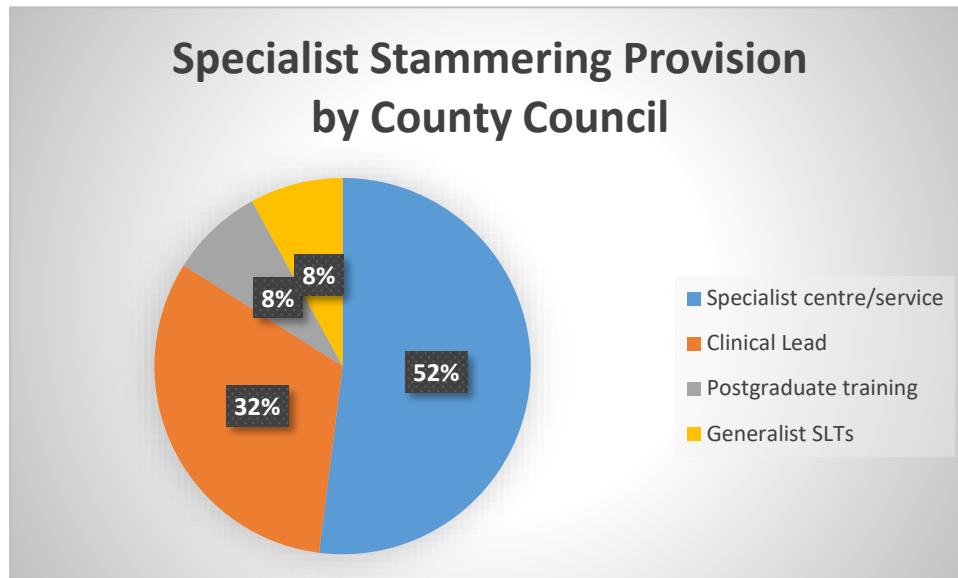


Figure 2: Proportion of county councils providing a range of generalist and specialist services to children and young people. Data available for 25 of 26 County Councils.

Unitary Authorities

There are 55 Unitary Authorities in England, excluding the Isles of Scilly, and we were able to collate data for 47 of these areas. Out of the responses received, we estimated that just over half offer access to a specialist service or centre.

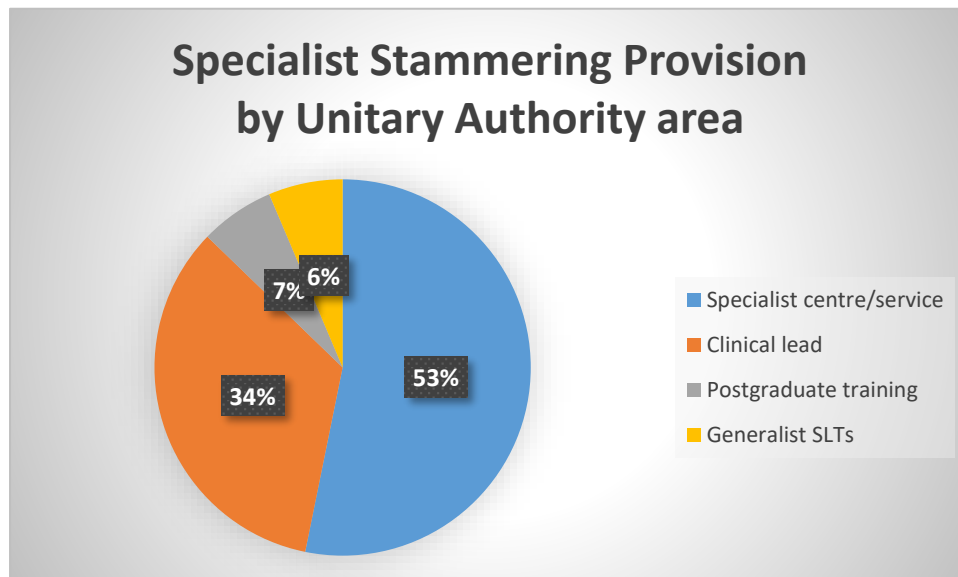


Figure 3: Proportion of unitary authorities providing a range of generalist and specialist services to children and young people. Data available for 47 of 55 unitary authorities

Metropolitan Districts

We were able to collate information for 35 out of 36 Metropolitan districts in total. Among the Metropolitan Districts we collated information for, 49% reported availability of specialist stammering services and/or centres within their local area compared with just 9% offering access to generalist SLTs. When considering our expectations of necessary support, just under half of areas offer a specialist service, and 20% of areas do not appear to offer specialist, targeted provision for children who stammer.

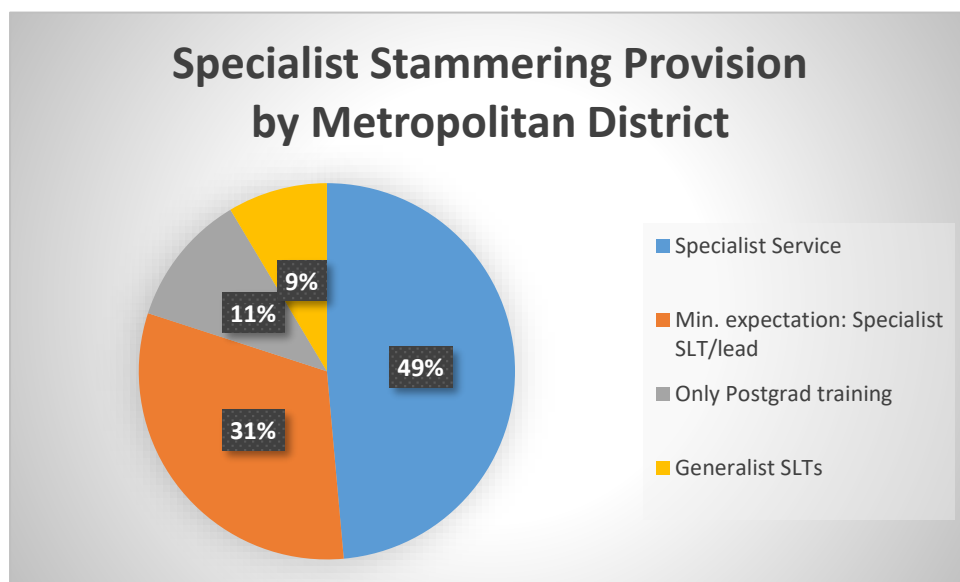


Figure 4: Proportion of metropolitan districts providing a range of generalist and specialist services to children and young people. Data available for 35 of 36 metropolitan districts.

London Boroughs

There are a total of 32 London boroughs, excluding the City of London, and we were able to collate data for 29 of them. As can be seen in figure 5, of the 29 areas that we have information about, 45% offer access to a specialist centre or service and 38% provide access to a clinical dysfluency lead.

It should be acknowledged that given the location of the national centre for stammering children, some London Authorities have agreements with the Michael Palin Centre for referring stammering children in their local areas.

As the country's capital and with a population of over 8 million people, it is unsurprising that London boasts a high proportion of registered SLTs relative to other areas of England – with a total of 2,435 registered SLTs according to the latest figures³⁹. In spite of this, the data suggests that less than half of London boroughs offer specialist services and 17% of areas do not meet the minimum requirement of access to a specialist dysfluency SLT.

³⁹ Health and Care Professions Council (HCPC), 'Age brackets and percentage of men and women in each profession across all areas on 30/08/2019': <https://www.hcpc-uk.org/resources/freedom-of-information-requests/2019/speech-and-language-therapists-data---august-2019/>

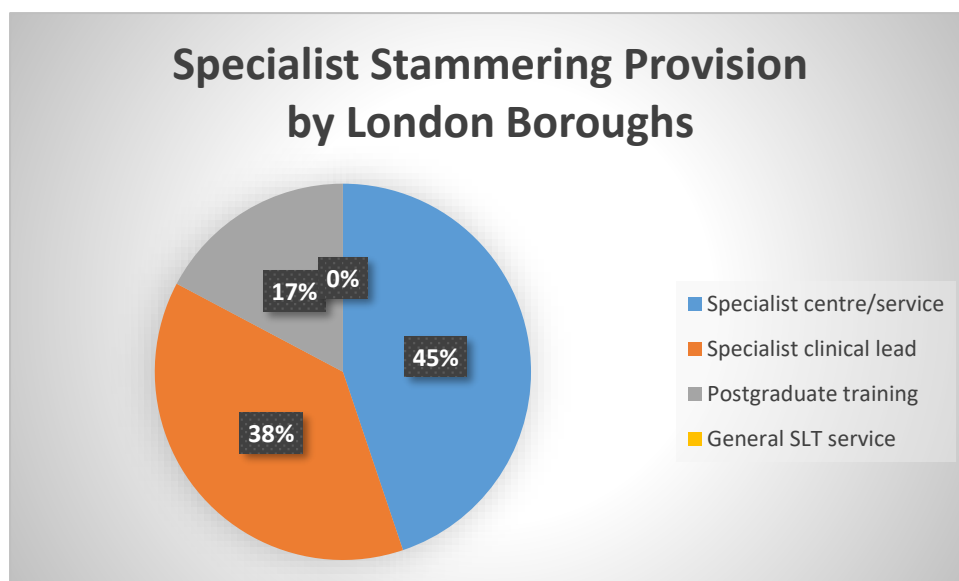


Figure 5: Proportion of London Boroughs providing a range of generalist and specialist services to children and young people. Data available for 29 of 32 London Boroughs.

Views of people who stammer

The comments below help to convey the extent to which support for children and young people who stammer is variable across England. As discussed in the introduction, stammering can have an impact on social, occupational and mental health outcomes in adulthood, and therefore early access to specialist intervention is crucial to off-set later development of these issues.

In our online questionnaire, we asked a series of questions about the individuals' experiences and parents' views of Speech and Language Therapy intervention for stammering. These are some of the things that they said:

"Very supportive, I had my therapist from a young age and saw her every Thursday for 14 years of my life. She gave me confidence in my speech and helped me to develop in areas where I wasn't comfortable in and I continued to have the same therapist for those 14 years which made it easier because she understood me."

- Durham

"I didn't get help until I was 9 years old. Then it was a 40 min bus ride which I went [on] my own... I stopped going because I lost heart."

- Birmingham

"I received Speech therapy on a regular basis. I attended 1 summer group and wished they done more of them as it really helped me"

- North Lanarkshire

"I feel like there is a need to make it more known in schools and have more support in place."

- Nottingham

"Always available to my son on contacting the local Speech and Language Centre"

- Buckinghamshire

"Was very on and off. Sometimes the speech therapist wasn't available. So sometimes I would go a few weeks without seeing anybody... when I plucked up the courage again, I was told as I'm full time and not in education, I can't get any support from the NHS"

- Hampshire

"I had no idea [help] existed for my stammer as a kid"

- Lancashire

Stammering Provision by Nation:

Scotland

NHS Scotland comprises 14 Health Boards, which are responsible for protecting and improving the health of their local population⁴⁰. FOI requests were sent to all Health Boards to find out more about the services available to children who stammer. Scotland also comprises 32 local authorities⁴¹ and FOI requests were also sent to some of these. Therefore, the information summarised reflects responses from both Local Authorities and NHS Health Boards in Scotland but is organised by Health Board area.



Summary

Data collected for Scotland suggests that only 7% of Health Boards areas provide specialist services, with most areas reporting access to SLTs with some postgraduate training.

Out of the 14 Health Boards we have information for, only one reported providing access to a specialist Dysfluency Clinic run by a specialist SLT one day a week. The majority of areas report that Speech and Language Therapy services provide access to SLTs with postgraduate training in stammering.

It is important to acknowledge that some Health Boards cover large geographical areas, which predominantly comprise sparse populations living in rural communities.

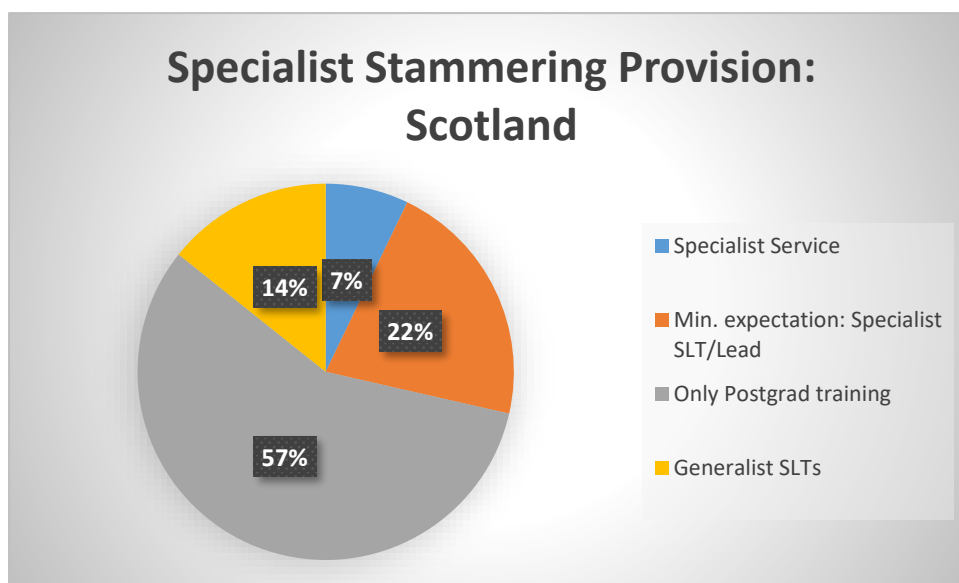


Figure 6: Levels of service provision available to children who stammer across the 14 Health Board areas in Scotland.

⁴⁰ NHS Scotland website. Accessed on 5.8.19: <https://www.scot.nhs.uk/organisations/>

⁴¹ Scottish Government website. Accessed on 12.8.19: <https://www.gov.scot/about/how-government-is-run/>

Stammering provision by nation: Wales

Healthcare services are planned, secured and delivered by 7 Local Health Boards (LHBs) in Wales⁴². FOI requests were sent to all LHBs to find out more about the services available to children who stammer across Wales. There are 22 Local Authorities in Wales⁴³ and some of these were contacted, however data has been organised by Health Board area.

Summary

Responses from Health Boards in Wales suggest that while all SLTs receive some additional postgraduate training in dysfluency management, the majority of areas offer either a specialist service or access to clinical stammering specialists.

As can be seen in figure 7, the majority of health board areas across Wales provide access to either a specialist service or a specialist clinician for children who stammer. However, it appears that less than half of areas provide a dedicated specialist stammering service.

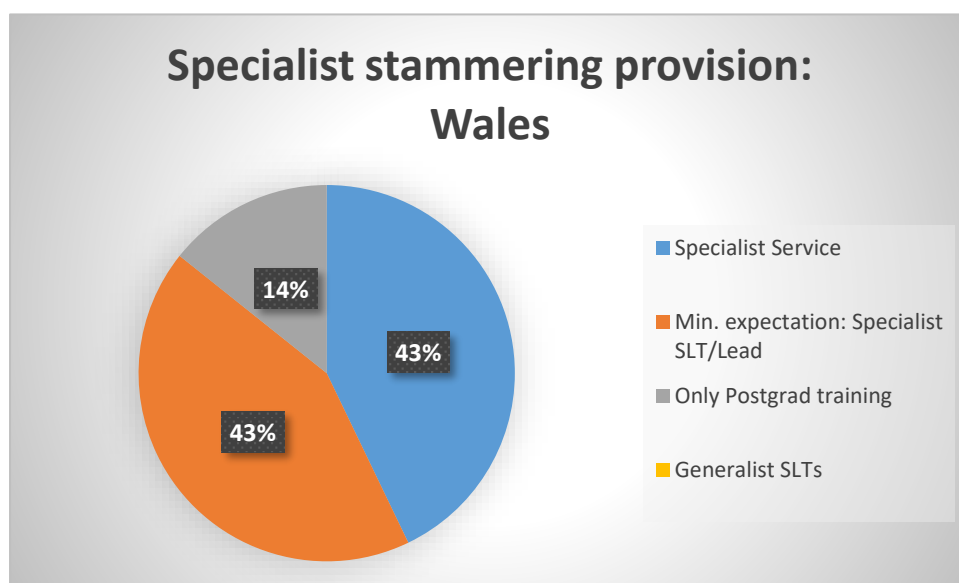


Figure 7: Levels of service provision available to children who stammer across the 7 Health Board areas in Wales.

⁴² NHS Wales website. Accessed on 5.8.19: <http://www.wales.nhs.uk/nhswalesaboutus/structure>

⁴³ The Welsh Local Government Association, accessed 12.8.19: <https://www.wlga.wales/about-us>

Stammering provision by nation: Northern Ireland

There are six Health and Social Care Boards (HSCs) in Northern Ireland, five of which provide integrated health and social care services across the country⁴⁴. FOI requests were sent to all HSCs to find out more about the services available to children who stammer across Northern Ireland.

Key findings

Over three quarters of the health and social care boards report access to specialist stammering services for children in their area. Feedback from Northern Ireland indicated that 4/5 Health and Social Care Boards offer a Specialist Service for children who stammer. Only one HSC reported availability of a generalist Speech and Language Therapy service.

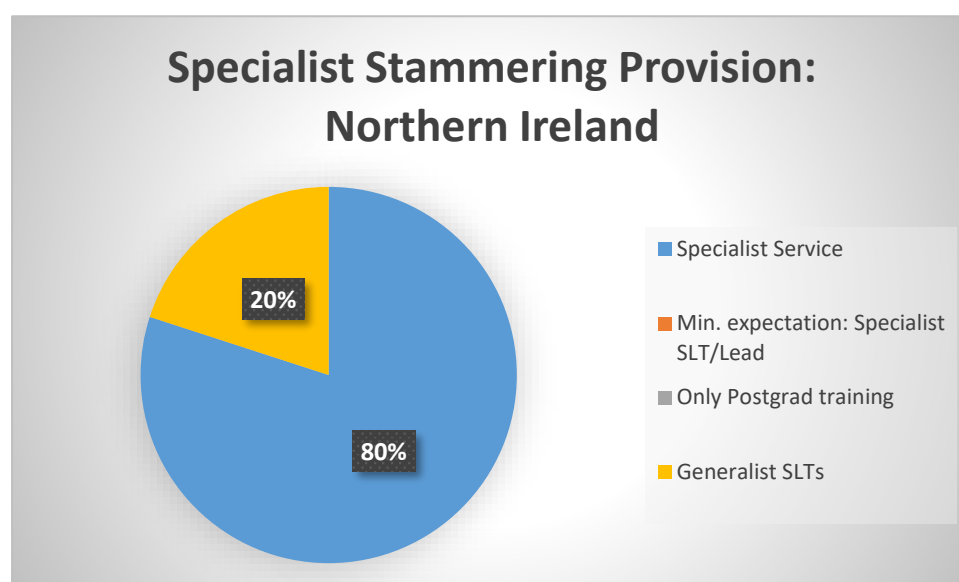


Figure 8: Showing levels of provision available to children who stammer across the 5 Health and Social Care Boards.

⁴⁴Health and Social Care Online website. Accessed 5.8.19: <http://online.hscni.net/hospitals/health-and-social-care-trusts/>

Views of people who stammer and their families

In addition to the quantitative data gathered, we also asked for comments from people who stammer living across the UK. We received the following comments from people in Scotland and Northern Ireland, which illustrate the variability of experiences in accessing specialist support as well as the effectiveness of the intervention when available.

“Lengthy waiting list. Short staffed. Under funded.”

- County Tyrone, N. Ireland

“Helpful, caring SLTs who helped me in school and on a week long course.”

- Dumfries and Galloway

“No speech language support offered...Early intervention is most important for people who stammer”

- Glasgow

“It worked. We focussed on sounds I had difficulty with. I still stammered afterwards, but much less frequently and I had much more control.”

- Aberdeenshire

“I had to find a private speech therapist in my local town”

- Midlothian, Scotland

Conclusion and Recommendations

Based on our findings, 45% of health providers⁴⁵ in the UK offer a specialist stammering service for children. When collapsed across local government area in England, around half of local authorities offer specialist stammering services, while less than half of health board areas in Wales and Scotland offer specialist provision. Health & Social Care Boards in Northern Ireland report the highest proportion of specialist stammering services.

It appears that across England and Wales the majority of areas offer a specialist service or at least have a clinical dysfluency lead with a dedicated amount of time to work directly with children who stammer and train other staff members. Scotland appears to have the smallest proportion of specialist provision for children and young people who stammer, with most SLTs receiving only some additional postgraduate training in dysfluency.

A recent report by Ofsted and the Care Quality Commission found access to therapy services, including Speech and Language Therapy, to be a weakness in half of the local areas inspected⁴⁶. They cited services that were overstretched to the point of being unable to deliver what was needed in local areas; challenges to funding resulting in a reduction in services; and long waiting times. Crucially in relation to our report, it was also noted that parents had particular concerns about delays in accessing specialist services. Our findings in the current report would further suggest that access to specialist services for children who stammer is inadequate.

There are just 16,637 SLTs registered across the UK compared to 39,886 Occupational Therapists and 55,671 Physiotherapists⁴⁷. Approximately 60% of SLTs work with children, and consequently the proportion of registered SLTs available to work with children and young people who stammer falls to 9,982⁴⁸.

Furthermore, not all 16,637 registered SLTs will be practising full-time, and others may not be practising clinically but rather will be employed in managerial or research roles. Recent data indicates that 97% of SLTs are female, which is likely to impact on the rates of part-time working. SLTs currently taking maternity leave will typically still be registered with the Health & Care Professions Council (HCPC), further reducing the proportion of SLTs working clinically.

Finally, an increasing number of SLTs are now working in the independent or voluntary sectors in England, impacting the number of SLTs available to work in these specialist services offered by NHS providers.

⁴⁵ 'Health providers' here refers to the Health Providers (England), Health Boards (Scotland), Local Health Boards (Wales) and Health & Social Care Trusts (Northern Ireland). This figure is based on calculating the number of services ranked as [1] for each nation as per the response of the provider and averaging this across the UK. See appendices for further information.

⁴⁶ Ofsted and the Care Quality Commission, 2017. Local area SEND inspections: one year on. Accessed online [18.10.19]: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/652694/local_area_SEND_inspections_one_year_on.pdf

⁴⁷ Health and Care Professions Council (HCPC) snapshot of professionals registered across the UK. The HCPC is the regulator of health, psychological and social work professionals and it is not possible to practise as one of these registered professions without registration with the HCPC: <https://www.hcpc-uk.org/globalassets/resources/data/2019/registrant-snapshot---april-2019.pdf>

⁴⁸ This figure was calculated based on the April 2019 HCPC statistics which recorded 16,637 SLTs registered in the UK. We calculated 60% of 16,637 to generate our figure of 9,982 SLTs.

Given that more than 10% of children and young people have a long-term Speech, Language or Communication Need (SLCN)⁴⁹, SLTs are likely to have large caseloads beyond those referred for stammering. Moreover, in areas of high socio-economic disadvantage, it has been estimated that up to 50% of children begin school with an identifiable SLCN⁵⁰, increasing the demands on the local service. Additionally, changes in commissioning and cuts to funding Speech and Language Therapy services put added pressure on specialist provision in local areas. Reports of cuts to training budgets also has an impact on opportunities to specialise in this clinical area. Consequently, children who stammer are at heightened risk of not being prioritised, especially where specialist service structures are not available.

Given the proportion of registered SLTs across the four nations of the UK, it seems reasonable to argue that the specialist stammering services reported in FOI responses, are unlikely to meet the demand in all local areas. As expected, England has the highest number of registered SLTs (13,275), compared with 1,315 in Scotland, 761 in Northern Ireland and 718 SLTs across Wales⁵¹.

Unfortunately, we were not able to analyse data in relation to the number of children referred for a suspected stammer in comparison with the number accepted onto the caseload, due to many NHS Trusts reporting that they did not specify the exact reason for referral in their records. This in itself presents a challenge in terms of tracking healthcare needs in local areas to inform commissioner decision-making. We would advocate for improvements in tracking specific reasons for referral to help commissioners in their service planning and decision-making.

Policy recommendations

It is imperative that Speech and Language Therapy services are arming SLTs with the advanced skills and resources to work effectively with this clinical population. Equally, steps need to be taken to raise awareness and improve understanding of stammering. Across the education and healthcare sectors, professionals need to know how to seek support for children who stammer in an attempt to maximise early identification and access to specialist intervention.

Such measures would not only be beneficial for these children and their families, but would also offer an opportunity to develop the evidence-base in this field. Targeted, on-going intervention delivered by clinical specialists would be the most effective way to offset longer-term adverse social, emotional, mental health and economic consequences.

We have put forward the following recommendations in an effort to facilitate and equalise access to specialist clinical services for children and young people who stammer:

- **Local access to a specialist stammering service for every child who stammers across England, Scotland and Wales**

Approximately half of health providers across the UK offer specialist services for children and young people who stammer. While we recognise that a large number of local authority areas in England and Health Boards in Wales reported access to clinical specialists in stammering compared with

⁴⁹ The Communication Trust https://www.thecommunicationtrust.org.uk/media/600984/ite_resource_2.pdf

⁵⁰ Royal College of Speech and Language Therapists, *The links between speech, language and communication needs and social disadvantage*. Accessed online [7.10.19]: <https://www.rcslt.org/-/media/Project/RCSLT/rcslt-social-disadvantage-factsheet.pdf>

⁵¹ HCPC breakdown of professionals registered in the four nations of the UK: <https://www.hcpc-uk.org/globalassets/resources/freedom-of-information/2019/02.-february/statistics-on-occupational-therapists---february-2019.pdf>

generalist SLTs, we are concerned that demand outstrips supply. Formation of structured specialist services for all children who stammer should be available in all local areas across the UK.

- **Early intervention should be prioritised**

Where resources are limited, services should prioritise early intervention for children who stammer and ensure no child referred for dysfluency waits more than 12 months to begin intervention with a specialist Speech and Language Therapist.

Given the increasing evidence that stammering is associated with bullying and later adverse mental health conditions, and that early intervention is more effective in this disorder, offering specialist, targeted intervention could offset adverse social, economic and mental health issues in later life.

- **A national awareness raising campaign**

It is imperative that parents feel confident about where they can seek advice if their child begins to stammer. A national campaign targeting young families, schools, education and health professionals that raises awareness about stammering and the role SLTs play in supporting these children would help to fill this knowledge gap.

- **Training for education and healthcare professionals**

To promote earlier identification and access to early intervention, all education and healthcare staff should have some understanding of what stammering is, the broader implications if left untreated and whom to refer for further advice. Training teaching staff to identify stammering is essential given the amount of time spent in the classroom, and will facilitate more relevant, timely referrals.

- **Health and Education need to work more closely together**

It became clear during the period of data collection that the changes in commissioning arrangements and move away from NHS models of service delivery, has had an impact on service organisation. While we focused on NHS providers, it remains unclear the extent to which non-NHS service providers do offer any specialist provision for children who stammer. To ensure that children do not fall through the gaps, health and education professionals and decision-makers need to be collaborating to meet the holistic needs of the child.

Appendix 1 – data collection: FOI requests

Between November 2018 and August 2019, Freedom of Information (FOI) Requests were sent to commissioners and providers of Speech and Language Therapy in the UK. Due to differences in commissioning across the four nations of the UK, FOIs were dispatched to the following recipients.

England

FOI requests were sent out to 145 Health Providers and 104 CCGs, and approximately 300 local authorities in England.

Local Authorities

There are 343 Local Authorities in England comprising five different types⁵². Given their involvement in local service provision and variation in commissioning, data has been organised by the 150 County Councils, Unitary Authorities and Metropolitan Districts in England that we gathered information about.

The following FOI request was emailed out to 300 local authorities including predominantly county councils, as well as some borough and district councils:

We are conducting research into the provision of specialist services for children who stammer in each local authority across the UK as part of our charity's commitment to improving access to effective intervention. Therefore, I would like to make a request under the Freedom of Information Act regarding the clinical provision commissioned in your local authority for children who stammer.

Could you inform us of whether service provision is available for children who stammer (between ages three and eighteen) within your local authority? This includes information about the structure of the Speech and Language Therapy service commissioned within your local authority and whether there are specialist services available specifically to children who stammer, e.g. dysfluency clinics. Where possible, please include details relating to any specified criteria for accessing this service, i.e. age range, community/clinic based service, exclusion criteria.

CCGs and Health Providers

Due to differences in commissioning arrangements within England, further FOI requests were sent to 104 Clinical Commissioning Groups (CCGs), following advice given by the local council. Many CCGs reported that they did not hold the required level of detail on service delivery that we had asked for and often referred us onto the local NHS Trust or non-NHS provider responsible for Speech and Language Therapy services in the local area. Of the 145 Health Providers contacted, 135 responded, with 84 providing information about their paediatric Speech and Language Therapy service. Of the 104 CCGs contacted, 98 responded. This was the FOI request sent out to health commissioners and providers:

- Do you provide a specialist service for children who stammer in your trust?

⁵² Gov.UK. Guidance: Local Government Structure and Elections. Accessed on 5.8.19: <https://www.gov.uk/guidance/local-government-structure-and-elections#structure>

- *This includes information about the structure of the Speech and Language Therapy service provided and whether there are specialist services available specifically to children who stammer, e.g. dysfluency pathways and/or specialist Speech and Language Therapists.*
- What age range does your service cover?
- Does your service have any other specified exclusion criteria?
- What geographical population does this cover?
- Number of referrals made to the service for children suspected of presenting with a stammer over the last year (January 2018 - January 2019)
- Number of children seen as part of the service in the last year (January 2018 - January 2019)

The additional two questions in this FOI request did not yield substantial amounts of data. Many NHS Trust providers stated they could not relay this information because either it would take longer to find the information than the amount of time allocated to FOI requests or because they did not record the reason for referral. Consequently, the limited data we have collated from these two questions were not included in our analysis, nor were the questions included when contacting Scotland, Wales and Northern Ireland.

Scotland

All 14 Health Boards in Scotland were contacted as well as several local authorities.

Wales

All 7 Local Health Boards in Wales were contacted as well as several local authorities.

Northern Ireland

All 5 Health and Social Care Boards were contacted.

Appendix 2 – data analysis

Data was analysed according to Health Board areas for Scotland and Wales and Health and Social Care Board areas for Northern Ireland. Therefore, we were unable to display data for individual local authority areas for these parts of the UK.

In England, information was gathered from commissioners (typically local councils or CCGs) as well as providers (typically NHS Trusts or social enterprises/independent organisations). In an effort to quantify large amounts of qualitative data, information received in response to the FOI requests was collated and ranked by the researcher on a scale of 1 – 4:

[1] Response referred to availability of a specialist stammering centre or stammering service (highest score)

[2] Response indicated availability of a Clinical Lead/Highly Specialist Dysfluency SLT or Specialist Dysfluency Speech and Language Therapist

[3] Response reported that SLTs within the community Speech and Language Therapy service have additional post-graduate training in stammering

[4] Response referred to support offered by generalist SLTs as part of the community Speech and Language Therapy service (lowest score)

In order to improve accessibility of the information in the report, it was important to represent data according to local authority areas in England, which is more relatable to the public. Local authority boundaries do not necessarily correspond with NHS regions, and therefore we were careful to display the information gathered in as accessible a format as possible. Consequently, for England, data was collated and presented in two formats by overlaying, where possible, local authority boundaries and NHS regions:

1. NHS Trusts – information provided by individual NHS Trusts was ranked and presented by Trust
2. Local Authority area – information gathered from local councils, CCGs and NHS Trusts was pooled and organised by local authority area (county councils, metropolitan districts, unitary authorities, London boroughs), through consideration of the geographical population each organisational body represented. The information gathered by local authority area was then allocated a ranking.

Limitations in data collection and analysis

As referenced in the body of the report, it is acknowledged that our findings will not be wholly representative of the provision available across the UK for a number of reasons. Here we summarise some of the limitations to our methodology in an effort to offer a transparent insight into the data.

Firstly, information was gathered by FOI request, which has some drawbacks, most notably independent providers are not obliged to respond to FOIs. Equally, not all public bodies responded and there were changes during the collection period around commissioning partnerships and merging of hospital trusts. We also acknowledge that some Local Authorities and CCGs provided information following consultation with the provider, often resulting in more detailed information, while others did not.

Consequently, this report is intended to provide a summary of the information gathered from those public authorities contacted.

The following discussion of the limitations should be considered when interpreting this report:

- **Definition of 'specialist stammering service'** – FOI requests were sent to commissioners and providers of Speech and Language Therapy services. It is possible that, given not all would have received input from clinicians, there may have been uncertainty about what constitutes a 'specialist stammering service'. Some responses stated a simple 'yes' or 'we provide a specialist stammering service', but it is difficult to know whether their definition of a specialist service was similar to the charity's definition.
- **Response quantity** – due to resource constraints it was not possible to contact every healthcare commissioner and provider in the UK. Efforts have been made to provide as representative a sample of NHS Health Trusts and CCGs in England as possible to evaluate the situation. However, it is possible that in some areas, relevant NHS Trusts have not been contacted who may provide a specialist stammering service. Equally, some NHS Trusts and CCGs did not respond to our request and so their data is not represented in the report.
- **Response quality** – as already alluded to, some responses were very detailed and outlined the nature of the service provided, while others offered yes/no answers, which made it difficult to determine the ranking. As a rule, if a response stated it provided a 'specialist service' this was ranked [1]. If the response stated 'specialist service' or simply responded 'yes' and then offered information detailing a service that did not constitute a specialist service, e.g. we have one specialist SLT or we provide extra training to community SLTs, then this would be ranked accordingly. We acknowledge therefore that the rankings are subjective to some extent but have worked hard to counter this as far as possible.
- **Organisation of data** – data was gathered from several sources and had to be coded by local authority area. Overlapping data gathered about NHS regions with local authority regions was a challenge and may not fully represent (or could over-represent) the service available to children in that area.
- **Non-NHS Providers** – all data in this report is based on NHS providers, however we know that many non-NHS providers, e.g. social enterprises, independent clinical practises and third sector organisations, are also offering Speech and Language Therapy to children. Attempts were made to gather information from schools, who may choose to commission an independent provider, but due to resource limitations this was not particularly effective.
- **Qualitative data bias** – the information gathered from children who stammer and their families was sought through an online questionnaire. It is recognised that this may have resulted in some bias. The questionnaire was hosted by Action for Stammering Children and so may have received a higher response rate from families already engaged with the charity or the Michael Palin Centre. It was not possible to gather additional information about the age or individual characteristics of those completing the survey, and so some responses may have been retrospective rather than reflective of the current context.

Appendix 3 – data

Data rankings for England, Scotland, Wales and Northern Ireland.

England – by local authority area

Local Authority (LA)	Provider contacted	Ranking
County Councils (26)		
Buckinghamshire	Buckinghamshire Health NHS Foundation Trust	1
Cambridgeshire	Cambridgeshire Community Services NHS Trust (CCS) and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)	1
Cumbria	Cumbria Partnership NHS Foundation Trust	2
Derbyshire	Derbyshire Community Health NHS Foundation Trust; Chesterfield Royal NHS Foundation Trust (North Derbyshire)	1
Devon	Torbay and South Devon NHS Foundation Trust	1
East Sussex	Kent Community Health NHS Foundation Trust	2
Essex	Provide CIC; North East London Foundation Trust; Essex Partnership University NHS Trust	1
Gloucestershire	Gloucestershire Care Services NHS Trust	2
Hampshire	Solent NHS Trust	1
Hertfordshire	Hertfordshire Community NHS Trust	1
Kent	Kent Community Health NHS Foundation Trust; East Kent Hospitals University NHS Foundation Trust	2
Lancashire	Lancashire Care Foundation Trust; Blackpool Teaching Hospitals Trust; University Hospitals of Morecambe Bay NHS Foundation Trust	2
Leicestershire	Leicestershire Partnership Trust	2
Lincolnshire	Lincolnshire Community Health Service; Northern Lincolnshire and Goole NHS Foundation Trust	1
Norfolk	East Coast Community Healthcare	4
Northamptonshire	Northamptonshire Healthcare NHS Trust	3
North Yorkshire	York Teaching Hospital NHS Foundation Trust; Harrogate and District NHS Foundation Trust; South Tees Hospital NHS Foundation Trust	1
Nottinghamshire	Nottinghamshire Healthcare NHS Foundation Trust	2
Oxfordshire	Oxford Health NHS Foundation Trust	1
Somerset	Somerset Partnership NHS Trust	1
Staffordshire	Midlands Partnership NHS Foundation Trust	4
Suffolk	West Suffolk Foundation Trust; East Coast Community Healthcare	3

Surrey	Children and Family Health Surrey (<i>Services are provided by 3 Surrey NHS providers: CSH Surrey, First Community Health and Care, and Surrey and Borders Partnership NHS Foundation Trust</i>)	N/A*
Warwickshire	South Warwickshire Foundation Trust	2
West Sussex	Sussex Community Health Foundation Trust	1
Worcestershire	Worcestershire Health and Care NHS Trust	1
Unitary Authorities (55 + Isle of Scilly)		
Bath and North East Somerset	Virgin Care	2
Bedford	Bedfordshire Community Health Services (<i>provided in partnership by East London NHS Foundation Trust (ELFT) and Cambridgeshire Community Services (CCS) NHS Trust</i>)	2
Blackburn with Darwen	-	N/A
Blackpool	Blackpool Teaching Hospitals NHS Trust	3
Bournemouth, Christchurch and Poole	Dorset Healthcare University NHS Foundation Trust	2
Bracknell Forest	-	N/A
Brighton and Hove	Sussex Community Health Foundation Trust	1
Bristol	Children's Community Health Partnership (emailed)	N/A
Central Bedfordshire	Bedford Community health Services (<i>provided in partnership by East London NHS Foundation Trust and Cambridgeshire Community Services</i>)	4
Cheshire East	East Cheshire NHS Trust	2
Cheshire West and Chester	Cheshire and Wirral Partnership NHS Foundation Trust; Central Cheshire Integrated Care Partnership	3
Cornwall	Cornwall Partnership NHS Foundation Trust	2
County Durham	North Tees and Hartlepool Hospitals NHS Foundation Trust	1
Darlington	North Tees and Hartlepool Hospitals NHS Foundation Trust	1
Derby	Derbyshire Community health Services NHS Foundation Trust	2
Dorset	Dorset Healthcare University NHS Foundation Trust	2
East Riding of Yorkshire	Humber Teaching NHS Foundation Trust	1
Halton	Chatterbug	N/A
Hartlepool	North Tees and Hartlepool Hospitals NHS Foundation Trust	1
Herefordshire	Wye Valley NHS Trust	2
Isle of Wight	Isle of Wight NHS Trust	3
Hull City	Humber Teaching NHS Foundation Trust	1

Leicester	Leicestershire Partnership NHS Foundation Trust	2
Luton	Cambridgeshire Community Services	2
Medway	Medway Community healthcare provides paediatric SLT	N/A
Middlesbrough	South Tees Foundation Trust	1
Milton Keynes	Central and North West London NHS Trust	1
North East Lincolnshire	Northern Lincolnshire and Goole NHS Foundation Trust; Lincolnshire Community Health Services	1
North Lincolnshire	Northern Lincolnshire and Goole NHS Foundation Trust; Lincolnshire Community Health Services	1
North Somerset	-	N/A
Northumberland	Northumbria Healthcare NHS Foundation Trust	1
Nottingham	Nottinghamshire Healthcare NHS Foundation Trust	1
Peterborough	Cambridgeshire Community Services NHS Trust (CCS) and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)	2
Plymouth	Livewell Southwest	N/A
Portsmouth	NHS Solent	1
Reading	Berkshire Healthcare Foundation Trust	1
Redcar and Cleveland	South Tees Foundation Trust	1
Rutland	Leicestershire Partnership NHS Foundation Trust	2
Shropshire	Shropshire Community Health NHS Trust (SCH); Midlands Partnership NHS Foundation Trust (MP)	2
Slough	Berkshire Healthcare Foundation Trust	1
Southampton	Solent NHS Trust	1
Southend-on-Sea	Essex Partnership University Foundation Trust	1
South Gloucestershire	Gloucestershire Care Services NHS Trust	2
Stockton-on-Tees	North Tees and Hartlepool Hospitals NHS Foundation Trust	1
Stoke-on-Trent	Midlands Partnership NHS Foundation Trust	4
Swindon	Work in partnership with the Fluency Trust	1
Telford and Wrekin	Shropshire Community Health NHS Trust; Shrewsbury and Telford Hospital Trust	2
Thurrock	North East London Foundation Trust	1
Torbay	Torbay and South Devon NHS Foundation Trust	1
Warrington	Bridgewater Community Healthcare NHS Foundation Trust	2
West Berkshire	Berkshire Healthcare Foundation Trust	1
Wiltshire	Virgin Care	4

Windsor and Maidenhead	Berkshire Healthcare Foundation Trust	1
Wokingham	-	N/A
York	York Teaching Hospital NHS Foundation Trust	1
Metropolitan districts (36)		
Barnsley	South West Yorkshire Partnership NHS Foundation Trust	2
Birmingham	Birmingham Community Healthcare NHS Foundation Trust	2
Bolton	Bolton NHS Foundation Trust	1
Bradford	Airedale NHS Foundation Trust; Bradford District Care NHS Foundation Trust	1
Bury	Pennine Care Foundation Trust	1
Calderdale	Calderdale and Huddersfield NHS Foundation Trust	1
Coventry	-	N/A
Doncaster	Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	2
Dudley	Black Country Partnership Foundation Trust	2
Gateshead	Gateshead Heath NHS Foundation Trust	2
Kirklees	Locala Community Partnerships	4
Knowsley	North West Boroughs Healthcare NHS Foundation Trust	3
Leeds	Leeds Community Healthcare Trust	1
Liverpool	Alder Hey Children's NHS Trust	1
Manchester	Manchester University NHS Foundation Trust	1
Newcastle upon Tyne	Newcastle upon Tyne NHS Foundation Trust	2
North Tyneside	Northumbria Healthcare Trust	1
Oldham	Pennine Care NHS Foundation Trust	1
Rochdale	Pennine Care NHS Foundation Trust	1
Rotherham	Rotherham NHS Foundation Trust	1
Salford	Salford Royal NHS Foundation Trust	4
Sandwell	Birmingham Community Healthcare NHS Foundation Trust; Sandwell and West Birmingham Hospitals	1
Sefton		4
Sheffield	Sheffield Children's NHS Foundation Trust	1
Solihull	Birmingham Community Healthcare NHS Foundation Trust; University Hospitals Birmingham	2
South Tyneside	South Tyneside and Sunderland NHS Foundation Trust	1
St. Helens	Bridgewater Community Healthcare NHS Foundation Trust	1

Stockport	Stockport NHS Foundation Trust	1
Sunderland	South Tyneside and Sunderland NHS Foundation Trust	1
Tameside	Tameside and Glossop Integrated Care NHS Foundation Trust	2
Trafford	Pennine Care NHS Foundation Trust	2
Wakefield	Mid Yorkshire Hospital NHS Trust	3
Walsall	Walsall NHS Healthcare Trust	3
Wigan	Bridgewater Community Healthcare NHS Foundation Trust	2
Wirral	Cheshire and Wirral Partnership NHS Foundation Trust	3
Wolverhampton	Royal Wolverhampton NHS Trust	2
London boroughs (32)		
Barking and Dagenham	North East London FT (NELFT)	1
Barnet	North East London FT (NELFT)	2
Bexley	Oxleas NHS Foundation Trust	3
Brent	London North West University Healthcare NHS Trust	2
Bromley	Bromley Healthcare	N/A
Camden	NHS Whittington Health and ACS	1
Croydon		1
Ealing	London North West University Healthcare NHS Trust	2
Enfield	Barnet, Enfield and Haringey Mental Health NHS Trust	N/A
Greenwich	Oxleas NHS Foundation Trust	2
Hackney	Integrated Speech and Language Therapy service (via Homerton Hospital and Hackney Learning Trust)	1
Hammersmith and Fulham	Central London Community Healthcare NHS Trust	1
Haringey	Whittington Health	1
Harrow	London North West University Healthcare NHS Trust	2
Havering	North East London Foundation Trust (NELFT)	3
Hillingdon	Central and North West London NHS Foundation Trust	3
Hounslow	Hounslow and Richmond Community Healthcare Trust	3
Islington	Whittington Health	1
Kensington and Chelsea	Central London Community Healthcare NHS Trust	1
Kingston upon Thames	Your Healthcare	3
Lambeth	Guys' and St Thomas' Foundation Trust	1

Lewisham	-	N/A
Merton	St George's University Hospitals NHS Foundation Trust	2
Newham	i) East London Foundation Trust; ii) Michael Palin Centre	2
Redbridge	North East London Foundation Trust (NELFT)	2
Richmond upon Thames	Hounslow and Richmond Community Healthcare Trust	2
Southwark	Guys' and St Thomas' NHS Foundation Trust	1
Sutton	Sutton Community Health Trust	2
Tower Hamlets	Barts Health NHS Trust	1
Waltham Forest	North East London Foundation Trust (NELFT)	1
Wandsworth	St George's University Hospitals NHS Foundation Trust	2
Westminster	Central London Community Healthcare NHS Trust	1
(City of London - not a borough)	Homerton Hospital	2

*N/A – refers to instances in which information was unavailable for that area. For instance no response from health provider/CCG, provider is non-public authority and so is not obliged to respond to FOI requests.

Wales – by Health Board area

WALES - 7 HEALTH BOARDS	Areas covered	Ranking
Aneurin Bevan University Health Board	<i>Blaenau Gwent, Caerphilly, Monmouthshire, Newport, Torfaen and South Powys.</i>	2
Cardiff and Vale University Health Board	<i>North and West Cardiff, South and East Cardiff, and the Vale of Glamorgan</i>	1
Cwm Taf University Health Board	<i>Merthyr Tydfil and Rhondda Cynon Taf</i>	3
Abertawe Bro Morgannwg University Health Board	<i>Swansea, Port Talbot, Bridgend</i>	1
Powys Teaching Health Board	<i>Welshpool, Newtown, Brecon</i>	2
Hywel Dda University Health Board	<i>Carmarthenshire, Ceredigion and Pembrokeshire</i>	1
Betsi Cadwalader University Health Board	<i>Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham</i>	2

Scotland – by Health Board area

SCOTLAND - Health Board	Areas covered	Ranking
NHS Ayrshire and Arran	<i>East, South and North Ayrshire</i>	3
NHS Borders	<i>Scottish Borders</i>	4

NHS Dumfries and Galloway	<i>Dumfries, Galloway</i>	3
NHS Fife	<i>Fife</i>	3
NHS Forth Valley	<i>Clackmannanshire, Falkirk, Stirling</i>	2
NHS Grampian	<i>City of Aberdeen, Moray, Aberdeenshire</i>	3
NHS Greater Glasgow and Clyde	<i>City of Glasgow, East Dunbartonshire, East Renfrewshire, Inverclyde, Renfrewshire, West Dunbartonshire, North Lanarkshire (part), South Lanarkshire (part)</i>	2
NHS Highlands	<i>Highland, Bute and Argyll</i>	4
NHS Lanarkshire	<i>North and South Lanarkshire</i>	2
NHS Lothian	<i>City of Edinburgh, West Lothian, East Lothian, Midlothian</i>	3
NHS Orkney	<i>Orkney Islands</i>	1
NHS Shetland	<i>Shetland Islands</i>	3
NHS Tayside	<i>Angus, City of Dundee, and Perth and Kinross</i>	3
NHS Western Isles	<i>Outer Hebrides</i>	3

Northern Ireland – by Health and Social Care Board

NORTHERN IRELAND - 5 HandSC TRUSTS	Ranking
Belfast Health and Social Care Trust	1
South Eastern Health and Social Care Trust	1
Northern Health and Social Care Trust	1
Southern Health and Social Care Trust	4
Western Health and Social Care Trust	1

UK-wide – by health provider

Nation	Organisational body	Total response no.	No. ranked [1]
England	Health provider (NHS Trust)	84	41
Scotland	Health Board	14	1
Wales	Local Health Board	7	3
Northern Ireland	Health & Social Care Trust	5	4
	TOTAL	110	49



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Action for Stammering

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Suffering in Silence Report: Addendum

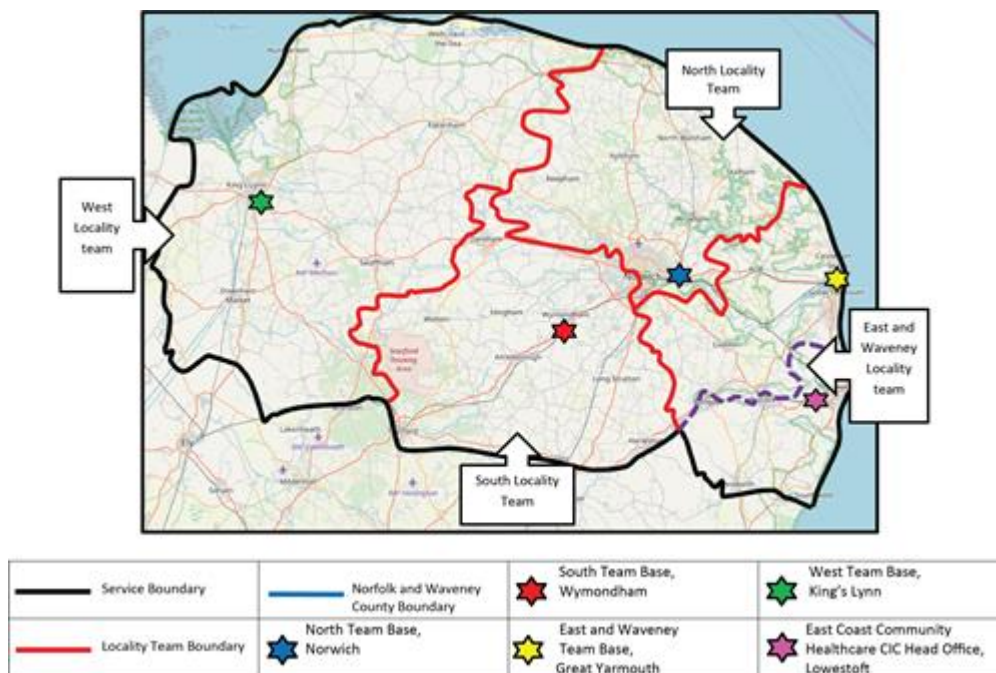
As a charity, we are committed to ensuring our record of specialist stammering services across the UK is as up-to-date and comprehensive as possible. Following publication of the report, some service providers have got in touch with us to supply more information about the structure of the service they offer in their local area. This information is detailed here.

Norfolk

Initially rated **4** due to information available at the time of publication, we have since received further information about the service provided by East Coast Community Healthcare in Norfolk.

Updated ranking: **1**

The service sees children and young people who stammer aged 0-19 years across Norfolk, Waveney and part of Suffolk (please see map below for service boundary):



Bristol & South Gloucestershire

At the time of publication, we did not have access to information about the services available in Bristol and South Gloucestershire that are provided by Bristol Community Health CIC (Community Children's Health Partnership). However, we have since received information about the service provided across this area:

Updated ranking: **1**