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## 12 Developmental Stuttering for Unserved and Underserved Populations

Thomas Law and Maram Al-Khaledi

### Key information for local and international policymakers

The purpose of this project is to inform political leaders, healthcare practitioners, professional organizations, and institutions about the risk and impact of developmental stuttering.

Developmental stuttering is a speech disorder that disrupts the natural flow of speech. It may begin between the ages of 2 and 4 (Yairi & Ambrose, 2013). Typical audible stuttering behaviours include repetitions of sounds (e.g., bu-bu-bus), prolongations (e.g., ssssssun), blocks (e.g., I have an -pause- apple), adding unnecessary sounds or changing words to conceal stuttering (e.g., um, um, I want a biscuit or I went- I walked to the park). Visual behaviours may include eye blinking, lips twitching, head nodding, or arm or body movements. This may have an impact on all social interactions, education, and employment.

### Incidence and prevalence

The incidence of developmental stuttering in children is estimated to range from 5% to 8% before 9 years of age (Craig et al., 2002; Månsson, 2000; Reilly et al., 2009). The incidence is much higher in younger children, with an incidence rate of 11.2% by the age of 4 (Reilly et al., 2013). The prevalence rate of developmental stuttering varies significantly across age groups. Prevalence is higher in preschool-aged children, ranging from 1.4% to 5.6% in children aged between 2 and 5 (Boyle et al., 2011; Craig et al., 2002; McKinnon, McLeod, & Reilly, 2007; McLeod & Harrison, 2009; Okalidou & Kampanaros, 2001; Proctor, Yairi, Duff, & Zhang, 2008). However, the prevalence of stuttering reduces significantly to 0.3% to 1.6% between ages 6 and 10 (Boyle et al., 2011; Craig et al., 2002; McKinnon et al., 2007; Van Borsel et al., 2006) and is estimated to be 0.53% between ages 11 to 20, 0.78% between ages 21 and 50 (Craig et al., 2002). Studies have shown that up to 85% of children who stutter will recover naturally without needing intervention (Kefalianos et al., 2017; Månsson, 2000; Shimada et al., 2018; Yairi & Ambrose, 1999, 2005). To date, the only reliable factor that predicts natural recovery is female gender (Kefalianos et al., 2017; Månsson, 2000; Reilly et al.,

2013; Reilly et al., 2009; Yairi & Ambrose, 2005). More girls outgrow developmental stuttering than boys.

### The impact of stuttering on an individual's life

Approximately 60% of children who stutter have been bullied by their peers (Blood et al., 2007), and in addition have higher anxiety than their fluent peers. Developmental stuttering may lead to social avoidance if disfluency persists into adulthood and is left unmanaged. People with more severe stuttering are less likely to obtain a higher degree (O'Brian et al., 2011), while stuttering decreases a person's chance of being employed and increases face discrimination and job termination (Blumgart, Tran, & Craig, 2010a).

### Key information for caregivers and healthcare practitioners

This section provides information on developmental stuttering for carers, family members, healthcare, social welfare, and educational practitioners. The aim is to improve awareness, early identification and care provided to people with developmental stuttering.

#### Identification

Developmental stuttering is a speech disorder characterized by both verbal and nonverbal behaviours, such as repetitions, blocks, prolongations, or facial grimaces. These behaviours disrupt the natural flow of speech. Typical disfluency is characterized by fewer than 10 incidents of disfluency with the production of 100 words, while typical stuttering disfluencies may consist of greater than 10 incidents of disfluency with the production of 100 words.

Other behavioral stuttering consists of part- and single-syllable word repetitions, while typical disfluency consists of interjections, revisions, whole word and phrase repetition. Awareness of disfluency is present for stutterers, while those who produce typical/normal nonfluency productions are rarely aware. In addition, typical disfluency usually consists of one-word repetitions in a slow rate of production as opposed to the production of two or more units of faster repetition by stutterers.

#### The impact of stuttering

Despite a high natural recovery rate, those who continue to stutter are significantly affected by the persistence of stuttering in all aspects of their life across their lifespan. Stuttering may cause distress in social situations and ultimately lead to social avoidance if disfluency persists into adulthood and is left unmanaged.

#### The importance of identification

At least 40% of stuttering adults are diagnosed with social phobia (Blumgart, Tran, & Craig, 2010b; Iverach et al., 2009a) and a higher rate of mood disorder (Iverach et

al., 2010). People with more severe stuttering are less likely to obtain a higher degree (O'Brian et al., 2011), along with hindering a person's chance of being employed (Klein & Hood, 2004). Approximately 40% of stutterers have not been promoted at work and 10% had their jobs terminated due to their stuttering (Blumgart et al., 2010a).

### How to help and support individuals who stutter once identified

It is important for carers, healthcare workers, and educators to be aware that the occurrence of stuttering is not readily controllable by the people who stutter. Several websites provide practical resources and suggestions for carers, healthcare workers and educators to support people with developmental stuttering. The links and are provided below.

#### Key Dos and Don'ts

It is important to follow the following suggested approaches when interacting with individuals who stutter:

- Maintain natural eye contact and be patient until the person who stutters has finished his/her sentence.
- Focus on the content of the person's speech rather than the fluency.
- Speak naturally to the person who stutters. There is no need to change the way you speak.
- Encourage and allow children who stutter to participate equally in class but only when they feel comfortable.
- Do not draw attention to a child's speech when he/she is stuttering.
- Make sure the person who stutters has equal turns in conversation.
- Do not finish the sentences or fill in words for people who stutter.
- Do not tell the person who stutters to "slow down", "take a deep breath", "think before you talk", "relax".

### Information for professionals working with people with developmental stuttering

The purpose of this section is to provide updated and evidence-based knowledge and research on the management of developmental stuttering for professionals in the underserved and unserved populations.

#### Assessment

People who stutter should be referred to a speech-language pathologist for assessment to provide a definite diagnosis and to formulate a management plan. The speech-language pathologist is responsible not only for providing assessment and treatment

and support for people who stutter but also coordinating care and making referrals to other relevant professionals such as psychologists and educators as required to support holistic care. In addition, early identification of developmental stuttering is crucial to allow for timely management and to assist in preventing development into advanced stuttering. It has been shown that developmental stuttering is more tractable when intervention is implemented in early childhood (Baxter et al., 2015; Brignell et al., 2021; Shenker & Santayana, 2018).

Appropriate support should be provided to children who stutter early to reduce the impact and prevent the development of negative psychosocial issues. It is also important for caregivers, healthcare workers, and educators to be aware that the occurrence of stuttering is not readily controllable by the people who stutter. Several websites provide practical resources and suggestions on how carers, healthcare workers and educators can support people with developmental stuttering.

### Resources for parents and teachers

Information is available from various websites to support parents and teachers. For example, there is information to identify stuttering from The Stuttering Foundation (2021a). There are also recommended strategies for parents to use when communicating with their child (The Stuttering Foundation, 2021b). Videos are offered for helping parents for children who stutter (The Stuttering Foundation, 2021c). Furthermore, there is guidance for those speaking with individuals who stutter (The Stuttering Foundation, 2021d). Leaflets are available from Resources (2021a) which provide information for those working with preschool and school-aged children who stutter. Additional resources are available for teachers communicating with students who stutter (The Stuttering Foundation, 2021e) and information for preschool teachers (The Stuttering Foundation, 2021f). Further information for teachers is also available at UTS (2021) and Resources (2021b).

### Update of assessment approaches

It is important to align with the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) framework when conducting the assessment of a person who stammers. The professional should consider the impact of developmental stuttering on the person's (a) body structure and function and (b) activities and participation, while taking into account (c) the environmental factors and personal factors that may contribute to the impact of stuttering or barriers to intervention (World Health Organization, 2001).

### Case history

A case history for developmental stuttering should include all questions in a typical case history of a speech and language assessment. The professional should also include stuttering-specific questions to understand the development, risk factors and impact of developmental stuttering, to assist in confirming the diagnosis, understanding its

impact, and establishing a holistic management plan. Stuttering-specific questions should include the following:

- The onset of stuttering
- A family history of stuttering
- Any changes of stuttering since onset
- Stuttering variability across speaking situations and languages spoken
- Family, parents, and carer's concerns, reactions, and expectations
- Self- or carer-perceived impact of stuttering
- Previous treatment or management

### Stuttering frequency and severity

A speech sample should be of adequate length and taken in a situation where natural conversation is encouraged. It is important to take into account the natural variability of stuttering across different speaking situations, so taking speech samples that reflect a variety of situations is helpful. It is recommended (Sawyer & Yairi, 2006) taking a 300-syllable speech sample to provide basic information and a 1200-syllable sample to provide comprehensive information about the person's stuttering.

### Percent syllables stuttered (%SS) and calculating stuttering-like disfluencies (SLD)

The number of stuttered syllables is divided by the number of total syllables spoken and multiplied by 100% to obtain the %SS. When calculating stuttering-like disfluencies (SLD), the clinician needs to first identify the syllables that contain SLDs. SLDs are disfluent behaviours that consists of part-word repetition, single-syllable word repetition and dysrhythmic phonation including prolongations, blocks, and broken words. Then the number of SLDs is divided by the number of total syllables spoken and multiplied by 100% to obtain the SLD.

### Stuttering severity

Although the frequency of stuttering provides an objective measure to the severity of stuttering, certain behaviours of stuttering may make this condition appear more severe. Consequently, a person may appear more severe than another person with the same stuttering frequency due to the additional associated behaviours exhibited. For this reason, it is recommended to take into account the subjective measure on stuttering severity, its frequency as well as behaviours. Stuttering Severity Rating (SEV or SR) utilizes an equal-appearing interval scale (Yairi & Ambrose, 1992; Yairi & Ambrose, 2005). An advantage of the stuttering severity scale is that it could easily be used by carers and people who stutter to monitor stuttering management and communicate with the clinician. Recent studies show that the stuttering severity rating scale is sufficiently valid and reliable to replace stuttering frequency measures (O'Brian et al., 2020; Onslow et al., 2018).

### Behaviours of stuttering

Several stuttering features proposed by researchers allow the clinician to assess a person's stuttering behaviours holistically and have been incorporated into assessments and checklists. These include the Johnson's disfluency categories (Johnson & Associates, 1959), stuttering-like disfluencies (SLD) (Ambrose & Yairi, 1999) and the Lidcombe behaviours data language (LBDL) (Teesson, Packman, & Onslow, 2005).

### Stuttering-related quality-of-life and impact of stuttering

Stuttering-specific quality-of-life tools may not be available in underserved communities. Given the absence of these tools, the clinician will need to make use of direct interviews with the person who stutters, his/her carers and relevant people in his/her everyday life to measure the impact of stuttering. In this case, questions may ask for the following information:

- Any experience of negative emotions and reactions from others to the person who stutters
- Situations in which the person has difficulties communicating
- The person's own perception about his/her stuttering
- Any impact on quality-of-life
- Any limitations to educational, vocational, and social participation and activities

The clinician should be aware that referral to professionals who specialize in psycho-emotional management should be made if emotional issues are identified which are beyond the professional knowledge and skills of the clinician.

### Update of evidence-based interventions

Interventions for early stuttering may consist of direct and indirect treatment components (Guitar, 2019). As suggested by its name, direct treatment aims to induce fluency by directly modifying the child's speech. In contrast, indirect treatment aims to enhance fluency by modifying the factors, such as motoric, linguistic, emotional, cognitive and environmental, that lead to disfluency in the child (Guitar, 2019; Yairi & Seery, 2014). To date, there are two evidence-based interventions available for early stuttering, for children below 6 years of age: The Lidcombe Program (Onslow, Packman, & Harrison, 2003) and RESTART DCM Method (de Sonnevile-Koedoot, Stolk, Rietveld, & Franken, 2015).

Evidence-based interventions for persistent stuttering involve the use of speech restructuring (Brignell et al., 2020). Speech restructuring is defined as using a novel speech pattern in order to eliminate stuttering while attempting to sound as natural as possible (Onslow & Menzies, 2010). During speech restructuring treatment, the person who stutters learns to speak in a different speech pattern to their natural speech. Speech techniques may include reduced speech rate, continuous vocalization, light

articulatory contacts, extended vowel production, modified phonation intervals, and gentle vocalization onset (Brignell et al., 2020; Onslow & Menzies, 2010).

Clinicians providing intervention for adults with persistent developmental stuttering should be aware of the high prevalence of mental health conditions in this population. It has been shown that the existence of mental health conditions significantly reduces the effect of stuttering treatment (Iverach et al., 2009b). Studies show that speech restructuring treatment in conjunction with cognitive behaviour therapy to reduce social anxiety improved speech outcome, quality of life, and psychological functioning (Menzies et al., 2008; Menzies et al., 2019). Therefore, it is important for clinicians to be aware of the need to, and benefits of, involve mental health professionals in the care of adults with persistent developmental stuttering.

If left unmanaged, developmental stuttering has a significant impact on a person's life. It not only affects a person's communication but also their socio-emotional wellbeing, educational attainment, and vocational achievement. Developmental stuttering has shown to be more tractable if managed during early childhood (Brignell et al., 2021). Therefore, early identification and intervention of developmental stuttering is important to avoid long-term adverse consequences.

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## 13 Toward Food Sovereignty and Security for People Living with Swallowing Disabilities in Globally Vulnerable Environments

Mershen Pillay

### Key information for local and national policy and lawmakers

The purpose of this chapter is to provide information for various stakeholders involved in the health care, education, and employment of people living with dysphagia (swallowing disabilities). Dysphagia refers to difficulty with swallowing (eating and drinking) due to motor and/or sensory deficits. Dysphagia may occur at birth, affect the elderly, or impact anyone affected by communicable illnesses such as COVID-19 and HIV/AIDS or the following non-communicable illnesses:

- Neurological disease such as head injury, stroke, motor neuron disease, Parkinson's, or dementia
- Diseases/trauma to the body such as head and neck cancers (tongue, nose, or larynx), cleft lip and palate
- Mental illness
- Work-related injuries, especially exposure to chemicals in the workplace
- Side effects of medications
- Age-related effects

Child health issues that may also involve dysphagia include: cerebral palsy, autistic spectrum disorder, cleft palate, intrauterine exposure to HIV/AIDS, or alcohol and drug effects. Information provided in this chapter should (a) increase the visibility of people with swallowing disabilities and (b) highlight the unique services needed within the framework of food sovereignty, defined as the transformation of food systems that address people's rights to healthy and culturally appropriate foods, along with the ability to decide how food is produced and distributed.

Governments should respect people's right to adequate, available, accessible, culturally acceptable (sustainable, *author's own words*) and nutritious food (International Planning Committee, 2009). It is also essential that all projects and plans developed