

The Need for and Benefit of Specialist Stammering Services

West Berkshire Health Scrutiny Committee Meeting 13/12/2022

What is stammering?

Stammering (also known as stuttering) is where someone knows exactly what they want to say, but the flow of their speech is disrupted. Someone who stammers may repeat words or sounds, stretch out sounds or get stuck when saying certain words. For some people there may also be signs of tension or effort when speaking. People may also swap certain words for other ones they find easier to say or avoid certain words, phrases or even situations completely. Every person's stammer is unique and it may vary from one day, hour or sentence to the next.

We do not know the exact cause of stammering, but we know that it is a neurological condition, meaning there are subtle changes in the brains of people who stammer. It is more common in people who have a family history of stammering, such as having a parent or grandparent who stammers. We also know it is not caused by anxiety, but many people who stammer may stammer more often when they are anxious or stressed.

Up to 2% of UK adults say they stammer, or roughly 3,228 people in West Berkshire (Office of National Statistics (ONS), 2022). This figure is higher in children, and approximately 8% or 1 in 12 young people will stammer at some point. In 2021, approximately 37,122 people in West Berkshire were aged between 0-19 years old, meaning that up to 2,970 young people in the county have or have had a stammer (ONS, 2022). There is currently no way of knowing which children will stammer for their whole lives and which will not. Likewise, there is no way of predicting who would benefit from speech and language therapy and what kind of support they may need.

What is the impact of stammering?

One of the biggest impacts of stammering on a person is the increased stigma that they face, even as children (Langevin et al, 2009; St Louis, 2015). Negative stereotyping about people who stammer is prevalent across society and it is often used as shorthand to indicate someone is less intelligent, anxious, dishonest, or even evil. These societal expectations often led to children and young people trying to avoid stammering at all costs, which may include swapping a word they expect to stammer on, reducing what they say to the absolute minimum or even avoiding certain situations completely.

Studies show that without support, children and young people who stammer are more likely to develop mental health difficulties such as anxiety and depression, especially in adolescence (Erickson & Block, 2013; Iverach et al, 2009). Many young people report feeling anxious about speaking because they are worried about negative responses from others (Blood et al., 2007; Klompas & Ross, 2004).

Even at a young age, children who stammer are more likely to be teased, ignored, or excluded from play by other children (Langevin et al, 2009). Teenagers who stammer are also more likely to be bullied or teased by other young people or experience social and romantic rejection (Erickson & Block, 2013; Van Borsel et al., 2011). While children who stammer are as intelligent as other children, they typically have a lower educational attainment than fluent speakers. (Blood & Blood, 2004; O'Brian et al, 2011). Negative

attitudes by employers and anxiety about potential stigma also means it can have an impact on employment prospects and promotional opportunities in adulthood (Gabel et al, 2004; Klein & Hood, 2004).

Without support, stammering can also have a significant impact on the families of a child who stammers. Parents of children who stammer report higher levels of emotional strain, financial constraints, family conflict and difficulties in managing their children's frustration (Erickson & Block, 2013; Blumgart & Tran, 2010; Millard & Davis, 2016).

How can Speech and Language Therapists support people who stammer?

Every child and young person who stammers is unique and studies have shown there is not necessarily a direct relationship between the frequency or severity of someone's stammer and the impact that it has on their daily life (Millard & Davis, 2016). This means it can be hard to predict which children and families will benefit from speech and language therapy, at what intensity and for long.

There are a range of evidence-based approaches for supporting young people who stammer. Early intervention at preschool age is known to be most effective through programs such as the Lidcombe Program, Palin Parent Child Interaction Therapy (PCI) and the Demands and Capacities Model (Brignell et al, 2021, Shafiei et al, 2018).

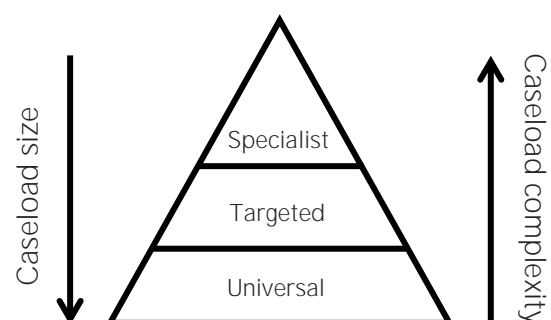
As children get older, support should be tailored to the needs of the child and may incorporate a range of different areas such as social communication skills, cognitive-emotional skills (e.g., building resilience) rather than just focusing on speech management strategies (Cook & Botterill, 2005). At this age, 'being fluent' is rarely the primary goal. A recent systematic review identified that as children get older, stammering therapy focuses less on eliminating stammering and more on supporting someone to manage and accept their stammer as part of who they are (Brignell et al, 2021).

What is a specialist stammering service?

SLT Service provision in Trusts across the UK often follows a tiered approach. Services are delivered at one of three levels, universal (useful to all people who stammer), targeted (needed for some people who stammer) and specialist (essential for specific young people who need more support).

As is the case in Berkshire, many trusts have specialist clinical services who provide support for more complex cases requiring specialist input. These services often include Hearing Impairment, Dysphagia, Alternative and Augmentative Communication (AAC), and Stammering.

These clinical areas typically have smaller caseloads but have a higher risk of long term physical or psychological impact if left unsupported. These caseloads also require a higher level of specialist intervention and staff may require additional post-graduate training in specialist approaches such as Solution Focused Brief Therapy or Cognitive Behavioural Therapy. Due to the uniquely fluctuating nature of stammering, not every child may require



specialist intervention for long periods of time (if at all). However, many benefit from this at specific points such as transitions between primary and secondary school.

Questions:

- What is the current pathway for children and young people who stammer within Berkshire? Is it based on current evidence? When was this last revised and have any concerns been identified by staff/clients about how this is being implemented?
- Based on the current model of service delivery, how many sessions are there for the specialist stammering service (including those currently vacant)? How many of these are vacant at present?
- How does the caseload of children who stammer compare to other specialist clinical pathways such as Hearing Impairment, AAC and Dysphagia? What is the size of these teams at present relative to the size of their caseload? How many children per session do staff on the stammering service currently hold and how does this compare with other specialist teams in Berkshire?

What are the benefits of a specialist stammering service?

“ I learnt many lessons, skills and strategies during Sam’s speech therapy sessions... I can honestly say that the support that Sam and I received in his early years paved the way for the very confident and outgoing boy we have today.”

Quote from a parent of a child who stammers about the specialist SLT support they received

A specialist stammering service provides trained, experienced SLTs with knowledge of a wide range of stammering therapies and techniques who can deliver tailored, effective, and evidence-based intervention for children and families at the intensity required. They are also able to provide training and support for generalist SLTs within an organization as required.

The *Every Child’s Chance of Fluency* Project (British Stammering Association, 2009) identified that while services who provided a ‘good’ or ‘outstanding’ level of support for children who stammer received more referrals, they were often referred at a younger age, and the time from referral to discharge decreased. SLTs (both generalists and specialists) within the trusts also reported feeling more confident to support children who stammer, and their opinion of their knowledge and competence in this area improved. By empowering all SLTs to work with children who stammer at a universal level, it reduced the number who required support from the specialist SLTs and lowered waiting times, meaning that the specialists could provide needed support for more complex cases.

NHS trusts rated as having a higher standard of service for children who stammer are those who employ specialist SLTs with the knowledge to advise and train other therapists, have the time to keep up to date with new evidence-based developments and can take the lead in developing treatment programs (Christie, 2000).

As is the case in Berkshire, in many NHS Trusts, generalist SLTs often have the expertise to offer universal and targeted support for children who stammer and their families. However, many generalist SLTs often report that they do not feel confident supporting children who stammer and that they do not have the time to be able to deliver specialist evidence-based practice at the recommended intensity (British Stammering Association, 2006). This means that without specialists who are confident supporting children and young people who stammer, these clients are likely to remain on waiting lists for longer periods of time. Generalist SLTs may also feel less confident providing intervention or discharging children or young people who stammer, meaning that they remain on caseloads for longer.

We asked therapists from the STAMMA SLT Peer Support Group about any potential risks of losing specialist stammering services. They told us:

- *“ Stammering cases are very different to generalist cases and often require a lot more direct input/time to have difficult conversations, manage expectations and deliver therapy which a generalist therapist may not always have. This is very different to the generalist caseload where you train others to deliver input. ”*
- *“ It will be more difficult for the wider team of therapists to achieve the level of knowledge needed to work with this client group, and the risk of causing harm by using an impairment-based approach is high. ”*
- *“ [Generalist] SLTs may not have a breadth of training to help them feel confident to deliver the most effective care nor will they be able to deliver the most effective care. Stammering therapy can be lengthy and they may not feel they have enough capacity to deliver the most effective care with their generalist caseload. ”*

It is known that without support children and young people who stammer have an increased risk of developing mental health difficulties such as anxiety and depression. The benefit of specialist services is that they can provide specialist interventions which also promote resilience and support their client's mental health. They are also able to liaise with other specialist teams such as CAMHS to develop a shared intervention plan if needed.

Over the past few years, the stammering community has undergone significant changes in the way that stammering is perceived and how intervention should be delivered. This shift from a medical model towards a more social model has led to changes in favoured terminology, intervention approaches and expectations of speech and language therapy. While some generalist SLTs may be aware of these widespread changes across the field of stammering, many are unlikely to have had time and capacity to engage with the rapidly changing evidence base. This means that without support, staff may unintentionally promote outdated and potentially harmful models of intervention.

Questions:

Without a specialist service or with a significantly reduced service:

- How would Berkshire Healthcare NHS Trust aim to support children who stammer who require long-term specialist input? If this was to be outsourced to specialist centres such as the Michael Palin Centre in London, how would this be funded by the Trust or Local Authority?
- How would staff have enough support or capacity to keep up to date with current research and evidence-based practice in the field of stammering?
- How would regular training be provided for generalist staff to ensure they could provide universal or targeted provision and how would this training be updated and reviewed in line with research evidence?
- How would specialist intervention for children and young people who stammer be delivered? How would the Trust ensure that care is equitable across the county and that staff providing this support are able to provide the intensity required?
- How would specialist staff access stammering specific clinical supervision internally?

The specialist stammering service in Berkshire

In 2019, Action for Stammering Children undertook a UK wide review of access to specialist services for children who stammer (Bernard, 2019). At this time, West Berkshire was given a rating of 1 (the highest level available), meaning that people have access to a specialist stammering service or centre available within the locality.

Berkshire Healthcare NHS Trust has commissioned a review of the stammering provision in the county. We are aware of the benefits of service reviews to ensure that provision for children and young people is equitable and based on the current evidence base. However, this review is being conducted while the team is significantly understaffed due to a very high level of vacancy. This means that information such as current caseloads and waiting lists may not reflect what the specialist service is capable of when it is working at full capacity. We hope that this is being taken into consideration and that the service review is looking at the service over the past 3-5 years to review how it can function when at full capacity and prior to the significant lockdowns and disruption caused by the impact of COVID-19.

While this service review is being undertaken, we believe that the specialist service has effectively been frozen, as when posts have become vacant these have not been advertised internally or externally to recruit new staff. While we appreciate that the Trust may be reluctant to recruit permanent staff to these posts while the service review is being undertaken, we question why bank staff or locums were not considered to fill these posts and maintain a consistency of the service. We are also aware that two previous members of staff offered to be flexible with their leave dates until the service review was complete to support this transition, but this was not taken up. We have concerns that depending on how long this service review takes, the specialist service will be in an unsustainable position due to current staff having to manage significant vacancies for extended periods of time.

At present there is a very limited specialist stammering service across both East and West Berkshire. This means that it is likely that the remaining specialists are unable to provide a good standard of care for those on their caseload due to having to balance large caseload sizes and long waiting lists. We would be interested to learn more about how this is having an impact on both staff and the children and young people who require specialist intervention for stammering, particularly complex cases such as adolescents who stammer.

Questions:

- What was the rationale behind the current service review? What did Berkshire Healthcare NHS Trust feel was not working well with their current service model that necessitated this review? Are other areas within the service also subject to similar reviews at present?
- What is the timeline for the service review for the stammering service and when are these changes expected to be implemented? What is the planned recruitment plan?
- While the service review is being undertaken, are there plans to use bank or locum staff to support the team and ensure consistency of care? If not, why not?
- At present the stammering service does not have a band 7 (Highly Specialist SLT) as the clinical lead for the service. Therefore, how are current staff within the stammering service accessing internal specialist clinical supervision in this field?
- Have there been changes over the past 12 months in the number of children who stammer who remain on the generalist caseload? Are children not being transferred to the specialist service due to concerns about the lack of specialist provision?
- How supported do generalist SLTs within Berkshire Healthcare NHS Trust feel in working with children and young people who stammer at present? Do staff feel confident supporting these children's needs?
- What managerial support does the stammering service receive at Band 8? Does the service have a specific service manager providing leadership, futureproofing of the service and engaging with the team to support service development? If not, why not?

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