Speech and Language Therapy An alliance with people who stammer in Ireland

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1.0 Acknowledgements

We acknowledge that this paper has been written on behalf of the Irish Association of Speech and Language Therapists (IASLT) by a working group drawn from members of the Special Interest Group in Stammering and comprised of Amy Connery, Callum Wells, Charlotte Mellon, Ciara Gleeson, Edel O'Dea, Fiona Ryan, Mary O'Dwyer and Penny Farrell. We also acknowledge the contribution that people who stammer have made to our understanding of our role as speech and language therapists in allyship, advocacy and in creating a culture of acceptance and celebration of the many diverse ways of communicating.

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2.0 Executive Summary

This document identifies the role of speech and language therapists (SLTs) in providing services for people who stammer across Ireland. Developmental stammering affects 4%-8% of children typically before 5 years of age, whereas prevalence in adulthood is generally accepted as 1% (Bloodstein & Bernstein Ratner, 2008; Yairi and Ambrose, 2013). Given current growing recognition of diversity and of the varied ways in which people communicate, it is timely to formulate a paper that sets out what is best practice for SLTs in Ireland who work with people who stammer. The evidence regarding factors that may lead to stammering are presented here. Variability is a hallmark of stammering and this variability, coupled with the fact that many children stop stammering as they age, can underpin the idea that stammering should be able to be controlled. A quest for the norm of fluency can be evident in many initial consultations with people who stammer and parents. The stigma which people who stammer can experience, coupled with practices of discrimination underpin the need for public awareness and education, and the importance of SLT's collaboration with the stammering community. This paper supports the rights of people who stammer to experience living without discrimination, without the expectation to conform to a norm of fluency, while also acknowledging their right to seek increased fluency as and how they wish to do so.

Definitions of stammering and its impact on people's lives are discussed in this document from a position which affirms and advocates for equality and positive valuing of neurodiversity. The role of SLTs as allies, their involvement with the stammering community, helping people who stammer to meet others who stammer and providing links to stammering groups such as the Irish Stammering Association (ISA) is discussed. An overview of the alliances and processes involved in speech and language therapy for people who stammer across the lifespan is presented. While these are not detailed clinical guidelines, future work should focus on setting clinical standards in Ireland. The position regarding the availability of SLT services for children and adults who stammer was surveyed in 2023 and the results are summarised in Appendix (ii) and also highlighted where appropriate throughout this document.

A number of recommendations are made to support the development of an equitable, quality SLT service for people who stammer which reflects best practice and is informed through consultation with service-users. A summary of these recommendations is presented below.

2.1 Recommendations

- The **creation of clinical specialist** posts in stammering is a key recommendation and forms the base for the implementation of all other recommendations.
- **Establishment of regional learning centres** (led by a specialist SLT) who provide training and consultation for SLTs in the region, and so develop knowledge and skills at a number of levels. Upskilling may range from basic knowledge for all SLTs, in order to reduce risk of harmful interventions, up to and including specialist skill for working directly with children and adults who stammer. Links with the university in their area would also be a significant step in ensuring that undergraduate students gain experience in working with children and adults who stammer.
- **Equal, adequate and timely access to evidence-based speech and language therapy** provision for children and adults who stammer is required to mitigate against the negative consequences of stammering. This will require setting a recommended standard regarding waiting times and best practice for assessment and intervention. The development of national clinical guidelines in the future will provide the framework for this access.
- The importance of **education and open discussion around stammering** is recognised as vital in the reduction of discrimination of people who stammer, and the stigma they may experience as a result. A campaign with key stakeholders including the Departments of Health and Education and supported by the IASLT is recommended, using all forms of media, to build and strengthen alliances between people who stammer and their communities.

- It is recommended that the Department of Education and Department of Children, Equity, Disability, Integration and Youth supported by IASLT and specialist SLTs **develop resources for teachers** working with people who stammer. Such resources would aim to increase teachers' knowledge around stammering and their understanding of the impact which their reactions may have on people who stammer. The intention would be to develop openness and encourage educators to talk directly to children, teens and adults who stammer about their preferences.
- SLTs can support people who stammer to access the Disability Access Route to Education (DARE), a third level alternative admissions scheme for school leavers with disabilities. The IASLT, SLTs and the ISA also have a role in **advocating for formal accommodations to be developed** at primary, secondary and third level in order to maximise access, participation and success for people who stammer in education. These will include accommodations related to oral exams, reading aloud, doing presentations in front of large audiences, and further developing supports available through the Reasonable Accommodations at State Examinations (RACE).
- **Increased funding and collaborative opportunities for research** activities specific to stammering is essential to ensure the delivery of person-centred and evidence-based services in the Irish healthcare system. In addition, opportunities, time and resourcing for SLTs to complete research activities in their workplace and to collaborate with academic researchers needs to be prioritised. This will ensure that the research completed has contextual relevance to their healthcare setting and the people who stammer with whom they work.

3.0 Introduction

While the terms “stammering” and “stuttering” can be used interchangeably, stammering will be used in this paper. Further definition is presented in the next section. Attempts to modify or eliminate stammering date back to ancient times when the Greek orator, Demosthenes, is reputed to have put pebbles in his mouth while speaking. Therapies have included hypnosis, speaking in altered ways (such as slowing rate, voicing all sounds, speaking with a particular rhythm) hypnosis, psychotherapeutic, pharmacological and speaking while the feedback (hearing oneself speak) has been altered in some way. However, alongside the search for fluency or for a “cure”, there has also been an acceptance of stammering as a particular way of speaking that did not need curing but simply needed time. *Dligid édteanga aimsir*, which translates from Irish as “wordlessness is entitled to time”, refers to a Brehon law which stated that people who communicated in ways different to the norm e.g. stammering, were entitled to more time in a court of law (Leahy, 2005). Such appreciation of the need to accommodate a stammer provides a basis for equal opportunity. Communication involves turn-taking between speakers which usually takes place without delay, and any disruption to this flow can be met with surprise and scrutiny by the communication partner/s who are experiencing the disruption, but not causing the delay. It has long been acknowledged that it takes two to stammer. For example, Yairi and Ambrose (2005) in describing classifications of stammering types consider that a behaviour/audible sound may be experienced and described as stammering by one listener and yet may not be experienced or described as such by another. St. Pierre (2012) considers how it takes two to stammer from the point of view that reactions to stammering (individual, social and cultural) can be hostile or affirming.

3.1 Social Model

SLTs have an ethical responsibility to be guided by current research which advocates for a stammering-affirming approach that seeks to support people who stammer to be open and confident about their stammering (Boyle, Milewski & Beita-Ell, 2019; Byrd et al. 2021; Connery, McCurtin & Robinson, 2020; Constantino, 2023; Tichenor, Herring & Yaruss, 2022; O'Dwyer, Walsh & Leahy, 2018 inter alia) . It should also be acknowledged that there is a potential to do harm when SLTs work with people who stammer. The literature has documented the sense of failure and guilt which many people who stammer experienced when their therapy focused on the acquisition of fluency and they were unable to achieve it (Sheehan, 1970). There is also a potential to do harm by not providing early intervention which supports people in a child's environment to respond to stammering in affirming ways.

3.2 Disability or not

Within the Irish healthcare system, stammering is classified as a physical and sensory disability. Most children and adults who stammer who seek therapy are seen within the primary care service. Some may receive therapy through disability or mental health services if they are involved with those services for other reasons. Some with adult-onset stammering may be seen by SLTs working within acute services. DARE is a third level alternative admissions scheme for school leavers whose disability has had a negative impact on their second level education. As stammering is a recognised disability in Ireland and where stammering has impacted on the person's education, it is possible for them to access this scheme. However, not all people who stammer identify with having a disability and some students consciously choose not to use this scheme. Others may be happy to do so and receive supports regarding access from the scheme and from the disability office at the third level. This points to the importance of remembering that each individual's experience of stammering is unique to them. Further information regarding the DARE scheme may be found at https://accesscollege.ie/.

This paper presents an understanding of stammering in line with a social model of health and in line with diversity-affirming approaches to therapy. There is a focus on the wider society outside of the clinic room and how educating people across many areas (parents, teachers, employers and the public in general) can help lessen the stigma and discrimination experienced by people who stammer. There is also a focus on the importance of openness, understanding and a willingness to celebrate difference as key components in therapy which aims to aid people who stammer to live well.

It is recognised that this paper has been written by professionals working in the field and with consultation with the ISA. It is envisaged that future work based on this paper would be carried out in partnership with people who stammer and their families and that their involvement is central to speech and language therapy planning and redesign.

4.0 Purpose and Intention

IASLT's mission is to support and empower SLTs through setting standards, informing policy and service delivery, fostering excellence in professional practice, supporting advancement of the evidence base and advocating for members and those they serve. This position paper was developed to support the delivery of this mission in relation to SLTs and people who stammer. A main objective is to provide clear policy on how to achieve inclusive and relevant SLT services for this group. This paper also provides guidance to SLTs and SLT managers regarding current research and their role within a social model of therapy which is stammer-affirming. It is also envisaged that it will be a resource for other groups interested in working with people who stammer in the reduction of stigma and discrimination.

4.1 Allies and advocates

The process of preparing this paper highlighted the commitment, energy and enthusiasm of SLTs to be allies and advocates for people who stammer. There is an awareness of the core role SLTs have in deconstructing “taken for granted” ideas and beliefs in society, including teachers and employers so that full participation by people who stammer is enabled. This paper provides guidance on workforce development and service models to support and promote the development of full participation across all domains of living (school, work, social situations, family) for people who stammer.

4.2 Opportunity for Equity

There is a significant lack of equity within Ireland for both children and adults who stammer and the service available in different areas. For example, according to results of a survey of the SLT Managers group, conducted in 2023 to inform this paper, 57% of children wait less than 4 months to be seen for assessment while 17% wait over 2 years. Not all areas in the country provide SLT services for adults who stammer, and across those that do, there is significant variation in waiting times. Group therapy for adults and children is inconsistently offered across services, with only 31% of respondents reporting that they provide this service.

There is an opportunity at this time to develop services for children and adults who stammer which are consistent across the country. This service should be grounded in an understanding of stammering as a way of speaking which is not pathologised. SLTs support understanding of stammering by providing education around stammering for children, their parents and families, teachers, adults, employers and society as a whole. In this way, the dominant narrative in Irish society, health services, schools and workplaces will become one that is better informed and supportive of people who stammer. This also involves continuing to develop links with the stammering community. As a result, stigmatising practices experienced and reported by people who stammer would be reduced, and participation in all aspects of living supported and facilitated for people who stammer. This is in line with the Health Information and Quality Authority (HIQA) guidance on a human-rights based approach to health and social care (2019). The vision of Sláintecare aims to deliver one universal health service for all, providing the right care, in the right place, at the right time (Sláintecare report, 2017). The goal of the Health Regions is to provide person-centred health and social care services that are informed by the needs of the people and communities in each region. It is clear that HSE services should endeavour to provide person-centred, high quality speech and language therapy at the appropriate time and place for people who stammer.

5.0 Defining Stammering

The literature highlights the diverse range of definitions of stammering available, with no consensus between stakeholders on the most accurate and representative one. There is, however, agreement that stammering is a highly complex and multidimensional condition resulting in a significant impact on an individual's life (Packman & Kuhn, 2009; Ward, 2018). In Appendix (i), Table 1 *"Sample of historical and more recent stammering definitions proposed in literature",* provides a detailed sample of how stammering has been defined from the 1960s, where the focus was on stammering as a learned behaviour, to more recent times where definitions reflect the complex embodied experiences of people who stammer.

5.1 Multi-factorial: Overt and Covert

A wide range of definitions of stammering have been proposed by multiple stakeholders including researchers, clinicians and individuals who stammer. Some definitions focus primarily on the overt speech characteristics of stammering, including part-word repetitions, prolongations and blocks (Yairi et al. 2001). Such definitions describe only that which can be observed in a given moment. Other definitions present a more holistic view of stammering and include features beyond the observable speech behaviours such as affective, behavioural and cognitive reactions (Yaruss & Quesal 2004). In doing so, they acknowledge that a number of strategies to avoid or conceal moments of stammering are integral to a definition of stammering (e.g. avoiding words and situations, manipulating speech (e.g. substituting words), and remaining silent) (Van Riper, 1973; Manning, 2010; Butler, 2013). Some people who stammer, are so adept at concealing or avoiding the overt features of their stammering that listeners are unlikely to identify them as people who stammer. Their stammering can be referred to as covert or interiorised stammering (Douglass et al., 2019; Cheasman & Everard, 2013).They are able to pass as fluent speakers. These people who stammer demonstrate that stammering is something that is experienced and felt and that stammering may not always be observed and heard by listeners (Perkins, 1984, Constantino, Manning and Nordstrom (2017). Some people who covertly stammer have reported not fully understanding the nature of their stammer prior to seeking support. (Douglass et al.,

2019) and others have not identified as people who stammer at all. Ed Balls, former Shadow Chancellor of the Exchequer in the UK, reported he only realised aged 41 years that what he was experiencing was covert stammering (Balls, 2016).

5.2 Genetics and Neurology

Following advancements in neuroimaging, the neurophysiological underpinnings of stammering have been integrated into definitions (e.g. Smith & Weber 2017). Our understanding of the origins of stammering has evolved significantly in the last 20 years, mostly due to advancements that have been made in genetics and neuroimaging techniques. There is now a significant amount of evidence that suggests that genetic factors play a role, and studies have demonstrated that stammering clusters in families (Yairi & Ambrose, 2013). Importantly, the research suggests that genetic factors alone cannot explain all cases of stammering, and environmental factors are also necessary for stammering to occur (Rautakoski, et al. 2012). In addition, differences have been found in both the structure (anatomy) and functioning (physiology) of brains of those who stammer when compared to non-stammering individuals. Specifically, the structure and function of left hemisphere areas that are responsible for speech motor planning and production (e.g., the left premotor and motor areas) have been identified as playing a role in stammering (Chesters et al. 2018; Garnett et al. 2018). In addition, differences in connectivity between brain regions such as the auditory and speech motor areas of the brain have been identified (Chow & Chang 2017; Smith & Weber 2017; Neef et al. 2022). It is important to note that research in this area is ongoing, and it is likely that we will have an improved understanding of the neurophysiological underpinnings of stammering with further advances in technology and genetics.

5.3 Neurodiversity

In recent times, the social model of disability has shaped definitions of stammering in acknowledging the disabling nature of an individual’s environment and wider society e.g. ableist stereotypes, biases and stigma. In addition, the neurodiversity movement seeks to promote the understanding of variation in structure, development and function as natural variations. In the literature, neurodiversity is a deliberate attempt to shift the discussion of disabilities away from talk about normal and abnormal, or able-bodied and disabled, to neurotypical and neurodivergent, thus highlighting the unique skills that come with different neurological ways of being (Constantino 2018). Such definitions and views of stammering highlight that stammered speech is a 'variation' rather than an impairment. By refocusing on natural variation and the unique skills, experiences, and traits of neurodivergent individuals, the emphasis is removed from pathology and impairment. With this move away from pathologising stammering, there is increased emphasis on the SLT profession adopting the client's terminology when they express a preference e.g. person who stammers vs. stammerer. For this position paper, the term person who stammers is used.

5.4 Developmental and adult-onset stammering

The onset of stammering for 95% of children occurs by age 4, with only 5% of children beginning to stammer beyond this age (Yairi & Ambrose 2005). It is rare for stammering to commence after the early childhood years. There is a paucity of research literature on this type of stammering and the majority of this research consists of specific case studies. Adult-onset stammering is characterised by sudden onset in adulthood, and includes neurogenic stammering (e.g. onset as a result of stroke, head trauma or drug usage) and adult-onset psychogenic stammering and functional neurological disorder. (e.g. triggered by prolonged stress or emotional trauma) (Manning & DiLollo 2018).

5.5 Cluttering

This paper confines itself to discussing stammering. Related to stammering and considered in conjunction with stammering, is cluttering. Cluttering is universally conceptualised as a multidimensional fluency disorder. Persons who clutter have a high frequency of normal disfluencies (e.g. revisions, interjections, phrase and syllable repetitions) and a low frequency of disfluencies typical for stammering. A higher than average frequency of disfluencies, dissimilar to those seen in stammering is considered to be a characteristic of cluttering. People may have both cluttering and stammering.

5.6 Definition of stammering used in this paper

Although most definitions have been guided by the observations and perceptions of listeners, a recent study developed a definition based on the perspectives of adults who stammer (Tichenor & Yaurss 2019). This definition, generated by data from 430 adults who stammer, describes stammering as a collection of behaviours and experiences that are presented in an adaptation of the World Health Organization's International Classification of Functioning, Disability and Health (WHO 2013). These include an initial loss of control or sensation of being stuck, an individual's personal reactions to this sensation (affective, behavioural and cognitive reactions), real-world limitations in life participation and environmental factors influencing the individual's communication. This is the definition adopted in this paper.

6.0 Impact of stammering

Communication plays an essential role in most aspects of an individual's life, including asserting one's needs, building relationships and sharing thoughts, ideas and emotions. Therefore, a condition such as stammering has the potential to have significant implications for one's life experiences. The negative influence which stammering has on an individual's life has been documented in the literature, with wide ranging impacts beyond the expected communication challenges (Connery et al. 2020). These include mental health difficulties (Craig et al. 2009, Iverach et al. 2009, Craig & Tran, 2014), occupational disadvantages such as reduced likelihood of being promoted and reduced earnings in the labour market (Klein & Hood, 2004, Gerlach et al. 2018), and compromised quality of life (Craig et al. 2009, Koedoot et al. 2011). Children who stammer as young as preschool age show an awareness of stammering and more negative speech-associated attitudes than children who do not stammer (Vanryckeghem and Brutten, 2007). There is also evidence of possible negative peer reactions to stammering (Langevin et al, 2009).

Conversely, some studies, although a minority, have reported less negative consequences of stammering for adults. For example, Brundage et al. (2017) found no significant difference between adults who stammer (n=50) and those who do not stammer (n=45) in their interpretation of threat associated with social and non-social situations. Additionally, a study by Boyle et al. (2019) involving data from 322 adults who stammer, outlined the benefits associated with stammering including increased sensitivity to others and stronger interpersonal relationships. Further, the benefits of stammering openly has been highlighted as it reveals an individual's vulnerability and thus positively impacts the development of intimate relationships with others (Constantino, 2019).

The impact of stammering is complex and influenced by many processes both internal and external to the person who stammers. The following diagram (Figure 1: *An Iceberg Continuum*) seeks to capture this complexity. Different levels are presented and the connections and interactivity between the different levels are highlighted, with examples of features outlined in Figure 2: *Examples related to parts of Iceberg Continuum.* The experience of stammering is personal to each individual and a dynamic process. The metaphor of an iceberg is used to demonstrate the overt and covert aspects of stammering. The iceberg is surrounded by the ocean and the sky above. What is in the water is hugely significant in terms of the impact of stammering on both the individuals who stammer and the rest of society. The idea of a continuum is used to highlight that experiences are always changing. Society can see stammering as a problem or as a valuable way of communicating that offers unique opportunities and experiences to celebrate difference and to be enriched by that difference. People who stammer can choose to be open and show their stammering more in some situations than others and that can change from one day to the next. The sky represents possibilities for all, including SLTs, to support children and adults who stammer to have the value of stammering verified and supported and so affirm who they are without the need to try and change.

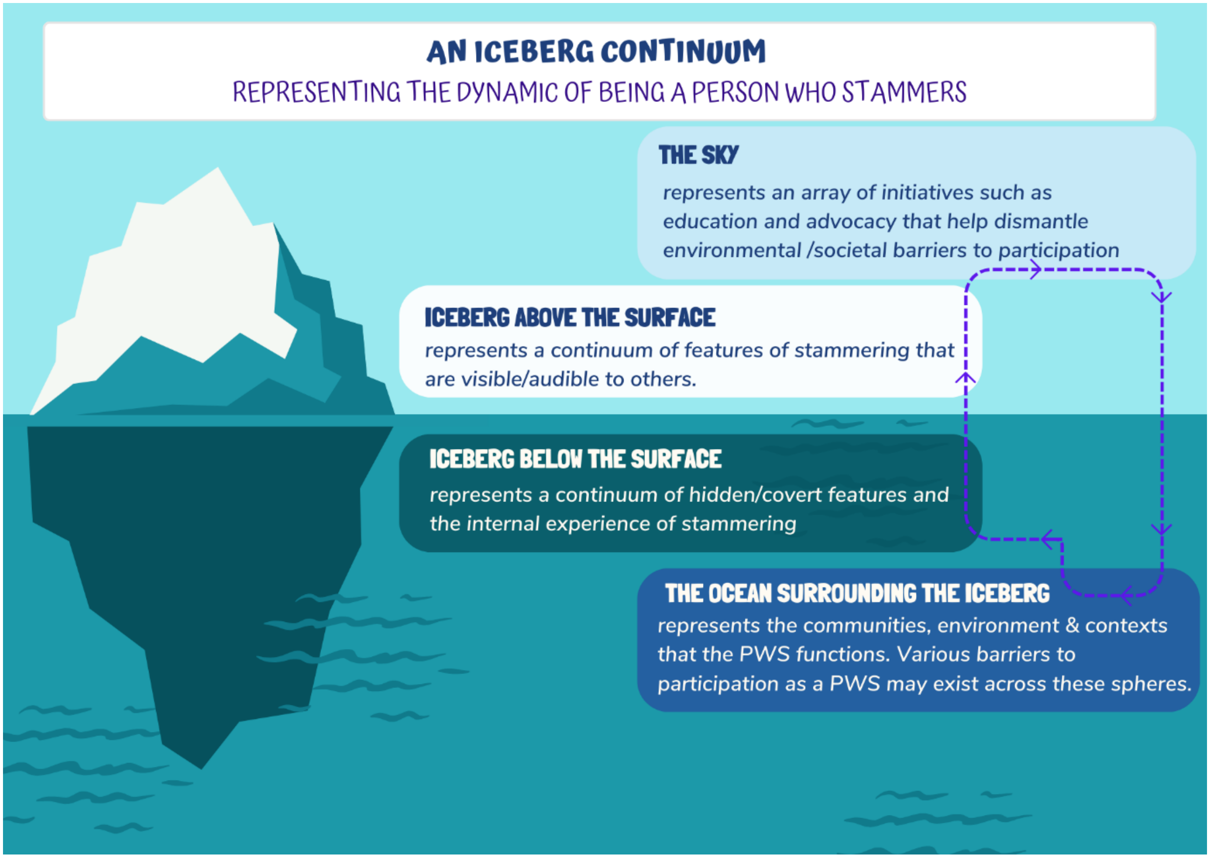

Figure 1: An Iceberg Continuum

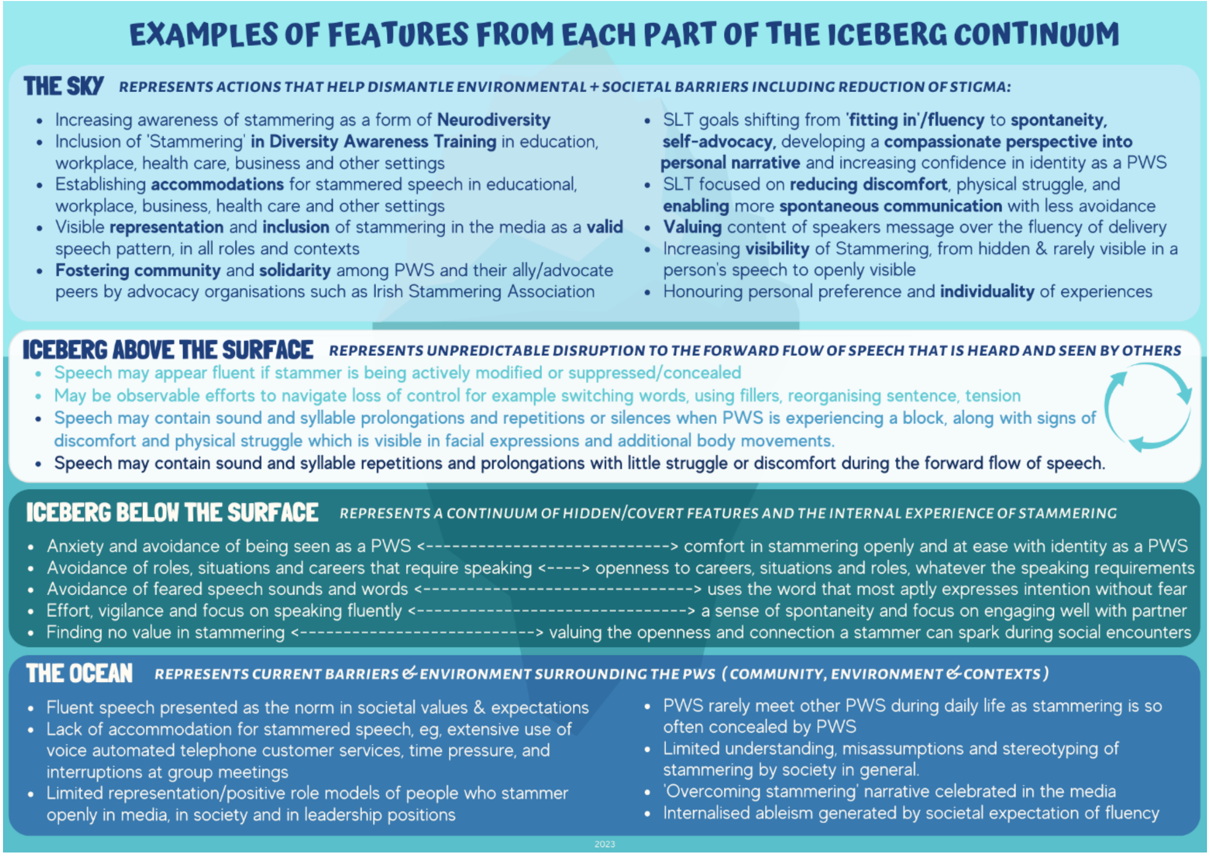

Figure 2: Examples related to parts of Iceberg continuum

7.0 The Role of Speech and Language Therapy

There are a number of areas in which SLTs can influence the experience of stammering for all involved, as they stand in the position of holding the tension between different viewpoints. For example, SLTs manage the expectations of parents who wish to focus on fluency, solely with the knowledge that the literature documents the view of many people who stammer who found this type of approach induced harm and feelings of failure and shame. SLTs can provide an informed, evidence-based service that supports people who stammer through advocacy and allyship. Blood et al. (2001) discuss the stigma felt by people who stammer across all areas of living. Boyle (2013), Blood and Boyle (2015), St. Louis (2015) and Boyle, Dioguardi and Pate (2016) have all focused on aspects of stigma and self–stigma. This is learned behaviour based on experiences of public stigma as children. Boyle's (2013, 2018) writings on stigma, self-stigma and strategies to reduce stigma signpost the role for SLTs to reduce stigma in a number of ways. A study (St. Louis et al., 2015) which explored public attitudes to stammering in different countries in

Europe found that attitudes in Ireland were more positive than other countries, for example, Italy but not as positive as some Scandinavian countries.

7.1 SLT-Client relationship

SLTs need to be aware of the importance of the therapeutic alliance in stammering therapy. The term therapeutic alliance refers to the evolving interactional and relational processes co-constructed between the client and therapist during therapy (Connery et al., 2022). The alliance and the mutual agreement of tasks and goals might be among the most critical elements for successful therapy (Sønsterud et al., 2019). They found that clinician characteristics are important too, and that SLTs who are more responsive to their clients' individual characteristics, facilitate positive outcomes. Connery et al. (2022) noted conceptualisations of the therapeutic alliance have primarily evolved from the discipline of psychotherapy and posited that there are differences in the experiences of the therapeutic alliance between different communication disorders. In light of these differences, it was recommended to gather client-based evidence to explore the therapeutic alliance in stammering.

7.2 Advocacy

The SLT has a role in preventing negativity around communication, promoting confidence, and openness around stammering. In therapy, the overt and covert elements of stammering are frequently explored using the Sheehan's (1970) metaphor of the iceberg. Campbell (2019) has reconstructed the classic stammering iceberg (see Figure 3: Iceberg) to incorporate features of public stigma into the sea surrounding the below-surface level of the iceberg.

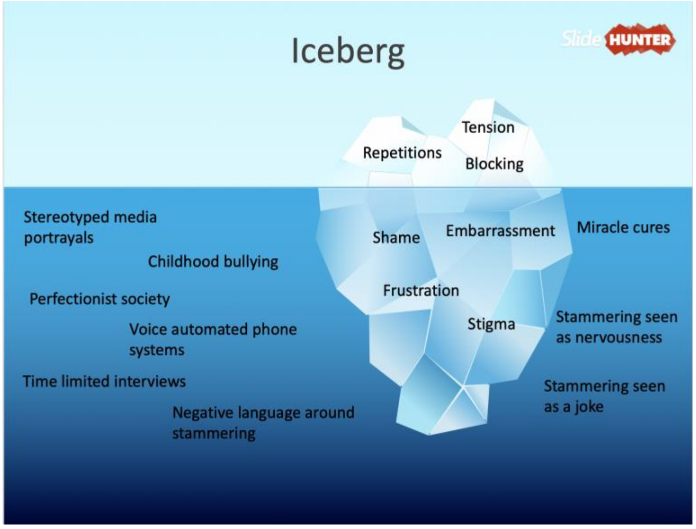

Figure 3: Iceberg, Campbell (2019)
https://www.redefiningstammering.co.uk/re-imagining-adult-stammering-therapy/

Concealment of overt stammering behaviours may be particularly prevalent in children and young people due to developmental pressures to “fit in” socially. Research with adults who stammer suggests that the effort associated with concealment has negative associations with mental health and quality of life (Gerlach et al, 2021). Thus, it is important for SLTs to promote and support openness and self-disclosure of stammering to prevent the long term negative impact that concealment may have.

Constantino et al. (2022) highlighted that while the experience of stammering is personal and varied, people who stammer understand their experience against the backdrop of society’s perception of stammering. Society’s understanding of stammering is almost entirely negative (Constantino et al, 2022). People who stammer may be stereotyped as nervous, shy, incompetent, and unintelligent (Doody et al, 1993; Ferguson et al, 2019). Constantino et al. (2022) further explain that these stereotypes are damaging regardless of whether the person who stammers believes them to be true. They might know that they are not anxious/nervous/unintelligent but will still not want others to perceive them that way.

While an individual may or may not choose to conceal their stammering identity to avoid experiencing stigma or discrimination in specific contexts, they may have one or more additional non-normative aspects to their identity, which also causes them to feel vulnerable and which they may choose to conceal in other specific contexts.

'Intersectionality' is a helpful model for exploring how a person's stammering identity may interact with other overlapping aspects of their identity (Daniels 2020). The term 'Intersectionality' was used originally by legal expert, Kimberle Williams Crenshaw in 1989 when highlighting the discrimination experienced by black women and how the experience of being both black and female compounds their experience of oppression. Likewise, a person's stammering identity overlaps and interacts with other aspects of their identity including their socio-economic, professional, gender and other identities in neutral, positive and negative ways.

The stress and anxiety triggered by the possibility of planned or unplanned disclosure can shift from one minority aspect of identity to another, depending on the specific social context an individual finds themselves in. A person who stammers may experience ongoing stress as they juggle several stigmatised minority identities across several realms of their life while rarely being free to be fully authentic. This experience is recounted by Daniels in 'A Life of Contradictions: What I've Learned About Resilience from Living with Multiple Marginalized Identities' (Daniels, 2020).

SLTs play a vital role in educating society to eliminate this stigma. Universal health approaches have been adopted in health services in line with advancements and research indicating the value of a population health based approach. Many SLT services offer advice clinics for parents, and education sessions for teachers in order to create an accepting environment for children who stammer.

7.3 Creating Community

SLTs should support those who stammer through allyship and creating a community. The research presented in this paper highlights the importance of a community presence which can be very empowering and supportive. People who share stigmatised identities can provide unique and important types of support to one another based on their shared experiences.

HSE, other publicly funded and independent SLT services can provide forums within their services to connect children and adults who stammer, and signpost them to additional organisations where they may connect with others. For example, SLTs and people who stammer may access the Irish Stammering Association (ISA). This is a nationally recognised charitable organisation, providing information and support to people who stammer in Ireland. The ISA promotes the understanding and value of stammering in society and fosters a spirit of mutual respect and understanding. There is value and importance in SLTs connecting with the stammering community through ISA. SLTs can learn about experiences directly from people who stammer and can introduce their clients to the broader stammering community through the services that ISA offers.

For up-to-date information about the ISA, its range of services, supports and events for people who stammer and their community, visit www.stammeringireland.ie.

7.4 Promoting Positive Mental Health

SLT practice promotes positive mental health at the levels of person, environment and wider community (IASLT, 2015). Gerlach et al. (2021) compared neurotypically "fluent" speakers with adults who stammer. The results indicated that variability in psychological health outcomes among adults who stammer is not entirely idiosyncratic. Stigma-identity related thoughts and behaviours are reliable predictors of distress and the adverse impact of stammering on quality of life among adults who stammer. Gunn et al. (2014) evaluated psychological functioning amongst adolescents seeking speech therapy for stammering. They found older adolescents (15–17 years) reported significantly higher anxiety, depression, reactions to stammering, and emotional/behavioural problems, than younger adolescents (12–14 years), although their scores on psychological measures fell within the normal range. There was no evidence that self-reported stammering severity is correlated with mental health issues. Briley et al. (2021) investigated young adults regarding the relationship between depressive symptoms and suicidal ideation and living with stammering. Compared to their fluent counterparts, males and females reported significantly elevated symptoms of depression. Although symptoms of depression among males who stammer were stable over time, depressive symptoms among females who stammer increased with age. Compared to males who do not stammer, males who stammer were significantly more likely to report feelings of suicidal ideation. There were no differences in suicidal ideation between females who do and do not stammer. SLTs should be aware of the associations between stammering and depressive symptoms, as well as the increased risk for suicidal ideation among males who stammer. SLTs should be familiar with onward referral processes where there is a comorbid mental health concern. SLTs can refer clients (children, teens and adults) to HSE Primary Care psychology service or recommend community mental health services as appropriate. SLTs can consult with HSE Primary Care psychology or the person's GP to determine which referral route is appropriate.

7.5 Education of teachers and employers

Research has found a lack of knowledge and negative attitudes of teachers towards children who stammer (Panico et al, 2018). SLTs play a role in making the school environment more supportive for children who stammer. Implicit and explicit ableist messaging can contribute to children's likelihood to conceal stammering (Gerlach-Houck et al, 2023). Teachers are key stakeholders for impacting the trajectory of a child's attitudes about their stammering by creating a safe and understanding school environment. For teachers to have this positive influence, it is important that they have accurate knowledge about stammering and skills in how to support a child who stammers. Teacher's focus should be on changing the environment around the child rather than changing the stammer itself.

Similarly, SLT intervention to support adults to live well with stammering, will have its best outcome in tandem with wider societal advocacy, which promotes understanding of stammering and allyship, especially among those in pivotal roles such as educators, employers and colleagues.

Diversity and inclusion is increasingly prioritised by contemporary employers and organisations, with a growing corporate awareness of the responsibility to identify and remove barriers, and to accommodate individuals who stammer to participate freely at all stages of their engagement with an organisation, from recruitment onwards. Creating stammering-friendly workplace cultures has an exponential impact on the well-being and thriving of employees who stammer.

SLTs can support corporate advocacy and education by informing Diversity, Equality and Inclusion policies. SLTs have a role in understanding the value of workplace support, and to signpost such supports to provide holistic support that empowers clients across all domains of daily life. Organisations such as 50 Million Voices, who educate with their global mission *'Transforming the world of work for people who stutter'*, and the ISA are useful resources to people who stammer and their communities . The ISA liaise with organisations and employers, including 50 Million Voices and Special Isterne, providing employment and interview support for people who stammer and their employers.

For up-to-date information about 50 Million Voices and Special Isterne visit https://www.50millionvoices.org/ https://www.specialisterne.ie/

8.0 Therapy across the lifespan

When considering intervention approaches, It is important to first of all consult with the person who stammers and their family, where appropriate, to gain information on what they want, on how ready they are for change, on what would be meaningful change for them. For example, they may not wish to access direct therapy but welcome support with advocacy at school or work. Manning (1999) detailed how change happens under the surface and over time. As such, SLTs need to consider service delivery, see Linklater (2020), as traditional 6 week episodes of care may not be most optimal. Furthermore regarding service delivery, SLTs should consider the possibility of providing group therapy as some people who stammer and in particular, as noted by Hearne et al., (2008), adolescents, may function best in group therapy. Group readiness needs to be discussed with the client first, as groups can be challenging in terms of negative/positive identity claims associated with groups and concealment. SLTs will also need to identify and address concealment, as Gerlach et al. (2021) report that level of concealment is more indicative of negative outcomes than severity of stammering.

Taking the above into account, and in consideration of best practice research and evidence, therapy approaches will be selected in conjunction with the person who stammers and their family. Therapy approaches used in stammering therapy can be broadly divided into three categories.

- Speak More Fluently:

  The "speak-more-fluently" approach focuses on fluency-shaping and speech re-structuring. This therapeutic approach focuses on techniques and strategies aimed at increasing fluency in speech for people who stammer. Techniques including fluency-shaping strategies such as easy onsets, constant phonation, light articulatory contacts etc are taught to elicit smoother speech patterns. The emphasis is on reducing the frequency and severity of stammering moments. Many adults who stammer reflected that as children, they "learned" to conceal stammering when the focus of speech therapy was solely fluency-shaping techniques, leading to reduced quality of life (Gerlach-Houck et al, 2023).

- Stammer More Fluently:

  This therapeutic approach emphasises acceptance and self-compassion, encouraging individuals to embrace their stammering and communicate authentically. It focuses on reducing avoidance of stammering and negative attitudes as well as modifying moments of stammering (Van Riper, 1973). Rather than solely focusing on fluency, the goal is to develop more comfortable speech and build confidence as a communicator. Techniques such as voluntary stammering, bouncing, and prolongations are employed to encourage individuals to stammer more freely and with less struggle. As well as focus on reducing avoidance behaviours (Sheehan, 1970) associated with stammering, this approach also fosters increased self-acceptance and well-being with a reduction of any negative impact resulting from avoiding or concealing stammering.

- Stammer More Proudly:

  This therapeutic philosophy emphasises embracing stammering as an integral part of one's identity and promoting a positive self-image. It encourages individuals who stammer to develop a sense of pride, self-advocacy, and empowerment regarding their communication style. The focus is on challenging societal stigmas, dispelling misconceptions about stammering, and fostering a supportive community. Simpson (2021), discusses how we are currently in an exciting time for stammering therapy in which the social model of disability and neurodiversity offer the frameworks for a new wave of therapy. Simpson (2021) explains that this approach aims to cultivate "cultural competence, stammering gain, allyship and stammer-friendly environments". Within this approach the person's ability to speak spontaneously (regardless of whether they are stammering or not) is emphasised (Constantino, Eichorn, Buder, Beck & Manning, 2020).

8.1 Speech and Language Therapy for Children who Stammer

8.1.1 Assessment

The 2023 survey completed to inform this paper showed inequitable services for children who stammer with some children accessing assessment within 16 weeks while children in other areas of the country wait over 2 years for assessment (see appendix ii). This highlights inequity in access to early assessment and intervention for children, conflicting with the recommendation that early intervention for preschool children should be shortly after onset where there are signs of social distress or avoidance (Onslow and O'Brian, 2013).

Assessment should be holistic and account for the fact that genetic and neurological factors underlie the cause of stammering whilst language and speech motor factors, environmental factors, and personal factors influence its onset, development, severity, and impact over time. In order to ensure a comprehensive assessment the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) can be applied, see Figure 4:

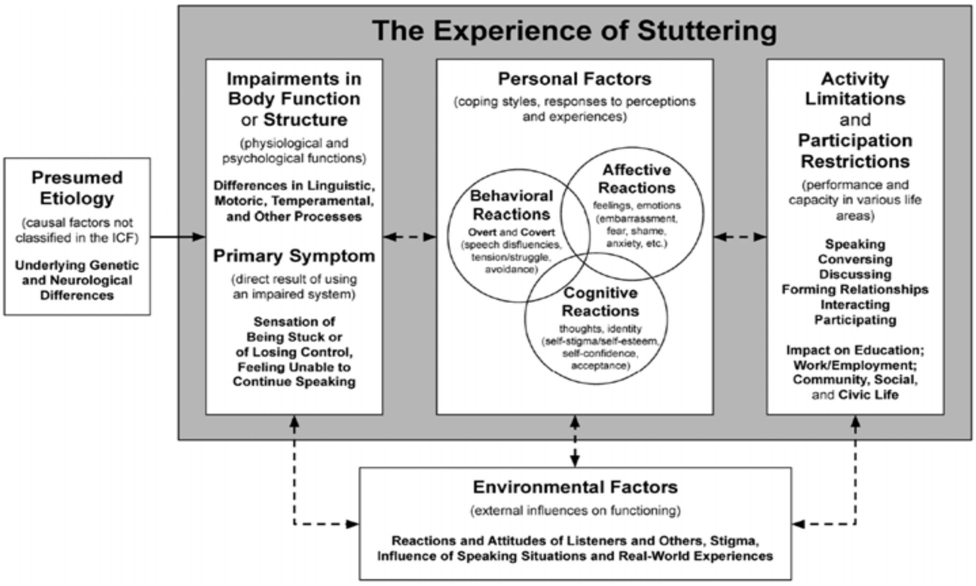

Figure 4: Update of Yaruss and Quesal's (2004) representation of how the World Health Organization's International Classification of Functioning and Health (ICF) can be applied to stammering. Copyright: © 2019 Seth E. Tichenor and J. Scott Yaruss.

The goals of assessment of stammering in children are to:

- Identify presence of stammering and differential diagnosis
- Explore nature and impact of stammering on the child
- Identify and agree desired outcomes for the child and their family

Use of solution focused discussion will support the child and family to describe the stammer, its impact and their desired outcomes. Communication skills are assessed through use of standardised assessment tools, attitudinal rating scales, stakeholder reports and clinical observation. A thorough assessment will explore the impact of all the factors outlined in the ICF, i.e.:

1. Impairments in Body Function or Structure
2. Environmental factors
3. Activity Limitations and Participation Restrictions
4. Personal Factors

It is crucial to educate parents on the origin and nature of stammering during this initial contact. The SLT also has a role in helping the child to understand their stammer and their self-identity in the context of stammering. This education and desensitisation begins during the assessment process, and continues throughout their involvement in SLT services.

8.1.2 Differential Diagnosis

Differential diagnosis is an ongoing process that will likely not be clear-cut following initial assessment. Consideration of the factors outlined in the ICF are considered (Tichenor & Yaruss, 2019) in order to differentiate between:

- "Normal non-fluencies" vs stammering-like disfluencies (SLDs).
- Stammering vs language related difficulties, e.g. Developmental Language Disorder, word finding difficulties or reading disorders.
- Stammering vs Childhood Apraxia of Speech or speech sound disorders.
- Stammering vs Normal nonfluencies associated with bilingualism
- Stammering and co-occurring cluttering

8.1.3 Therapy

Therapy approaches for children aged 7 years and younger include the following:

- Indirect Approaches e.g. Palin Parent-Child Interaction (PCI; Kelman & Nicholas, 2008) and RESTART-DCM (de Sonneville-Koedoot et al, 2015).
- Direct Approaches e.g. Lidcombe Program (Onslow et al, 2003), Mini KIDS (Waelkens, 2018), and CARE (Byrd, 2023)

Therapy approaches for school-aged children include the following:

- Avoidance Reduction Therapy for Stuttering - ARTS (Sheehan & Sisskin, 2001)
- Stuttering Modification Therapy (Guitar, 2014; Van Riper, 1973) and encouraging spontaneity (Constantino, 2020)
- Blank Centre CARE Model (Byrd, 2023)

When deciding on a therapy approach for early childhood stammering the following are some key considerations:

- For preschool aged children, implementation of indirect intervention prior to any direct intervention is recommended (Kelman & Nicholas, 2008, Yaruss et al, 2006).
- Studies comparing direct versus indirect therapy for preschool children (The RESTART Randomised Trial; de Sonneville-Koedoot et al 2015; Franken et al, 2005) found that both therapy approaches reduced stammering with no difference in outcome. The direct and indirect approaches are based on different assumptions regarding mechanisms underlying outcome (delivering verbal contingencies for the direct Lidcombe approach versus balancing demands and capacities for RESTART-DCM). However, common components of the two approaches include an increase in one-on-one time that parents spend with their child and emotional support for parents. It has been questioned whether removing the operant treatment element of the Lidcombe approach (verbal contingencies) is necessary and whether it's actually the quality time between parent and child in a calm environment that is making the difference.
- Byrd et al (2021) advocates that children should be empowered to be confident communicators and should receive explicit training in communication competencies and self-disclosure skills in order to empower them to communicate confidently regardless of the presence of stammering.
- SLTs have a role in explaining to parents that direct approaches which focus on fluent speaking may, by promoting fluency, lead to concealment of stammering. Research has found that efforts to conceal stammering are associated with reduced quality of life and increased psychological distress among adults (Gerlach-Houck et al, 2021).
- Considering the therapy approach options in consultation with families is a key component in collaborating with children and their families as they learn about stammering from a number of viewpoints. Lambert's (2013) factors for successful outcomes highlights the importance of therapeutic relationship and hope/expectancy from therapy.

Choosing a particular approach based on a sound rationale and being able to problem solve when difficulties are encountered while using a particular therapy programme are essential. Bernstein Ratner (2005, p.173) has written clearly about the need for therapists to learn to "'dismantle' therapies to identify their process mechanisms". The choice needs to be linked with the need to tailor therapy for a particular child/family.

Working with children will involve working with their families, teachers and other significant people; providing information, dealing with their concerns, assessing their sensitivity, helping them with desensitisation, as and if appropriate. This work will be most effective if it is based on an in-depth understanding of the individual and their specific environment. This involves gathering the stories which the child and family members have about stammering and, if these stories are problem-based, facilitating the development of a narrative which fits better with their hopes and ambitions while using their strengths and skills. This work will involve fostering openness and honesty about stammering for all involved – therapists, family members and as appropriate for the child if they have awareness of their stammering and are bothered by it.

8.2 Speech and Language Therapy for teenagers who stammer

Adolescents who stammer can face many challenges as they are a population simultaneously striving for independence from adults and social connection with their peers at a time when social fears surge and lifelong habits take root. Hearne et al., (2008) investigated the experiences of adolescents who stammer. Some key findings are summarised below:

- Adolescents may function best in group therapy due to the camaraderie they experienced.
- The adolescent may not see therapy as important if stammering is not interfering with activities conducted with their peer group.

- Adolescents may not appreciate people raising the subject with them, although they expressed some interest in having awareness raising programmes in schools.
- Going to university or starting work may be the trigger for some adolescents to seek therapy.
- Considerable lack of awareness amongst family, friends and teachers about stammering was reported by the participants.
- The overall lack of awareness about stammering is potentially a barrier to accessing supports. The view that further education about stammering should be made available was expressed by the majority of participants.

8.2.1 Assessment

As children grow older with the lived experience of stammering, their experience of stammering will involve more than observable stammering behaviours (Tichenor et al., 2022), and so assessment and intervention must take this into account. Broad-based measurement and consideration of stammering is essential. From the perspective of the person who stammers, the severity of the problem is as much or more represented by the intrinsic features identified, as by the more obvious surface behaviours (Plexico et al, 2005). Measuring observable stammering behaviours does not capture the stammering experience. Yaruss & Quesal (2006) developed the *Overall Assessment of the Speaker's Experience of Stammering* (OASES) self-reporting tool based on the ICF biopsychosocial framework. The tool captures multiple faceted change, both observable stammering behaviours and more subtle such as attitudinal change towards communication and self-image as a communicator. Compared to self-rated stammering severity and the other stigma-identity constructs, concealment was the strongest predictor of psychological distress and adverse impact of stammering on quality of life (Gerlach et al., 2021).

8.2.2 Therapy

As stammering persists in children, it would be expected for them to come to view themselves and their world through the lens of a person who stammers. As such, reducing overt stammering behaviours may not be sufficient to change their negative identities associated with being a person who stammers and so deeper change may require interventions more mindful of the entire experience of stammering. Using the ICF framework in stammering intervention is generally recommended (Pertijs et al, 2014). Some intervention approaches used with this age group include:

- Avoidance reduction therapy (Sheehan, 1970)
- Stammering modification (Van Riper, 1973)
- Narrative practice (O'Dwyer & Ryan, 2020).
- Integrating acceptance and commitment therapy (Everard & Cheasman, 2020).
- Group therapy (Everard et al., 2020).
- Transtheoretical approach (Rodgers, 2022). Assessing adolescents' readiness to make positive changes to living with stammering, and to provide motivational interviewing strategies that clinicians can employ to help propel adolescents toward personally significant change.
- Stammer-Affirming (Constantino, 2022). Neuroaffirmative approach to therapy.
- Fluency shaping for observable stammering behaviours (Ingham, 2003)

8.3 Speech and Language Therapy for adults who stammer

According to the 2023 survey of the SLT Manager Group, conducted to inform this paper, SLTs working in areas where services are provided for adults who stammer, report that very few referrals are received. While the reasons for this may be varied, SLTs must ensure that adults who stammer along with referral sources (for example, GPs, third level education disability services) are educated on the type of service available and on how SLT can support adults who stammer to participate fully in all of life's activities with no focus on "cure". It is recommended that the SLT service supports, informs and educates the adult who stammers, alongside their family, work, and social networks. This will facilitate an environment where stammered speech is seen as a natural variation that is accepted and accommodated. The process will support persons who stammer to develop positive / neutral identities as people who stammer. SLTs can help people who stammer to meet with others who stammer so that feelings of isolation are reduced. Meeting with others will provide positive support from those who have lived experience of learning to live well with their stammer. Supporting adults who are attending therapy to link with the stammering community is an important component of therapy. The ISA offers many supports including online support groups and education support, and the international stammering community can be accessed online also. In time, it is hoped that people who stammer will see their speech pattern represented incidentally in all contexts, including leadership roles, media etc. Speech and language therapy also has a role in helping members of the stammering community to understand and navigate the unpredictable disruptions to forward flow of their speech in comfortable, confident and spontaneous ways and to become competent at self-advocating and educating others so that they may flourish across all areas of living.

The experience of adults who stammer, while varying considerably, will often be marked by trauma. This trauma may stem from both the physical struggle involved in participating in social interactions in many life contexts since childhood and the sense of shame, stigma, and anxiety that may be experienced because of societal values on fluent speech. Consequently, speech and language therapy addresses cognitive, emotional and behavioural aspects of stammering. It is important to not pathologise appropriate reactions to experiences of shame, bullying and discrimination. At the same time, it is important to recognise when onward referral to counselling or psychology services is appropriate. SLTs who have specialised in stammering may access extra training to support their work with the cognitive and emotional aspects of stammering.

8.3.1 Assessment

Assessing stammering in adults requires a multi-dimensional comprehensive assessment that includes an evaluation of speech and stammering, communication attitudes, emotional well-being, and quality of life. The influence of societal attitudes is important to include in the evaluation by considering the individual's experiences within their social and cultural context. Assessment should adopt a client-centred approach, involving active collaboration between the SLT and the person who stammers. It is crucial to explore the individual's own goals, concerns, values, and preferences, to develop a personalised intervention plan. The OASES and the WASSP are two examples of assessments that may assist in the development of intervention plans. Yaruss and Quesal (2006) developed a framework applying the ICF to stuttering. The Overall Assessment of the Speaker's Experience of Stuttering (OASES) focuses on the speaker's experience of stuttering (Yaruss & Quesal, 2006). Similarly, the Wright-Ayre Stuttering Self-Rating Profile, (WASSP, Wright & Ayre, 2000) is based on the ICF framework, and was developed to assess the person who stutters perceptions of stuttering behaviours, thoughts and feelings about stuttering, avoidance of speaking situations and any perceived disadvantage due to stuttering. . The role of stigma and self-stigma as discussed in section 6 (Boyle, 2013;2018) can be further explored with the Boyle's (2013) Self Stigma Scale and approach-avoidance conflict (Sheehan, 1970), can be used to explore the impact of stammering on a person's life.

8.3.2 Therapy

Therapeutic interventions may involve assertiveness training, group therapy, peer support, and involvement in stammering advocacy initiatives.

The previously detailed differing therapeutic philosophies of "Speak more Fluently", "Stammer more Fluently" and "Stammer more Proudly" recognise the diverse needs and preferences of adults who stammer. Some individuals may prefer to focus on achieving greater fluency, while others may find greater value in embracing and accepting their stammering. A holistic approach that combines elements from these philosophies can provide individuals with a range of strategies and support tailored to their specific goals and aspirations.

As outlined already in this paper, SLT intervention to support individuals to live well with stammering, across all domains and life stages, will have its best outcome in conjunction with wider societal interventions and advocacy, which promote allyship, understanding and accommodations of stammering.

9.0 Current Service Provision for people who stammer in Ireland

Public speech and language therapy services are available in Ireland to children with stammering, however access is reduced for adults with acquired stammering, and further reduced for adults who have stammered from childhood. Delays in and/or lack of service provision for both children and adults will often drive families to seek private services, thus leading to health inequities. A survey was conducted of the IASLT SLT Manager Group in publicly funded services in 2023, to further explore current services available to people who stammer. A detailed summary of responses is included in Appendix (ii).

9.1 Childhood

Developmental stammering affects 4%-8% of children typically before 5 years of age. Thus, many children will be referred to HSE Primary Care services via Public Health Nurses following developmental checks, via preschool teachers or parent referrals. Children who have stammering co-occurring with other developmental presentations may access services through Disability and Mental Health services.

According to the survey, waiting times for access to speech and language therapy varies nationally and across different settings. In some Primary Care Services, children will wait less than 4 months for an assessment with a SLT, and receive intervention within 4 months of same. In other areas, children will wait significantly longer for assessment i.e. up to 18 months and can also wait much longer for any individualised or targeted intervention i.e. from 2 to 2.5 years.

In an effort to manage lengthy waiting lists, many primary care services offer parent advice clinics and universal approaches to stammering intervention. The evidence base indicates the need for targeted and early intervention for children who stammer, and thus both universal and targeted interventions are recommended.

9.2 Adulthood

In Primary Care adult services, people who stammer may wait 0 – 8 months for assessment and receive intervention soon after. However, some settings have reduced services for adults who stammer or may have none at all. Staffing difficulties and recruitment challenges have led to reduction of services to adults, and those who stammer may not be prioritised in the context of caseloads with acquired communication and swallowing difficulties.

Adults may also access SLT as inpatients in acute settings, however there is limited access for adults who acquire stammering as part of their neurological condition e.g. Traumatic and Acquired Brain Injury, Stroke, Meningioma and Radio-oncological cohorts. Stammering may also be indicated on mental health admissions to acute hospitals. With limited pathways of care for onward referral, there can be a negative impact on patients' engagement across the Multi-Disciplinary Team for inpatient rehab and discharge progress.

10.0 Recommendations regarding service provision

The development of a national clinical guideline for SLTs working with people who stammer is required urgently to provide a standard to base the development of services for people who stammer. Clinical Guidelines should outline the standard regarding the below recommendations.

10.1 Development of a dominant narrative that celebrates stammering

The importance of education and open discussion around stammering is recognised as vital in the reduction of discrimination of people who stammer and in creating a society that knows how to facilitate full participation by people who stammer. SLTs and the IASLT have an essential role in building and strengthening the alliance between people who stammer and their communities. An awareness campaign funded by the Departments of Health and Education and supported by IASLT is recommended using all forms of media.

10.2 Improving supports for people who stammer in educational services

A coordinated approach should be taken by key stakeholders (including the Department of Education and Department of Children, Equity, Disability, Integration and Youth supported by IASLT, and Specialist SLTs in working with organisations such as the ISA on the development of resources for teachers working with people who stammer. Such resources are required to increase educators' knowledge around stammering in general and understanding of the impact of their reactions on people who stammer. It is recommended that there is a focus on openness and talking directly to the children, teens and adults who stammer about their preferences. Formal accommodations developed at primary, secondary and third level will maximise access, participation and success for people who stammer in education. These will include accommodations related to reading aloud and doing presentations in front of large audiences, and further developing supports accessed through RACE.

10.3 Equal access to a timely and evidenced based service

Equal access to speech and language therapy provision for children and adults who stammer is required. This will require setting a recommended standard regarding waiting times for assessment and intervention. Increased access to evidence-based speech and language therapy services for both children and adults who stammer is an urgent priority, particularly in light of the negative impact stammering has on an individual's quality of life.

10.4 Adult services

Further development of adult services for stammering is required to include support for those who stammer with onset from childhood, as well as those with adult-onset stammering. There is a need for a cohesive pathway from children's to adults' services with longer term support for those who need it, and referral pathways between acute and primary care services.

10.5 Prioritisation and waitlisting

SLTs who are proficient in best practice relating to stammering are best placed to determine prioritisation and management of people who stammer on speech and language therapy caseloads.

Early assessment and intervention post onset of stammering is more effective than if the child is placed on a waiting list. Onslow and O'Brian (2013) recommend that intervention for early childhood stammering should commence before the age of 5 years, and should be immediate where there are signs of social distress and avoidance. Front loading services at referral stage is likely to lead to less children persisting in stammering and remaining on speech and language therapy caseloads further into childhood. Waitlist initiatives to target lengthy waiting times for assessment are essential, and access to intervention within appropriate timeframes is recommended.

The variable nature of stammering leads to fluctuating levels of frequency and severity of stammering at any one time, and the impact of stammering on the person may vary according to their contributing factors. Placing people on waiting lists for stammering intervention can lead to inappropriate timing of intervention, leading to inefficient use of resources.

The vision of Sláintecare and the Enhanced Community Care (ECC) framework aims to deliver "the right care, in the right place, at the right time, (Sláintecare report, 2017), regardless of where the service user lives. Thus, HSE services should endeavour to provide speech and language therapy at the appropriate time for people who stammer in an equitable manner across the Republic of Ireland.

10.6 Intervention Pathways

It is recommended that services adopt a universal health approach to drive and promote a culture of acceptance and inclusivity for people who stammer. Building awareness of stammering in the community and in the context of recent developments in the field of neurodiversity, will enhance and support the experiences that people who stammer have when communicating. SLTs play a key role in decreasing stigma and reducing the tendency towards concealment of stammering. SLT services are engaging in some education supports to families, schools and other key stakeholders. It is recommended that services continue to develop and strengthen their education pathways and universal supports to further create a supportive community and culture for stammering.

Targeted and specialist intervention approaches are key to supporting people who stammer from early childhood through to adulthood. It is recommended that service pathways include comprehensive assessment of the stammer, and where required, provide both individualised and group interventions for stammering.

The ever changing landscape, and emerging evidence around neuro-affirmative practices has necessitated the review of intervention pathways for those who stammer. It is recommended that SLT services continue to review and update pathways in line with current research. Pathways should support person centred care in line with evidence based practice, and practice based evidence. Integral to any pathway, is supporting the person's choice in management of their stammer, in the context of neuro-affirmative models of care. Creative and innovative pathways have developed in some areas of the country such as intensive camps, and groups for children and adults.

According to the 2023 survey of SLT Managers, most publicly funded speech and language therapy services are not providing group intervention to people who stammer. It was noted that, given the small cohort of people who stammer on a typical SLT's caseload, it may be difficult to gather sufficient numbers of clients to develop groups. The benefit of groups has been widely acknowledged (Hearne at al 2020), and services may consider connecting with neighbouring teams and devising care pathways to include groups across geographical boundaries.

10.7 Staffing, Clinical Education and Continuing Professional Development

There continues to be challenges with the education of SLT students and their clinical preparation for working with children and adults who stammer. Third-level educators often have insufficient time to teach these students about stammering and other conditions affecting speech fluency. This is likely due to the expansion of the scope of practice of SLTs in recent times, with SLTs now providing services to clients with a diverse range of communication and swallowing needs. Additionally, there are frequently limited clinical opportunities for students to gain experience working with children and adults who stammer, resulting in many SLTs graduating with no clinical experience of stammering. In some universities, there is also insufficient focus on the preparation of SLTs for targeting the psychological impact of stammering. This results in many newly graduated SLTs lacking the competence and confidence required to best support those who stammer. It is recommended that Universities consider the level of education provided to Speech and Language Therapy students in the area of stammering. Speech and Language Therapy providers also have a responsibility in their commitment to providing sufficient Clinical Practice Placements, which include exposure to the stammering population.

Once graduated, Coru -registered SLTs have an ongoing commitment to learning and professional development. SLT managers and employers must support SLTs to further develop their clinical skills, and many teams already provide in-service training days, and journal clubs. The IASLT have regular CPD days, including those in conjunction with the Special Interest Group in Stammering, have run workshops and invited experts to present to SLTs. SLTS and their employers must continue this commitment to continually increase confidence and update the knowledge base of clinicians working in this field.

10.8 Clinical Specialists

This position paper welcomes the support and recommendations from the HSE outlined by the HSCP Deliver Framework (2012 – 2026) and Advanced Practice framework (2023). These publications outline the need for career progression, recognition and development of clinical specialism for Health and Social Care professionals to develop and improve services universally. Nationally, there is a lack of Clinical Specialism in the area of stammering. It is recommended that further Clinical Specialist posts in Stammering are established in order to develop the SLT skills base. Development of Clinical Specialist posts will ensure that support to people who stammer will be of high quality and evidence based. SLTs will have increased access to peer supervision, upskilling and training, which will promote the clinical area of stammering amongst the SLT profession.

10.9 Regional Centres

It is recommended that the way to develop services for people who stammer in a consistent manner across the country is through the establishment of a network of regional centres. Each centre would be led by a clinical specialist SLT in stammering who would lead the work in that region. Each region may have different challenges for example, in one area it may be that existing services for children have not been developed in line with the evidence base for best practice whereas in another areas, this service for children may already be in place to some extent, but links with schools and the provision of education for teachers are limited. Centres would be aligned with the HSE Health Regions that are currently in development at the time of writing this paper. As the centres would be linked through a national network, resources to support service developments would be considered at national level, and in line with the HSE's Sláintecare strategy. The "centre" would be operationalised across the region providing training and consultation for local SLTs and so, develop knowledge and skills at a number of levels. Skill development may range from basic knowledge for all SLTs, so as to avoid giving of advice that could be harmful, up to and including specialist skill for working directly with children and adults who stammer. Links with the university in their area would also be a significant step in ensuring that undergraduate students gain experience in working with children and adults who stammer.

10.10 Research

Increased funding and collaborative opportunities for research activities specific to stammering is essential to ensure the delivery of person-centred and evidence-based services in the Irish healthcare system. In addition, opportunities, time and resourcing for SLTs to complete research activities in their workplace and to collaborate with academic researchers needs to be prioritised. This will ensure that the research completed has contextual relevance to their healthcare setting and the people who stammer that they work with.

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12.0 Appendices

Appendix (i)

Table 1: Sample of historical and more recent stammering definitions proposed in the literature.

Definition type	Example from the literature
A classical or operant conditioned behaviour	*"Stuttering is that form of fluency failure that results from conditioned negative emotion"* (Brutten & Shoemaker 1967, p.61).
A collection of atypical speech behaviours	Stuttering is *"disorders in the rhythm of speech in which the individual knows precisely what he wishes to say, but at the time is unable to say it because of an involuntary, repetitive prolongation or cessation of a sound"* (WHO 1977, p.202).
Stammering defined from the perspective of the speaker	Stuttering is a *"temporary overt or covert loss of control of the ability to move forward fluently in the execution of linguistically formulated speech"* (Perkins 1984, p.431).
Application of the ICF (WHO 2013) to acknowledge aspects of stammering beyond the observable speech features	*"Stuttering can involve negative affective, behavioral, and cognitive reactions (both from the speaker and the environment), as well as significant limitations in the speaker's ability to participate in daily activities and a negative impact on the speaker's overall quality of life"* (Yaruss & Quesal 2004, p.35).
A neurodevelopmental, epigenetic, multifactorial disorder	*"Stuttering is a neurodevelopmental disorder whose primary symptoms are disfluencies, involuntary disruptions in the normal flow of speech"* (Smith & Weber 2017, p.2485). See also *"Multifactorial Dynamic Pathways Theory of Stuttering"* (Smith & Weber 2017, p.2486).
Application of the social model of disability	*"Our impairment is the fact that we speak with hesitations, blocks, prolongations, and repetitions due to specific neurological and genetic factors. We are disabled, on the other hand, by the fast pace of society; by people who interrupt our speech; by those who deny us jobs because of our speech; and by a multitude of ableist stereotypes, biases and stigmas"* (St Pierre 2019, p.9).
Application of the neurodiversity conceptualisation of disability	*"Rather than focusing on pathology and impairment, neurodiversity emphasizes natural variation and the unique skills, experiences, and traits of neurodivergent individuals. People who stutter are beginning to work with*

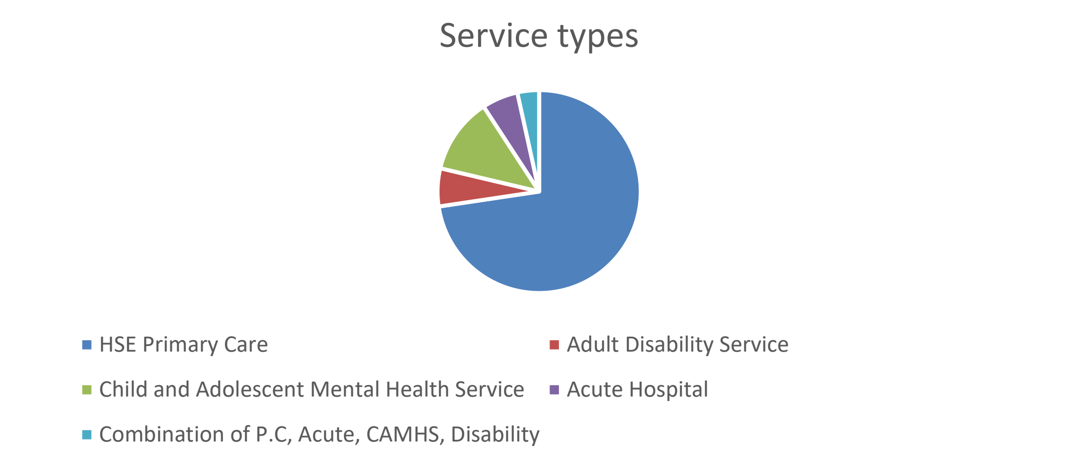
	and derive value from these concepts" (Constantino 2018, p.382).
Collectively defined by adults who stammer	Updated adaptation of the ICF (WHO 2013) as it applies to stammering and based on qualitative data from 420 adults who stammer (Tichenor and Yaruss 2019, p.9): Stammering is *"a constellation of experiences beyond the observable speech disfluency behaviors"* including the following: ● Presumed aetiology: Underlying genetic/neurological differences ● Impairments in body function or structure: sensation of anticipation, feeling stuck, or losing control ● Personal factors: affective, behavioral, and cognitive reactions ● Activity limitations and participation restrictions: e.g. forming relationships, impact on employment ● Environmental factors: e.g. reactions and attitudes of listeners

Appendix (ii)

Survey on Service provision for People Who Stammer in HSE services

A survey was distributed to 127 Speech and Language Therapy Managers in Publicly funded services in Ireland in June – July 2023. The purpose of the survey was to gather data regarding waiting lists, service provision and staff resources specific to stammering. There was a 30% response rate, with 38 completed responses received. The results are detailed below, with comments categorised into themes.

1. Which Service Area do you work in ?



2. Does your department provide a service to the following?

Clinical Populations	Response Percent
Children who stammer	83%
Adolescents who stammer	83%
Adults who stammer with onset from childhood	47%
Adults with acquired stammering	55%

Average Waiting times for Children who stammer

3. In your service, How long do children wait for Initial Assessment of stammering?

Waiting time		Response percent
0 – 4 months		57%
4 – 8 months		20%
8 – 12 months		8%
12 – 18 months		8%
18 – 24 Months		0%
24 + months		0%
N/A		17%

4. In your service, How long do children wait for initial intervention for stammering?

Waiting time		Response Percent
0 – 4 months		53%
4 – 8 months		25%
8 – 12 months		8%
12 – 18 months		0%
18 – 24 Months		0%
24 + months		3%
N/A		14%

5. In your service, How long do children wait for Further Intervention for stammering?

Waiting time		Response Percent
0 – 4 months		30%
4 – 8 months		28%
8 – 12 months		19%
12 – 18 months		8%
18 – 24 Months		0%
24 + months		3%
N/A		17%

Average waiting times for Adults who stammer

6. In your service, How long do adults wait for an initial assessment of stammering?

Waiting time		Response percent
0 – 4 months		38%
4 – 8 months		5%
8 – 12 months		5%
12 – 18 months		3%
18 – 24 Months		0%
24 + months		3%
N/A		38%

7. In your service, How long do adults wait for an initial intervention for stammering?

Waiting time		Response percent
0 – 4 months		43%
4 – 8 months		3%
8 – 12 months		3%
12 – 18 months		3%
18 – 24 Months		0%
24 + months		3%
N/A		43%

8. In your service, How long do Adults wait for a Further Intervention for stammering?

Waiting time		Response percent
0 – 4 months		35%
4 – 8 months		3%
8 – 12 months		5%
12 – 18 months		3%
18 – 24 Months		0%
24 + months		3%
N/A		49%

Do you have any further comments about waiting times ?	
Primary Care	Network waiting lists may vary within former LHO's
	SLT Managers do not always have oversight of waitlists, as these are being managed by Network Managers in some areas.
	Some adult services not currently operating due to staffing issues, service varies across networks
Acute Services	Waiting lists not applicable in acute services
	24-28 Hours as inpatient on wards, no outpatient service Once assessed as an inpatient, we provide a limited intervention service. The limited service is not due to the fact it is a stammering diagnosis but due to limited resourcing in general and an inability to provide sufficient intervention services for any client group.

9. Does your service provide groups for people who stammer?			
	Yes		31%
	Comments		
	Weekly for children and adults; bimonthly for adults and intensive for adults and week long camp for children		
	Due to commence Dream Speak Live group in 2024		
	Yes, depending on : Demand, relevant numbers and appropriateness of clients for the group		
	Some SLTs provide intervention groups for children in the school holidays		
	PCI delivered individually but also through group		
	Older school-age groups / Adolescent groups offered in combination with individual input based on the child / young person's needs and priorities.		
	School aged group provision -focus on confidence and resilience		
	No		63%
	Comments		
	We could but do not have sufficient numbers of clients.		
	Not currently but do at times		
	Numbers have decreased over the past number of years, thus, group care pathways not currently running		
	Very low numbers referred for group intervention		
	Currently reviewing group pathways (Palin/Neurodiversity)		

10. Are Education sessions for stammering offered to:	
Parents/Care givers?	57%
Teachers/ Education staff?	36%
Other (please specify):	64%

Comments	
Primary care services	Some services are currently re-designing pathways and plan to implement education pathways in the future, including families, carers, and other professionals
	Education and advice is often provided individually or on Phone consultations with education staff, or via Youtube videos
	Education may not be focused on stammering -training is around total and inclusive communication, AAC, communication support needs for people with progressive diagnosis etc
Acute Services	Provide patient information leaflets and onward referral to PCC- not an acute hospital service stream unless on mental health or acquired neurology pathway and even at that is a lower priority in context of acuity
CAMHS	We work in CAMHS so stammering cases aren't frequent. Often have comorbidities such as ADHD or Tourettes. Psychoeducation delivered to child's parents and teachers as needed but not usually a parent group or teacher group. More likely school meeting/consultation with collaborative working and coaching.

11. Does your service link with the Irish Stammering Association (ISA), and/or forward information to relevant stakeholders regarding events organised by ISA?		
Yes		59%
Comments		
The SLTs who have developed a specialism in Stammering are linked with ISA		
Forwarded by manager to team - usually received through SLT managers' group		
Adolescent support		
No		41%
Comments		
n/a at present but have knowledge of the ISA		
Only if received in general circulation		
Haven't seen any forwarded information re events		

12. With regards to staffing in your service, select all of the below statements that accurately describes your team?		
A Clinical Specialist SLT in Stammering is present on the team		8%
All SLTs on the team work with people who stammer		60%
Some SLTs specialise in stammering, while others do not manage any cases with stammering		26%
Other (please specify):		17%
Comments		
General baseline skillset across the team		
Usually only 1 SLT on the team, maybe 1.5 WTE so the therapists try their best to meet the ax and tx needs with access to clinical supervision and peer support		
Due to reduced resources, working more at tier 3 (universal/ general supports) and tier 1 (communication impacting on all areas of life) due to prioritisation of FEDS.		
There is one Adult SLT who primarily sees Adults who stammer and who has recently completed the ECSF, Almost all Primary Care Paed SLTs work with children who stammer but I also have Sen SLT who specialises in Stammering, having completed many courses including ECSF, DCM, etc and she supports all others.		
Nil stammering service - not prioritized in context of Acute service		

13. Has your service provided any CPD/Additional training for SLTs in the area of stammering?	
Yes	10%
No	37%
Comments	
Many teams have availed of training courses from the Michael Palin Centre	
Some teams have accessed Mini-Kids training	
In-Service upskilling via SLTs with stammering expertise, within team, and with other teams across the CHO	
SIG and IASLT arranged workshops	
Staff avail of CPD days as they arise, particular recent interest in neurodiversity and stammering. Newer staff have identified stammering as a goal as part of their PDPs this year.	
Ongoing CPD provided by specialist SLT, also supervision and consultation re. fluency / stuttering offered to all SLTs in Dept.	

14. With a growing interest in working in ways that support and value neurodiversity, has your service modified it's pathway/service to people who stammer ?	
Yes	32%
No	21%
In progress	32%
Comments	
Yes	Parent information sessions have been adapted to reflect an understanding of stuttering that reflects the continuum of experiences of people who stutter
	Therapists have a growing interest in working in ways which ensures neurodiversity is valued and supported.
	Dream Speak Live initiative, will broaden the intervention options available.
	In mental health there is a dual focus when working with people who stammer - communication and anxiety management.
	Yes, there has been a significant change and move toward practice that is more up to date, and linked to more recent research in the last 3 - 5 years. Inclusion of stuttering and recognition of neurodiversity has change the way intervention is shaped and delivered for people who stutter
	Yes - we no longer work on curing the stammer/stutter but work on educating all communication partners and making the environment as supportive as possible for the young person who stammers. In terms of working directly with the young person, we now focus on having open conversations about stammering, and encouraging them to accept and reduce anxiety about their talking through using methods such as pseudostuttering in different settings, arming the young person with a power

14. With a growing interest in working in ways that support and value neurodiversity, has your service modified it's pathway/service to people who stammer ?		
		statement to use in case they are asked about their stammer and promoting their confidence and independence
		This is individual, as autonomous practitioners service provision is at the discretion of the individual therapist and their clients needs
	In progress	Currently working on a new pathway informed by current understanding of stammering and neurodiversity
		We are beginning to consider stammering in a neuro-affirming way.
		Yes, we have heard back from SLTs who have attended SIG days and we have adapted our stammering pathway to ensure stammering referrals are triaged and managed separately to the general caseload
		We are currently in the process of developing pathways in the context of post-pandemic service provision (long waitlists, increase in complexity of cases) and with advancements in nueroaffirmative practices
	No	Not at dept level but SLTs are more mindful of providing intervention options to clients
		No, all adults who use the service can access SLT via referral.
		Neuroaffirmative approaches have been used for a number of years
		No, not core business of acute hospital service in acute phase
		Not specifically- but have tried to apply general principles of neuro affirmative practices across the board

15. Does your service have any other initiatives for stammering?			
1	**No**		76%
	Comments		
	Not a frequent reason for referral.		
	Not currently but would welcome hearing about what is offered in other services so that we could also explore other options		
2	**Yes**		22%
	Comments		
	Camp, groups, intensive groups for adults, regular groups for adults		
	Aligning adults and children		
	Supporting DARE applications and/or accommodations in school		
	Evening groups for adolescents who stutter		
	Patient information handouts provided and links to online platforms		
	Yes we did have a public awareness stand in thelocal shopping centre pre covid		
	We mark Stammering Awareness Day- different initiatives within clinics e.g. notices boards, leaftlets.		
	We offer online training and resources for teachers.		
	Provide early contact and advice post referral		
	Intensive camp for children and teens in summer which focuses on confident communication, self-disclosure and self-advocacy.		
	Parent information webinar for those with early childhood stuttering. This is run for parents of clients on the assessment waitlist		

16. Do you have any other comments regarding service provision for stammering in Ireland?	
	Comments were categorised into themes below:
	Adult Services
	There is limited to no access for adults who acquire a fluency disorder as part of their neurological condition e.g. TBI/ABI, Stroke, Meningioma/GBM Radio-oncological cohorts; it is also largely seen in mental health admissions to acute hospitals - again no pathways of care for onward referral - which can have a detrimental impact on patients engagement across the MDT for inpatient rehab and discharge progress. It is not a priority area for referrals sent out of acute to PCC services locally. Look forward to hearing the results of your survey - thanks for your work on this.
	There is no funding for acute hospital services for the clinical stream of dysfluency; if funding is going to be achieved across any of the clinical pathways, SLT's need to sit on Clinical Advisory Boards for the National Clinical programs for which funding is sourced from the Dept of Health; SLT's need to be more proactive in dedicating their time to clinical advisory boards and putting themselves forward for H&SCP Clinical Leads- these are mainly occupied by Physiotherapists and hence the funded posts for all new clinical streams include Physiotherapy posts and not SLT posts.
	National Clinical Programmes are found at https://www.hse.ie/eng/about/who/cspd/ncps/ ; those relevant to stammering would include: ADHD, Mental Health, Neurology, Rehab Medicine, Stroke & Trauma . Best of luck with your survey
	Our service delivery primarily to residential services not day services with dysphagia often prioritised.
	There is an unmet need for those with communication difficulties and stammering in our service. Primary care do not accept referrals. Private assessments if used are self funding. New directions in day services and a move towards supporting job coaches and meaningful employment any communication difficulties including stammering is a potential barrier to successful placement and employment.
	if referral indicated for acquired dysfluency in context of stroke, TBI or new neurological condition this is included in the onward referral to sub-acute rehab or primary care - in many instances the referrals we sent for dysfluency are not accepted or sit on a waitlist for over 2 years in PCC
	Disability Services
	In the day service for young adults including those transitioning from school we provide a communication service 1 day a week. Easy reads; Communication passports/books/Dictionaries; visuals; OOR; ipads; Lamh signs; pacing boards; sensory items; TEACCH and PECS used for service delivery to those with a diagnosis of ASD and intellectual disability. Those with stammering would be supported in the same way as appropriate.
	We have adapted the mainstream resources, or used previous resources from Down Syndrome International, but these would need to be updated
	Up-skilling SLTs and education of SLT students
	It would be great if there were specialist hubs that we could refer complex cases to, especially for adolescents and adults who stammer if it is really impacting their functioning.
	Access to ongoing training, updated position statements, recommended care pathways, ways to connect with clinical specialists etc would be welcome.
	CPD and resources for people with intellectual disability who stammer would be very beneficial.

	16. Do you have any other comments regarding service provision for stammering in Ireland?
	Significant investment required in CPD for all SLT Staff
	All staff would like further training to increase their awareness.
	There is a need for specialist centre or perhaps clinical specialist posts so that staff can access the range of specialist training required to work with this complex client group e.g CBT, motivational interviewing, narrative therapy, BSFT, compassion focused therapy,
	The number of adult and adolescent referrals are very low therefore SLT's have not followed up on CPD re stammering. Higher priorities in relation to the national access policy in paediatric services eg Autism and more complex delays.
	I would welcome an IASLT position paper to highlight the need for additional training among SLT's and remove the fear of working with children and adults who stammer
	I would welcome more sharing of information / communication about service developments nationally in the area of stammering. There is an ongoing need for further training opportunities to be funded through HSE / IASLT (e.g. Palin PCI).
	My final year research project looked at SLT students confidence in working with children and adults who stammer (2009) and, at this time, the general findings were that students felt underprepared and I would imagine this hasn't changed to a huge extent. I do think there's a need to explore additional training for SLT students at undergraduate level.
	There are CPD requirements and a link in with a specialist welcome, so that all SLTs would be more comfortable working in the area of stammering.
	An improved career structure would allow for many more specialisms which is required for client need such as this - low frequency but high need.
	Community awareness
	A media campaign dispelling myths and raising awareness about stammering would be welcome. There is a lot of stereotyping on TV shows etc
	There is not enough information/education of the wider public
	It seems to be very variable! I wish more info was provided for Teachers when training around stammering.
	Other
	Needs to be more equitable across the country
	Greater understanding of potential to do harm with this client group needed