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COMMENTARY

From individual to global: Human rights and aphasia

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Abstract

This commentary marks the 70th anniversary of the Universal Declaration of Human Rights by examining Article 19 and its application to people with aphasia. This group of people still face lack of access, stigmatisation, exclusion, disadvantage and social withdrawal as well as poor public awareness of aphasia and inadequate prioritisation of support and resources. Nevertheless, a range of creative initiatives at individual, healthcare, local community, national and global levels have helped to connect and empower people with aphasia. Such initiatives include provision of accessible information in a range of media, inclusion of people with aphasia in decision-making and as research partners, awareness raising campaigns to counter attitudinal barriers, organisation of community aphasia groups, development of guidelines for best practice, national aphasia associations and international collaborations such as Aphasia United. While ongoing work and resourcing is needed to expand these efforts further, they have helped people with aphasia to be heard and to protect their sense of dignity which underlies human rights. A human rights approach can unite, politicise and refocus these efforts, and highlight the essential role of communication in fostering a better quality of life.

Keywords: *Article 19; Universal Declaration of Human Rights; United Nations; aphasia; stroke*

From individual to global: Human rights and aphasia

On December 10th 1948, the Universal Declaration of Human Rights (United Nations, 1948) was proclaimed by the United Nations General Assembly in Paris. Article 19 captured the fundamental place of language and communication as a human right: “Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers”. At exactly this time, in the shadow of the Second World War, George Orwell was finishing his novel *1984* (Orwell, 1949) with its warning about how the manipulation and restriction of language can curtail people’s most basic freedoms. The link between language, agency, autonomy, and liberty was very clear in his dystopic vision.

Seventy years on from the Universal Declaration of Human Rights, this journal is marking that milestone by highlighting the role of language in achieving human rights and positioning the efforts of the speech-language pathology (SLP) profession within a human rights framework. Language is one

of the defining features of humanity. As Davidson (2011, p. 23) wrote, language is: “... the glue that binds us together as social animals. Each language has its own way to articulate reality and dreams and so create poetry, myth, history and laws”. When language breaks down, as can happen after brain injury, this richness of human experience is at risk. Moreover, deviation from *normal* language, communication or behaviour can mean people are “consigned to the margins in communities and ... denied their human rights in the most fundamental of ways” (Wickenden, 2013, p. 16).

The focus of this commentary is to explore how the rights enshrined in Article 19 of the Universal Declaration of Human Rights are threatened for people with aphasia, but also how they are being protected and reclaimed. For this purpose, the words “to seek, receive and impart information and ideas” will be interpreted to include the social interaction within which they occur. People rarely seek, receive or impart information and ideas in a vacuum or without purpose. Rather, through interaction they access their communities, become educated, influence, guide or protect others, strengthen relationships, or assert themselves.

Through these encounters, conversations and exchanges, human beings negotiate their place with others, achieve a sense of self, and a sense of dignity which underlies human rights.

Aphasia is most commonly caused by stroke, one of the leading causes of disability in adults. Occurring in approximately a third of all strokes (Engelter et al., 2006), aphasia is a loss of language ability which can affect verbal expression, comprehension, reading and writing. It does not imply loss of intelligence. Nevertheless, people with aphasia report they are frequently treated as if it does, leading to feelings of stigmatisation and exclusion (Parr, Byng, Gilpin, & Ireland, 1997). Aphasia can rob people of their “freedom of expression” at a fundamental level, threatening their identity, and disrupting their ability to demonstrate competence, share experience, and participate in life as before (Shadden, Hagstrom & Koski, 2008). Aphasia frequently depletes social networks (Vickers, 2010), impedes return to work (Morris, Franklin, & Menger, 2011) and results in “third party disability” for families (Grawburg, Howe, Worrall, & Scarinci, 2013). After a stroke, people with aphasia have more depression, decreased participation and social withdrawal than those without aphasia post stroke (Hilari, 2011) and the condition impacts significantly on quality of life (Hilari, Needle, & Harrison, 2012). In addition, our Information Age demands a high level of language competence so an inability to understand and respond to the speedy, continuous flow of information, or manage digital technology is also disempowering (Brandenburg, Worrall, Rodriguez, & Copland, 2013; Kelly, Kennedy, Britton, McGuire, & Law, 2016).

Aphasia impairment is not in itself a human rights issue but rather the degree to which people with aphasia have access to full participation, inclusion and dignity is. Several researchers have discussed aphasia in these terms. Horner (2013) noted the importance of the Universal Declaration of Human Rights along with other international covenants of relevance to people with aphasia, particularly the Convention on the Rights of Persons with Disabilities (United Nations, 2006). She also reviewed the range of United States constitutional and statutory rights, legal supports, professional ethics standards, accreditation guidelines, and clinical standards for capacity/competence assessment, in order to show that there are formalised ways to preserve rights to access and participation for people with aphasia. Wickenden (2013), writing about the World Report on Disability (World Health Organization and the World Bank, 2011), also urged SLPs to “broaden their lens and become much more political animals” (p. 19). She noted the importance of the Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities, the International Classification of Functioning, Disability and Health (ICF; World

Health Organization, 2001) and community-based rehabilitation (CBR; World Health Organization, 2010) in order to embrace human rights approaches nationally and internationally. She suggested a focus beyond SLP services to ensure that each person with aphasia is “acknowledged as a person and a citizen” (Wickenden, 2013, p. 17). Siegert, Ward, and Playford (2010) highlighted the surprising lack of attention to human rights in the rehabilitation literature, arguing: “It is time then for health professionals in rehabilitation to begin to take rights seriously” (p. 971). Using a case study of a woman with aphasia post stroke, they argued that “an ethical approach to understanding, measuring and improving outcomes in rehabilitation requires an explicit perspective on human rights” (p. 965).

Below are a few examples from a large body of literature on what has been attempted or achieved to promote human rights for people with aphasia on several levels: for individuals and their families; within healthcare and rehabilitation services; in local communities; nationally; and globally.

Individuals and families

There are many ways individuals and families can be empowered to exercise their rights in the context of aphasia. The shift in health policy to person/patient/family centredness (Davidson & Worrall, 2011) encompasses respect for individuality and values, acknowledgement of the expertise of lay knowledge, autonomy, shared decisions, a positive therapeutic alliance, and the need to view people within their social context. There has also been an increased interest in narrative approaches (Hinckley, 2008; Shadden et al., 2008), valuing personal stories of recovery (Green & Waks, 2008) and recognition of patient narratives as valuable feedback on care (Hersh, 2015). Narrative approaches include hearing stories of marginalised groups that have not traditionally been aired such as those of Indigenous people with aphasia (Armstrong, Hersh, Hayward, Fraser, & Brown, 2012; McClellan, McCann, Worrall, & Harwood, 2014). Aphasia is increasingly understood as a family problem (Howe et al., 2012) which means prioritising the goals of both people with aphasia and family members. In some health systems, family, friends and other communication partners are now routinely offered assistance and training to promote satisfying interactions with people with aphasia (Simmons-Mackie, Raymer & Cherney, 2016), and supported conversation for aphasia is well recognised as good practice (Kagan, 1998). There is a proliferation of aphasia-friendly, accessible informational materials (Rose, Worrall, Hickson, & Hoffmann, 2011), such as those developed by the Stroke Association in the United Kingdom (https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf), accessible websites (Kerr, Hilari & Litosseliti, 2010),

and videos to support people with aphasia and families, such as The Treasure Hunt created to help children understand aphasia (<http://www.brain-facts.org/diseases-disorders/injury/articles/2011/stroke-treasure-hunt/>).

Healthcare and recovery

The ICF (World Health Organization, 2001) has been embedded into healthcare systems with its focus on a holistic view of disability and emphasis on activity, participation and contextual factors (Howe, 2008). Rehabilitation options are now offered beyond the impairment to include functional therapy, communication partner training, and group therapy. Kagan and Simmons-Mackie (2013) have called for SLPs to be more proactive, educate others about how aphasia can mask competence, and badge communication as an activity of daily living. This would encourage greater acknowledgement by healthcare teams of the importance of communication, and perhaps reduce inappropriate discharge from rehabilitation. In addition, ongoing research efforts, including more randomised controlled trials, are increasing the evidence base so that aphasia treatments can be valued, funded, and offered at the right time and at the right intensity (Brady, Kelly, Godwin, Enderby, & Campbell, 2016). People with aphasia are increasingly viewed as partners in research (Hersh, 2014). Broad notions of access are influencing healthcare (Cruice, 2007), providing options for improving communication accessibility in acute, rehabilitation and long-term care settings (Simmons-Mackie et al., 2007), and demonstrating how technological interventions might reduce social isolation (Marshall et al., 2016).

Local communities

In the broader community, awareness of aphasia is low and on average less than 10% of the population know anything about it (Code et al., 2016). Most people take communication for granted and, in contrast to visual, hearing or physical disability, find it hard to imagine what language impairment might be like. This increases feelings of isolation for people with aphasia. Dedicated aphasia centres and organisations, like the Aphasia Institute (<http://www.aphasia.ca/>), the Adler Aphasia Centre (<https://adleraphasiacenter.org/>), and the Talkback Association for Aphasia (<http://www.aphasia.asn.au/>), and local community aphasia groups (Rose & Attard, 2015) are safe places to practice conversation and gain support, and are important in building confidence, friendships, and social connections. Many initiatives have sought to reduce environmental and attitudinal barriers and encourage community participation for people with aphasia, one example being increasing access to museums and

galleries (Duchan, Jennings, Barrett, & Butler, 2006).

Nationally

Increasingly, countries have national aphasia consumer organisations, for example: the National Aphasia Association in North America (<https://www.aphasia.org/>), the Australian Aphasia Association (<https://aphasia.org.au/>), Aphasia NZ in New Zealand (<http://www.aphasia.org.nz/>), and the Stroke Association in the United Kingdom (<https://www.stroke.org.uk/what-stroke/what-aphasia/>), and these organisations hold national consumer conferences. The National Aphasia Association has developed a Bill of Rights (<https://www.aphasia.org/aphasia-bill-of-rights/>). In 2014, the Australian Aphasia Rehabilitation Pathway was launched (<http://www.aphasiapathway.com.au/>), an example of a national collaboration for best practice for aphasia recovery, and in 2015, the Australian Stroke Foundation launched their accessible online resources for the stroke community, including for people with aphasia and their families (<https://enableme.org.au/>).

Globally

In recent years, productive international alliances have encouraged global responses to aphasia. Worrall et al. (2013) introduced Aphasia United (www.aphasiaunited.org), “an overarching body for the global aphasia community” (p. 108). Since then, Aphasia United has developed best practice recommendations (Simmons-Mackie et al., 2017), available in aphasia-friendly form (<http://www.aphasiaunited.org/wp-content/uploads/2016/05/English-aphasia-friendly-version.pdf>) and translated into many different languages (<http://www.aphasiaunited.org/best-practice-recommendations/>). Aphasia United has developed a website and social media presence, made a recommendation to clarify terminology around aphasia internationally (Worrall et al., 2016) and, in 2017, it supported the first international consumer conference for people with aphasia held in the United Kingdom. The website for the Collaboration of Aphasia Trialists includes information on organisations to support and connect people with aphasia internationally (<http://www.aphasia-trials.org/index.php/aphasia-support>) although many Majority World, low and middle-income, countries are without any services for people with aphasia (Wickenden, 2013). An international collaboration with a rights agenda has explored aphasia in Indigenous communities in Canada, New Zealand, Australia and South Africa (Penn & Armstrong, 2017; Penn et al., 2017), acknowledging the multiple layers of disempowerment for those already disadvantaged through a colonial and

neo-colonial history of displacement, subjugation and loss of culture.

Conclusions

People with communication disability are marginalised in society and even within disability movements (Wickenden, 2013), and there is a long way to go to reverse this situation. However, the examples of local groups of people with aphasia, the growing SLP evidence base, shifting community values towards inclusion for people with disabilities, technological options to aid accessibility and connection, and local, national and global collaborations, all point to progress. A human rights perspective should be exploited as a framework for more ambitious goals for people with aphasia well before the next 70 years elapse: to argue for more comprehensive global coverage of healthcare systems which include SLP services; to expand our agenda to include how aphasia intersects with social determinants of health; to strive for an aphasia-friendly environment in which communication disability is legislated and protected as it is for physical disability; and to have strategies in place so that people with aphasia can be equal partners in initiatives and research, take an increased role in the disability movement and determine their own agenda. A human rights perspective could prompt people with aphasia and SLPs to be more politicised and empowered to effect change. This perspective applies to other acquired communication disorders as well as aphasia. It unites diverse efforts to improve access, inclusion and quality of life for people with aphasia into a cohesive campaign, and strengthens the arguments for funding and other resources to support social inclusion and participation outcomes. With language and communication as central aspects of humanity, the need to protect, and advocate for the rights of people with aphasia to participate and be included at all levels is paramount, and the Universal Declaration of Human Rights provides an essential underpinning to support this goal.

Declaration of interest

No potential conflict of interest was reported by the author.

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References

- Armstrong, E., Hersh, D., Hayward, C., Fraser, J., & Brown, M. (2012). Living with aphasia: Three Indigenous Australian stories. *International Journal of Speech-Language Pathology*, 14, 271–280. doi:10.3109/17549507.2011.663790.
- Brady, M.C., Kelly, H., Godwin, J., Enderby, P., & Campbell, P. (2016). Speech and language therapy for aphasia following stroke. *Cochrane Database of Systematic Reviews*, CD000425. doi:10.1002/14651858.CD000425.pub4.
- Brandenburg, C., Worrall, L., Rodriguez, A.D., & Copland, D. (2013). Mobile computing technology and aphasia: An integrated review of accessibility and potential uses. *Aphasiology*, 27, 444–461. doi:10.1080/02687038.2013.772293.
- Code, C., Papathanasiou, I., Rubio-Bruno, S., de la Paz Cabana, M., Villanueva, M.M., Haaland-Johansen, L., ... Robert, A. (2016). International patterns of the public awareness of aphasia. *International Journal of Language and Communication Disorders*, 51, 276–284. doi:10.1111/1460-6984.12204.
- Cruice, M. (2007). Issues of access and inclusion with aphasia. *Aphasiology*, 21, 3–8. doi:10.1080/02687030600798071.
- Davidson, B., & Worrall, L. (2011). Living with aphasia: A client-centred approach. In I. Papathanasiou, P. Coppens & C. Potagas (Eds.), *Aphasia and related neurogenic communication disorders* (pp. 255–274). Boston, MA: Jones & Bartlett Publishers.
- Davidson, J.P. (2011). *Planet word*. London, UK: Penguin.
- Duchan, J., Jennings, M., Barrett, R., & Butler, B. (2006). Communication access to the arts. *Topics in Language Disorders*, 26, 210–220. doi:10.1097/00011363-200607000-00005.
- Engelter, S.T., Gostynski, M., Papa, S., Frei, M., Born, C., Ajdacic-Gross, V., ... Lyrer, P.A. (2006). Epidemiology of aphasia attributable to first ischemic stroke: Incidence, severity, fluency, etiology, and thrombolysis. *Stroke*, 37, 1379–1384. doi:10.1161/01.STR.0000221815.64093.8.
- Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). A qualitative investigation into third-party functioning and third-party disability in aphasia. *Aphasiology*, 27, 828–848. doi:10.1080/02687038.2013.768330.
- Green, C., & Waks, L. (2008). A second chance: Recovering language with aphasia. *International Journal of Speech-Language Pathology*, 10, 127–131. doi:10.1080/17549500801971517.
- Hersh, D. (2014). Participants, researchers and participatory research. *Journal of Clinical Practice in Speech-Language Pathology*, 16, 123–126.
- Hersh, D. (2015). “Hopeless, sorry, hopeless”: Co-constructing narratives of care with people who have aphasia post-stroke. *Topics in Language Disorders*, 35, 219–236. doi:10.1097/TLD.0000000000000060.
- Hilari, K. (2011). The impact of stroke: Are people with aphasia different to those without?. *Disability and Rehabilitation*, 33, 211–218. doi:10.3109/09638288.2010.508829.
- Hilari, K., Needle, J.J., & Harrison, K.L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation*, 93(1 Suppl 1), S86–S95. doi:10.1016/j.apmr.2011.05.028.
- Hinckley, J.J. (2008). *Narrative-based practice in speech-language pathology: Stories of a clinical life*. San Diego, CA: Plural Publishing.
- Horner, J. (2013). Communication access, rights and policies. In N. Simmons-Mackie, J. King & D. Beukelman (Eds.) *Supporting communication for adults with acute and chronic aphasia* (pp. 303–324). Baltimore, MD: Paul H. Brookes Publishing.
- Howe, T. (2008). The ICF contextual factors related to speech-language pathology. *International Journal of Speech-Language Pathology*, 10, 27–37. doi:10.1080/14417040701774824.
- Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., Gilbert, J. (2012). “You needed to rehab ... families as well”: Family members’ own goals for aphasia rehabilitation. *International Journal of Language and Communication Disorders*, 47, 511–521. doi:10.1111/j.1460-6984.2012.00159.x.

- Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology*, 12, 816–830. doi:10.1080/02687039808249575.
- Kagan, A., & Simmons-Mackie, N. (2013). Changing the aphasia narrative. *ASHA Leader*, 18, 6–8.
- Kelly, H., Kennedy, F., Britton, H., McGuire, G., & Law, J. (2016). Narrowing the “digital divide”: Facilitating access to computer technology to enhance the lives of those with aphasia: A feasibility study. *Aphasiology*, 30, 133–163. doi:10.1080/02687038.2015.1077926.
- Kerr, J., Hilari, K., & Litosseliti, L. (2010). Information needs after stroke: What to include and how to structure it on a website. A qualitative study using focus groups and card sorting. *Aphasiology*, 24, 1170–1196. doi:10.1080/02687030903383738.
- Marshall, J., Booth, T., Devane, N., Galliers, J., Greenwood, H., Hilari, K., ... Woolf, C. (2016). Evaluating the benefits of aphasia intervention delivered in virtual reality: Results of a quasi-randomised study. *PLoS ONE*, 11, e0160381. doi.org/10.1371/journal.pone.0160381
- McClellan, K.M., McCann, C.M., Worrall, L.E., & Harwood, M.L.N. (2014). “For Māori, language is precious. And without it we are a bit lost”: Māori experiences of aphasia. *Aphasiology*, 28, 453–470. doi:10.1080/02687038.2013.845740.
- Morris, J., Franklin, S., & Menger, F. (2011). Returning to work with aphasia: A case study. *Aphasiology*, 25, 890–907. doi:10.1080/02687038.2010.549568.
- Orwell, G. (1949). *Nineteen eighty-four: A novel*. London, UK: Secker & Warburg.
- Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with language loss after stroke*. Buckingham, UK: Open University Press.
- Penn, C., & Armstrong, E. (2017). Intercultural aphasia: New models of understanding for Indigenous populations. *Aphasiology*, 31, 563–594. doi:10.1080/02687038.2016.1213788.
- Penn, C., Armstrong, E., Brewer, K., Purves, B., McAllister, M., Hersh, D., ... Lewis, A. (2017). De-colonizing speech-language pathology practice in acquired neurogenic disorders. *SIG 2 Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders*, 2, 91–99.
- Rose, M., & Attard, M. (2015). Practices and challenges in community aphasia groups in Australia: Results of a national survey. *International Journal of Speech-Language Pathology*, 17, 241–251. doi:10.3109/17549507.2015.1010582.
- Rose, T., Worrall, L.E., Hickson, L.M., & Hoffmann, T.C. (2011). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology*, 13, 335–347. doi:10.3109/17549507.2011.560396.
- Shadden, B., Hagstrom, F., & Koski, P.R. (2008). *Neurogenic communication disorders: Life stories and the narrative self*. San Diego, CA: Plural Publishing.
- Siebert, R.J., Ward, T., & Playford, D. (2010). Human rights and rehabilitation outcomes. *Disability and Rehabilitation*, 32, 965–971. doi:10.3109/09638281003775360.
- Simmons-Mackie, N.N., Kagan, A., Christie, C., Huijbregts, M., McEwen, S., & Willems, J. (2007). Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. *Aphasiology*, 21, 39–66. doi:10.1080/02687030600798287
- Simmons-Mackie, N., Raymer, A., & Cherney, L. (2016). Communication partner training in aphasia: An updated systematic review. *Archives of Physical Medicine and Rehabilitation*, 97, 2202–2221. doi:10.1016/j.apmr.2016.03.023.
- Simmons-Mackie, N., Worrall, L., Murray, L.L., Enderby, P., Rose, M., Paek, E.J., & Klippi, A. (2017). The top ten: Best practice recommendations for aphasia. *Aphasiology*, 31, 131–151. doi:10.1080/02687038.2016.1180662
- United Nations (1948). *Universal declaration of human rights*. Retrieved from <http://www.un.org/en/universal-declaration-human-rights/>.
- United Nations (2006). *Convention on the rights of persons with disabilities*. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.
- Vickers, C.P. (2010). Social networks after the onset of aphasia: The impact of aphasia group attendance. *Aphasiology*, 24, 902–913. doi:10.1080/02687030903438532.
- Wickenden, M. (2013). Widening the SLP lens: How can we improve the wellbeing of people with communication disabilities globally. *International Journal of Speech-Language Pathology*, 15, 14–20. doi:10.3109/17549507.2012.726276.
- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva, Switzerland: World Health Organization.
- World Health Organization. (2010). *Community based rehabilitation guidelines*. Retrieved from <http://www.who.int/disabilities/cbr/guidelines/en/>.
- World Health Organization and the World Bank (2011). *World report on disability*. Geneva, Switzerland: World Health Organization.
- Worrall, L., Simmons-Mackie, N., Wallace, S., Rose, T., Brady, M., Pak Hin Kong, A., ... Hallowell, B. (2016). Let’s call it “aphasia”: Rationales for eliminating the term “dysphasia”. *International Journal of Stroke*, 11, 848–851. doi:10.1177/1747493016654487.
- Worrall, L., Howe, T., O’Callaghan, A., Hill, A., Rose, M., Wallace, S., ... Rohde, A. (2013). The World Report on Disability as a blueprint for international, national, and local aphasia services. *International Journal of Speech-Language Pathology*, 15, 106–112. doi:10.3109/17549507.2012.721004.