Further reading

Holm, A., Dodd, B., Stow, C., & Pert, S. (1996). Speech disorder in bilingual children: Four case studies. *Osmania Papers in Linguistics*, *22–23*, 46–64.

McLeod, S. (2012). Multilingual speech assessment. In S. McLeod & B.A. Goldstein (Eds), *Multilingual Aspects of Speech Sound Disorders in Children*, pp.113–143. Bristol: Multilingual Matters.

McLeod, S. (Ed.). (2007). *The International Guide to Speech Acquisition*. New York: Thomson Delmar Learning.

McLeod, S., Harrison, L.J., & Wang, C. (2019). A longitudinal population study of literacy and numeracy outcomes for children identified with speech, language, and communication needs in early childhood. *Early Childhood Research Quarterly*, *47*, 507–517. Available at https://doi.org/10.1016/j.ecresq.2018.07.004

Pascoe, M., Klop, D., Mdlalo, T., & Ndhambi, M. (2018). Beyond lip service: Towards human rights-driven guidelines for South African speech-language pathologists. *International Journal of Speech-Language Pathology*, *20*(1), 67–74. Available at https://doi.org/10.1080/17549507.2018.1397745

Stow, C. & Dodd, B. (2005). A survey of bilingual children referred for investigation of communication disorders: A comparison with monolingual children referred in one area in England. *Journal of Multilingual Communication Disorders*, *3*(1), 1–23. Available at https://doi.org/10.1080/14769670400009959

Verdon, S., McLeod, S., & Wong, S. (2015). Supporting culturally and linguistically diverse children with speech, language and communication needs: Overarching principles, individual approaches. *Journal of Communication Disorders*, *58*, 74–90. Available at http://dx.doi.org/10.1016/j.jcomdis.2015.10.002

11 Augmentative and Alternative Communication in Underserved or Unserved Populations

Shakila Dada, Janice Murray, and Martine Smith

Key information for regional and national governments

There is a crucial need for governments, nongovernmental organizations, service providers, and educators to identify persons with complex communication needs early in order to implement appropriate Augmentative and Alternative Communication (AAC) intervention. The purpose of this chapter is to inform governmental bodies, professional organizations, and health and educational service providers about the impact of AAC for persons with complex communication needs living in underserved and unserved communities. People with complex communication needs are those "*having limited or no access to functional verbal speech and are unable to use speech to meet their daily communication needs*" (Biggs, Carter, & Gilson, 2018, p.443).

AAC encompasses any form of communication used to supplement or replace oral speech when is it insufficient to meet communication needs (American Speech-Language-Hearing Association, 2015). The word 'augmentative' is important as it acknowledges that some persons require the use of supportive strategies to enhance their existing, partly functional, spoken communication abilities. Alternative communication refers to strategies that replace natural speech. Depending on the nature of the complex communication needs, AAC strategies can either augment communication abilities or provide an alternative method of communication.

Access to appropriate forms of AAC is critical in supporting communication and promoting the participation and inclusion of persons with severe communication disabilities (Beukelman & Light, 2020). AAC communication modes can include the use of external aids such as alphabet boards and picture communication boards, or technology-based aids that include speech-generating devices (SGDs), or unaided approaches (the use of gestures and manual sign language). The aim of all AAC strategies, techniques, symbols, and technologies is to maximize communication interaction and improve the participation of persons with complex communication needs in all aspects of life. AAC provides children with the right and the ability to express themselves and be heard as stated in Article 12 and 13 of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989). This incorporates being listened to and having rights to freedom of expression that includes the expression of views and participation in decisions about their lives. According to International Classification

of Functioning, Disability and Health (ICF) (World Health Organization, 2001), participation is an important outcome for persons with disabilities and can be facilitated through environmental factors.

The incidence and prevalence of communication needs

The global incidence and prevalence of complex communication needs that would require AAC is unclear and estimating this prevalence is difficult. It is estimated that approximately 97 million individuals worldwide have a disability which has an impact on the development of natural speech (Light, McNaughton, & Caron, 2019). First, one challenge in determining incidence and prevalence is that many different diagnoses or impairments can result in a profile that includes complex communication needs and the underlying impairments can vary greatly across age groups. Second, few impairments indicate the presence of complex communication needs. For example, while many individuals with a diagnosis of cerebral palsy can benefit from AAC, many others can communicate effectively with speech. Third, there is no standardized assessment protocol to identify complex communication needs or the potential to benefit from AAC. Although formal standardized assessments may be appropriate in some situations, often more qualitative, situation-specific, informal assessments are used, making collation of data difficult.

The impact of the absence of communication needs

Data are collected by groups, such as Surveillance Cerebral Palsy Europe (Surveillance of Cerebral Palsy (n.d.), but these are location- and diagnosis-specific and do not provide an estimate of the total number of persons who need AAC. Data specifically calculated for potential AAC needs across the UK suggest that 0.5% of the population requires some form of AAC, equating to over 250,000 individuals in the UK alone (Creer, Enderby, Judge, & John, 2016; Enderby, Judge, Creer, & John, 2013).

The World Health Organization (WHO) estimates that over one billion people, or 15% of the global population, live with a disability, with 80% of these living in low- and middle-income countries (World Health Organization, 2011). Sub-Saharan Africa is estimated to have the highest incidence of disability in the world with almost 66% of its population living with a disability (McLachlan & Schwarts, 2009). In South Africa, the prevalence of disability is estimated at approximately 13% and severe disability at approximately 5% (Statistics South Africa, 2013). The prevalence of communication disabilities, including those that might benefit from AAC, for South Africa is estimated to be 6–12% in children over the age of 5 years.

There is a wide range of children and adults with different disabilities, all of whom can benefit from AAC. Regardless of disability or age, the common factor is that communication needs and effective social participation cannot be met using speech alone. AAC can benefit individuals with congenital disabilities (e.g., cerebral palsy, developmental disability, intellectual disability), acquired disabilities (e.g., stroke, traumatic brain injuries, neurodegenerative diseases) or neurological differences (e.g., autism spectrum disorder). The intervention needs of a person with a developmental

disability differ from those of someone who developed language normally and then experienced loss of ability due to an acquired disorder. Furthermore, the physical abilities of people who can benefit from AAC will also vary, with some individuals having no physical limitations and others having severe physical disabilities; for example, many young people with autism spectrum disorder benefit from AAC but do not have any recognizable physical challenge (Binger, Kent-Walsh, Ewing, & Taylor, 2010). There may be those living with Parkinson's Disease who benefit from technology that amplifies their speech output, making it intelligible and accessible during most conversations. Similarly, persons in need of AAC may have a range of cognitive abilities, with some individuals having no cognitive impairments while others may have severe cognitive difficulties.

The role of AAC intervention also varies for different populations. For some, AAC intervention is aimed at supporting expressive language abilities as a short-term supportive measure (e.g., children with speech motor dysfunction, Down Syndrome, language impairment and dyspraxia). AAC may be a means of expanding vocabulary and supporting expression while speech is still developing. For others, AAC represents a permanent means of expressive communication (e.g., individuals with severe cerebral palsy and individuals with severe cognitive impairment). Hence, AAC can enhance the communication of persons with communication needs in a variety of ways.

Over and above their underlying communication impairments, persons who require AAC may be at increased risk of language and literacy difficulties, partly because their access to education is often more limited. In fact, it is well documented that even in well-served communities, persons who use AAC typically fail to achieve literacy levels commensurate with their cognitive capacities (Smith & Murray, 2016; Soto & Zangari, 2009). A recent report (Human Rights Watch, 2015) found that many children with disabilities in South African schools face discriminatory practices which serve as barriers to receiving quality education. The barriers include: limited access to education with the same curriculum as children without disabilities; costs of education; increased vulnerability to violence and abusive practices; and inadequately trained teachers. These barriers have resulted in young persons with disabilities leaving school with a lack of the basic life skills needed to find employment or to continue with further education (Human Rights Watch, 2015).

Key information for health professionals, social workers, community leaders, and educational practitioners

Early intervention incorporating both low- and high-tech AAC can be effective in enhancing expressive and receptive language abilities (Dada, Flores, Bastable, & Schlosser, 2020). Furthermore, AAC systems can improve the quality of life of individuals who require AAC by enhancing their access to education and participation in society. Communication occurs between individuals. For this reason, a core focus of effective AAC interventions involves training of communication partners, that is, the people around the person who uses AAC such as peers, family, teachers, and colleagues to support communication (Kent-Walsh, Murza, Malani, & Binger, 2015).

How to identify the need for appropriate AAC systems

AAC strategies should be used to provide methods of communication for persons with complex communication needs, such as people who cannot use speech adequately to express themselves. AAC can be appropriate for the person that has slurred, distorted and unintelligible speech and the child who has a limited vocabulary. AAC can be used to promote expressive and receptive communication and includes the use of both written and spoken communication. AAC can be used in a variety of settings, including homes, schools, universities, hospitals, care homes and communities. To reiterate, it can be used with individuals who require communication assistance which is either temporary (children/adults with tracheostomy) or permanent (children/adults with athetoid cerebral palsy).

As stated previously, there are both unaided and aided AAC systems. A combination of aided and unaided AAC systems is frequently recommended for children. This combination is referred to as multimodal communication similar to the way that children are supported to develop language in a more typical way (Braddock, Hilton, & Loncke, 2017).

AAC intervention is complex as it is not only about choosing one AAC system but recognizing how to combine various AAC techniques and systems to enhance the individual's communication abilities and participation across different life contexts. Where possible, advice should be sought from experts in the field of AAC as they will have experience of the range of AAC systems available and the conditions resulting in complex communication needs. These individuals will be well placed to detail the nuances of AAC and match them to individual needs and settings.

There are devices that provide line drawings, provided by Picture Communication Symbols (Tobii Dynavox, 2021), Widgit symbols (Widget Software, 2021), Pixon symbols (PRC-Saltillo, 2021), and Blissymbols (Blissymbolics Communication International, 2021). Software for most of these devices is commercially available. PCs are readily available and used extensively internationally, particularly by school-aged children who use AAC (Dada, Murphy, & Tönsing, 2017). There are also open-source websites where symbols are available through Bildstöd (2021), Open Symbols (2021), and Global Symbols (2021). Blidstöd is a free resource developed by DART, a centre for AAC in Sweden. This resource allows practitioners to create picture-based material for communication. OpenSymbols is a collection of open-licensed picture 50,000 symbols that can be used for augmentative communication. This platform hosts links to various open course symbol libraries. Global Symbols is a platform hosting links to various open course symbol libraries that allows practitioners to create boards to aid communication with thousands of free images.

Aided symbols can also be displayed using AAC devices. These devices use batteries, electricity, and electronics to function. Dedicated AAC devices, which are designed solely for communication purposes, may allow recording of individual or multiple messages, such as iTalk2 (2021) and Go Talk (2021). The advantage of these devices is that they use digital recording and messages can be stored in any language. There are also dedicated AAC devices that allow for more extensive pre-stored vocabularies, usually in English, such as Liberator Rugged (2021), Indi 7 (2021), and TouchChat Express (2021).

Non-dedicated AAC devices are an alternative to dedicated high-technology AAC devices. Most devices have the advantage of being cost-effective, light and mobile, and are considered socially more acceptable (Hyatt, 2011). They are not designed solely for communication purposes. Non-dedicated AAC devices may be desktop or laptop computers, smart phones or tablets, which are used as multipurpose systems (Glennen, 1997). These devices can be adapted by loading appropriate AAC communication software for use as AAC communication systems. However, the lack of ruggedness and risk of water damage or breakage if dropped are major factors to consider, as are the lack of technological support and quality control, which influence the use of non-dedicated AAC devices (AAC-RERC, 2011). McNaughton and Light (2013) noted that perhaps the greatest danger of non-dedicated high-technology AAC devices is that the excitement of having the equipment may result in a focus on the technology alone, while the end goal of AAC – namely communication and increased interaction of persons with complex communication needs through the use of available technologies – may be neglected. This reinforces the need for knowledge and expertise in the workforce supporting those with complex communication needs. Another important type of technology is low-technology AAC which uses resources such as paper and cardboard to make communication books using alphabet charts, pictures from magazines, or even physical objects to share their message. This type of technology may be more affordable and does not rely on electricity.

Information for professionals working with persons who use AAC

AAC should be accessible to all needing such support regardless of level of disability. All individuals are considered candidates for AAC intervention if their communication abilities do not meet their communication needs. AAC services should include assessment, selection of the appropriate approach/approaches and training. It is important that encouragement is given to the individual and their caregivers in usage and extending use of the device in different environments as well as having regular reviews in order to establish whether the chosen approach is still appropriate for the individual.

Assessment approaches for AAC

The goal of an AAC assessment is not to identify whether an individual can use a communication aid, but rather to determine the full range of system components (i.e., the many modes of communication) that will optimize communication for that individual in different settings. Assessment is an ongoing process and decisions need to be continuously reviewed as skills emerge or are lost and as communication needs change (Murray et al., 2019). Assessment ideally involves a team approach with input from several different professionals, family members, caregivers, and the person who requires AAC. Effective assessment is dynamic and draws on a combination of standardized assessments as well as other informal assessments and observation. Examples include the Triple C Checklist of Communication Competence (Bloomberg, West, & Johnson,

1999); The Functional Communication Profile (Kleiman, 2014), and the Test of Aided Communication Symbol Performance (Bruno, 2010). Many standardized measures require a verbal or motor response such as naming pictures or pointing to stimulus items. It may be necessary to modify the response mode for those whose motor skills preclude these responses. Any such changes in administration procedures necessarily change the nature of the assessment task and mean that standardized scores cannot be used, but a descriptive summary of the person's abilities could be extrapolated.

Assessments typically include a case history, an ecological inventory (i.e., an inventory of the communication opportunities, needs, and barriers experienced across the day), a self-report of communication needs, and some measure of sensory and motor status. A cognitive communication assessment is also required, to identify what kinds of symbols best meet the language and communication skills and needs of the person. A process of feature matching (Murray et al., 2019; Shane & Costello, 1994) supports the identification of the optimal match between the resources presented by an individual and the demands and requirements of specific tools and modes of communication. It is also important to consider cultural and linguistic factors during the assessment, including the preferred language of communication partners and the availability of vocabulary. Finally, a comparison with typically developing peers to identify gaps in social participation is valuable.

In order to select an appropriate AAC system, the findings of these assessments should be matched to the features of the system in order to ensure a good fit between the person (capabilities, needs and goals), their environment (physical and social) and the AAC system.

Becoming competent in using AAC takes time and relies on opportunities to learn from others as well as on ongoing support and guidance. Healthcare professionals, educators, and family members need to recognize the challenges of using AAC and the importance of supporting communication for persons that require AAC. Sociocultural models of language development emphasize the value of immersion in a language community where learners see competent partners modelling the use of the communication system (typically spoken language) that they are expected to acquire and use. Individuals who use AAC also need to be exposed to communication partners who model communication using AAC. Communication partners therefore play a pivotal role in establishing and maintaining communication competence in persons who use AAC and in validating AAC modes of communication (Von Tetzchner, 2018). Communication partner training is a key element when introducing AAC interventions and the potential for such training must be considered by healthcare professionals when prescribing AAC systems.

The goal of AAC intervention is to enhance the communication of individuals who use AAC and to ensure the development of adequate and functional communication skills such that they are able to participate fully in their daily lives. AAC intervention, when possible, should occur in the natural environment of everyday conversations, e.g., at home, the workplace, in the classroom, to enhance generalization and should incorporate a combination of aided and unaided communication modalities. There are no prerequisites for AAC intervention, and a variety of strategies and techniques should be implemented to determine the most effective means of communication (Brady et al., 2016). A list of resources is presented in Table 11.1.

Discussion

Communication is a basic human right. AAC provides access to communication for persons with complex communication needs. Many AAC systems are easily made and accessible, irrespective of available resources. The use of paper, media-available images or real objects may offer anyone a means of indicating their preferences, interests and needs. These resources are typically available in most contexts and merely require some creative thinking to support people to convey their desired message. Irrespective of location, persons who benefit from AAC should have access to informed health professionals, social workers, and educational practitioners who are able to offer informed choices of the most appropriate AAC system for the individual now and in the future, whether this refers to developing skills or losing skills. The key aim of any AAC system is to enable those who require it to have ready access to a means of communication, supporting them to participate in a variety of contexts. This aspiration of all AAC users

Table 11.1 Resources for practitioners.

Assessment tools
Functional gaze control project
The Communication Matrix
I-ASC: Identifying Appropriate Symbol Communication
Open-source symbols
Open Symbols
Bildstod Symbols
Global Symbols
Assistive technology need mapping
The World Health Organization (2021) offers the Rapid Assistive Technology Assessment tool (rATA)
CALL Scotland offers iPad Apps for Complex Communication Support Needs
Intervention resources
Indian Institute of Cerebral Palsy
Centre for Alternative and Augmentative Communication
General information
World Health Organization (2018). Global Cooperation on Assistive Technology (GATE).
World Health Organization (2021). Assistive Technology.
The UN Refugee Agency (2021). Improving communication accessibility for refugees with communication disabilities through capacity building.

resonates with the underlying tenets of the ICF (World Health Organization, 2001) supporting effective participation.

Useful websites

AAC-RERC. (2011). Mobile devices and communication apps. Available from http://aac-rerc.psu.edu/index.php/pages/show/id/46 (accessed August 2021).

Bildstöd (2021). DART-Centre for AAC and AT in the project KomHIT. Available at www.bildstod.se

Blissymbols (2021). Blissymbolics Communication International. Available at https://www.blissymbolics.org/

CALL Scotland (2020). iPad Apps for Complex Communication Support Needs Augmentative and Alternative Communication (AAC). Available at https://www.aacscotland.org.uk/files/cm/files/iPad-Apps-for-Complex-Communication-Support-Needs.pdf.

Centre for Alternative and Augmentative Communication (2021). Available at https://www.up.ac.za/centre-for-augmentative-alternative-communication/article/2938080/co-designing-health-education-materials.

Communication Matrix. (2021). Available at https://www.communicationmatrix.org/

Functional Gaze Control Project. (2021). Functional Gaze Control. Available at https://www.ucl.ac.uk/gaze/gaze-project

Global Symbols (2021). Global Symbols CIC. Available at www.globalsymbols.com

GoTalk 9+ (2021). Attainment Company. Available at www.attainmentcompany.com

Indi 7 (2021).Tobii Dynavox. Available at www.tobiidynavox.com

Indian Institute of Cerebral Palsy (2012). II CP. Available at http://www.iicpindia.org/publications.php

iTalk2 (2021). ABlenet Inc. Available at https://www.ablenetinc.com/

Liberator Rugged (2021). Liberator. Available at www.liberator.co.uk

Picture Communication Symbols (PCS). (2021). Tobii Dynavox. Available at www.tobiidynavox.com

Pixon Symbols (2021). PRC-Saltillo. Available at www.prc-saltillo.com

Tobii Dynavox (2021). Assistive technology for communication. Available at www.tobiidynavox.com

TouchChat Express (2021). Saltillo. Available at www.saltillo.com

Widgit Symbols (2021). Symbol Software Services. Available at www.widgit.com

References

American Speech-Language-Hearing Association. (2015). AAC: More than three decades of growth and development. Available at http://www.asha.org/public/speech/disorders/AACThreeDecades/

Beukelman, D.R. & Light, J.C. (2020). *Augmentative & Alternative Communication: Supporting Children and Adults with Complex Communication Needs*, 5th ed. Baltimore, MD: Brookes.

Biggs, E., Carter, E., & Gilson, C. (2018). Systematic review of interventions involving aided AAC modeling for children with complex communication needs. *American Journal on Intellectual and Developmental Disabilities*, *123*(5), 443–473.

Binger, C., Kent-Walsh, J., Ewing, C., & Taylor, S. (2010). Teaching educational assistants to facilitate the multisymbol message productions of young students who require augmentative and alternative communication. *American Journal of Speech-Language Pathology*, *19*, 108–120. Available at https://doi.org/10.1044/1058-0360(2009/09-0015)

Bloomberg, K., West, D., & Johnson, H. (1999). *The Triple C: Checklist of Communication Competencies*. Scope: Box Hill, Victoria, Australia.

Braddock, B.A., Hilton, J., & Loncke, F. (2017). Multimodal behaviors in autism spectrum: Insights from typical development inform AAC. *Perspectives of the ASHA Special Interest Groups*, *2*(12), 116–126.

Brady, N.C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B.T., Paul, D., Romski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, *121*(2), 121–138. https://doi.org/10.1352/1944-7558-121.2.121

Bruno, J. (2010). *Test of Aided-communication Symbol Performance*. Pittsburgh, PA: Dynavox Mayer Johnson.

CALL Scotland. (2020). iPad apps for complex communication support needs: Augmentative and Alternative Communication (AAC). Available at https://www.aacscotland.org.uk/files/cm/files/iPad-Apps-for-Complex-Communication-Support-Needs.pdf

Centre for Alternative and Augmentative Communication. (2021). Available at https://www.up.ac.za/centre-for-augmentative-alternative-communication/article/2938080/co-designing-health-education-materials

Creer, S., Enderby, P., Judge, S., & John, A. (2016). Prevalence of people who could benefit from augmentative and alternative communication (AAC) in the UK: Determining the need. *International Journal of Language and Communication Disorders*, *51*(6), 639–653. doi:10.1111/1460-6984.12235

Dada, S., Flores, C., Bastable, K., & Schlosser, R.W. (2020). The effects of augmentative and alternative communication interventions on the receptive language skills of children with developmental disabilities: A scoping review. *International Journal of Speech-Language Pathology*, *23*(3), 247–257.

Dada, S., Murphy, Y., & Tönsing, K. (2017). Augmentative and alternative communication practices: A descriptive study of the perceptions of South African speech-language therapists. *Augmentative and Alternative Communication*, *33*(4), 189–200.

Enderby, P., Judge, S., Creer, S., & John, A. (2013). Examining the need for provision of AAC methods in the UK. *Advances in Clinical Neuroscience and Rehabilitation*, *13*(4), 20–23.

Glennen, S.L. (1997). Augmentative and alterative communication systems. In S.L. Glennen & DC. De Coste (Eds), *Handbook of Augmentative and Alternative Communication*, pp.59–96. New York: Singular.

Human Rights Watch. (2015). "Complicit in exclusion": South Africa's failure to guarantee an inclusive education for children with disabilities. Available at https://www.hrw.org/ report/2015/08/18/complicit-exclusion/south-africas-failure-guarantee-inclusiveeducation-children

Hyatt, G.W. (2011). The iPad: A cool communicator on the go. *Perspectives on Augmentative and Alternative Communication*, *20*(1), 24–27.

Kent-Walsh, J., Murza, K.A., Malani, M.D., & Binger, C. (2015). Effects of communication partner instructions of individuals using AAC: A meta-analysis. *Augmentative and Alternative Communication*, *31*(4), 271–284.

Kleiman, L.I. (2014). *Functional Communication Profile, Revised*. Austin, TX: Pro-Ed.

Light, J., McNaughton, D., & Caron, J. (2019). New and emerging AAC technology supports for children with complex communication needs and their communication partners: State of the science and future research directions. *Augmentative and Alternative Communication*, *35*(1), 26-41. Available at https://doi: 10.1080/07434618.2018.1557251

McLachlan, M. & Schwartz, L. (2009). *Disability and International Development: Towards Inclusive Global Health.* New York: Springer.

McNaughton, D. & Light, J. (2013). The iPad and mobile technology revolution: Benefits and challenges for individuals who require augmentative and alternative communication. *Augmentative and Alternative Communication*, *29*(2), 107–116.

Murray, J., Lynch, Y., Meredith, S., Moulam, L., Goldbart, J., Smith, M., & Judge, S. (2019). Professionals' decision-making in recommending communication aids in the UK: Competing considerations. *Augmentative and Alternative Communication*, *35*(3), 167–179.

OpenSymbols. (2021). Open Symbols: Open-licensed communication symbols for everyone. Available at www.opensymbols.org

Shane, H.C. & J. Costello, M. (1994). Augmentative communication assessment and the feature matching process. *American Speech Language Hearing Association*. New Orleans, LA.

Smith. M. & Murray, J. (Eds). (2016). *The Silent Partner? Language, Interaction and Aided Communication.* Havant: J&R Press.

Soto, G. & Zangari, C. (2009) *Practically Speaking: Language, Literacy and Academic Development for Students with AAC Needs.* London: Brookes.

Statistics South Africa. (2013). Statistical release P0302: Midyear population estimates 2013. Available at http://www.statsa.gov.za/publications/P0302/P 0302 2013.pdf

Surveillance of Cerebral Palsy in Europe (SCPE). (2000). Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. *Developmental Medicine & Child Neurology*, *42*(12), 816–824. doi: 10.1017/s0012162200001511. PMID: 11132255

United Nations General Assembly. (1989). Convention on the Rights of the Child, 20 November 1989. *Annual Review of Population Law*, *16*, 95–501.

UN Refugee Agency (2021). Improving communication accessibility for refugees with communication disabilities through capacity building. Available at https://www.unhcr.org/protection/operations/60e5ad650/improving-communication-accessibility-refugees-communication-disabilities.html

von Tetzchner, S. (2018). Introduction to the special issue on aided language processes, development, and use: An international perspective. *Augmentative and Alternative Communication*, *34*(1), 1–15.

World Health Organization. (WHO). (2001). *International Classification of Functioning, Disability and Health: ICF*. Geneva: Switzerland.

World Health Organization. (WHO). (2011). World Report on Disability. Available from https://www.who.int/disabilities/world_report/2011/report.pdf

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.,