

INFORMATION ABOUT APHASIA FOR THE NATIONAL DISABILITY INSURANCE AGENCY (NDIA)

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was passed in 2006 to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006). Similarly, The *Universal Declaration of Communication Rights* (International Communication Project, [ICP] 2014) asserts that: “Communication is the most fundamental of human capacities. People need to be able to communicate to fulfil their social, educational, emotional, and vocational potential. Barriers to communication impair an individual’s ability to:

- relate to and interact with others
- understand learn, share and apply knowledge
- achieve and maintain good physical and mental health
- participate appropriately and safely in purposeful occupations and/or leisure activities
- have fair access to the justice system and other public services.” (ICP, 2014).

IS APHASIA A COMMUNICATION DISABILITY?

Yes, it is! Aphasia is a communication disability due to an acquired impairment of language modalities caused by focal brain damage. Aphasia may affect participation and quality of life of the person with aphasia as well as their family and friends. This chronic disability masks competence and affects functioning across relationships, life roles and activities, thereby influencing social inclusion, social connectedness, access to information and services, equal rights, and wellbeing in family, community and culture.

Within the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF), aphasia is coded as an impairment of the mental functions of language, a communication activity limitation, and an interpersonal relationship participation restriction (WHO,

2001). It is caused by neurological damage to the language parts of the brain as a result of a stroke, focal traumatic brain injury, or a type of progressive disorder called primary progressive aphasia. It can occur in isolation or with other disabilities. The NDIA provides considerable funding and inclusion of capacity building for a person's physical needs, however this needs to also be the case for people with communication difficulties, i.e., people with aphasia, who also require supports on a day to day basis over the long term. Including capacity-building opportunities for an individual in their NDIS plan can represent a long-term financial benefit for funding bodies if adequate supports are implemented early and effectively.

THE FUNCTIONAL IMPACT OF APHASIA

The direct result of aphasia is impairment of language processing, which in turn significantly disrupts communication. Since communication is at the core of most of one's daily life, aphasia has significant and far-reaching consequences. Negative social outcomes for people with aphasia such as social isolation, reduced participation in activities, and loss of friendships are frequently reported in the literature (Brown, Davidson, Worrall & Howe, 2013; Code, 2003; Code & Hermann, 2003; Cruice, Worrall, & Hickson, 2006; Parr, Byng, Gilpin, & Ireland, 1997; Sarno, 1997; Natterlund, 2010; Zemva, 1999). Likewise, emotional problems in people with aphasia are highly prevalent (e.g., Hilari et al., 2010; Kauhanen et al., 2000; Thomas & Lincoln, 2008).

ASSOCIATED DEFICITS: Aphasia is often accompanied by coexisting disorders. For example, motor speech disorders such as dysarthria (weakness and poor coordination of speech muscles) or apraxia of speech (problems with planning production of correct speech sounds) often coexist with aphasia. Next, chronic motor impairment such as weakness or paralysis of one side of the body is common (Allina Health, 2006). People with aphasia may also experience coexisting changes in body sensation or visual perception (Allina Health, 2006). Many people with aphasia report fatigue. In addition, depression is extremely common in people with aphasia, with a prevalence of 70% at 3 months and 62% at 12 months, and increasing from 11% to 33% across the next 12 months (Kauhanen et al., 2000). As noted by Baker et al. (2018), "the high incidence of depression and lack of psychological intervention shown in current Australian stroke outcome data demonstrates an evidence-practice gap for the psychological care of people with aphasia" (p. 1870). These conditions complicate the impact of aphasia on daily life.

LIVING SITUATIONS: People with aphasia are less likely to be discharged home from inpatient settings than stroke patients without aphasia (Flowers et al., 2016). Not only is discharge to a residential setting not preferred by most patients, but also living among unfamiliar people can be especially challenging for someone with a communication disability. Poor understanding of aphasia and communication can lead to medical errors, adverse events and personal suffering. For example, a study by Bartlett et al. (2008) found that people with communication disability were 6 times more likely to have adverse events than people without communication disability. Without adequate funding and supports, this could be the result for many people with aphasia who would otherwise benefit from capacity building supports to facilitate their discharge and ability to remain home.

PARTICIPATION: Many people living with aphasia report that they had interests, hobbies, and activities prior to the onset of aphasia. However, such engagement often disappears with the challenges of communication disability and resulting identity and confidence problems. In general, people with aphasia report significantly fewer leisure and recreation activities than before the stroke (Sjöqvist Nätterlund, 2010). Qualitative interviews with people with aphasia have revealed that “doing things” or engagement in meaningful activities is a vital component of living well with aphasia (Brown et al., 2010, 2011, 2012; Grohn et al., 2012, 2014), and engagement in social and leisure activities are key rehabilitation goals for people with aphasia (Worrall, et al., 2011). Engagement in leisure and recreational pursuits has been found to be an important component of good physical and mental health (Goodman et al., 2017; Street et al., 2007), and has the potential to decrease social and economic costs (Street et al., 2007). Therefore, there is long-term value by ensuring adequate community participation and capacity building are funded in the NDIS plans of people with aphasia.

EMPLOYMENT: Many people with aphasia who were employed prior to onset are anxious to return to work. However, employment can be very challenging for people with aphasia. Research highlights that only between 14% to 28% of working-age people with aphasia return to employment (Caporali & Basso, 2003; Graham et al., 2011; Parr et al., 1997). Graham et al. (2011) reviewed the literature on successful return to work for young (i.e. under 65) working-age stroke survivors with and without aphasia. They found that the rate of return to work for survivors with aphasia was 28.4% compared to 44.7% for all young working-age stroke survivors. Additionally, “younger survivors with aphasia

were less likely to return to their jobs post stroke than those without aphasia” (Graham et al., 2011, p. 952). Much of the literature cites barriers to return to work for people with aphasia. Not only must individuals deal with the challenges of aphasia, but also with the lack of adaptations, misunderstanding by employers and barriers within the work environment. This has long term financial impacts on the person and also their required supports. Ensuring there is adequate funding for capacity building to support a person with aphasia to communicate may yield an increase in return to some form of paid employment /volunteering and subsequently result in a reduction in supports required for assistance with community participation or daily living supports. The long-term benefits for the person with aphasia, their employers, and the wider community far outweigh the immediate hesitation in providing adequate funding.

SOCIAL CONNECTIONS & ISOLATION: Aphasia can have a devastating impact on social life. In a systematic review of 70 studies on social support, Northcott et al. (2016) report that loss of contact with friends, less involvement in social activities and strain within the family are common outcomes of stroke. These negative impacts are highly exacerbated when aphasia is present. Family and social dynamics tend to shift after the onset of aphasia, and people with aphasia often find it difficult to take part in family/social activities and describe higher dependence on family/friends (Fotiadou et al., 2014). Vickers (2010) found significant shrinkage of social networks after the aphasia onset compared to social networks before onset. Studies have found people with aphasia who report no friends at one-year post onset (Hilari & Northcott, 2006), which can be caused by a loss of shared activities, reduced energy levels, physical disability, aphasia, unhelpful responses of others, environmental barriers, and changing social desires. People with aphasia often report that they feel like spectators, instead of participants in social events. This social exclusion and disengagement lead to social withdrawal and loneliness. Despite being with other people, people with aphasia are often not fully included or connected (Parr, 2007). Researchers have suggested that reduced social relationships and contact are comparable to “smoking up to 15 cigarettes a day” in relation to the damaging impact on health and wellbeing (Holt-Lundstad & Smith, 2012, p. 43). This could be directly related to their communication difficulties as well as insufficient funded supports to provide necessary education and training. This may lead to inability of families/friends to provide informal supports to a person with aphasia and the individual requiring increases in their funded supports for activities of daily living / community participation. Through adequate capacity building included in

NDIS plans, these health risks could be overcome and represent better value for money in the long term.

QUALITY OF LIFE: Health-related quality of life in aphasia is affected by the factors of emotional distress, aphasia severity, communication and activity limitations, other medical problems, and social factors (Hilari et al., 2012). Aphasia is associated with greater disability compared to stroke patients without aphasia (Flowers et al., 2016; Gialanella et al. 2011). Aphasia has been reported as the largest negative impact on health-related quality of life out of 60 diseases and 15 health conditions in a large cohort of individuals (Lam & Wodchis, 2010).

WHAT SERVICES HELP?

Services that can help people with their aphasia are speech pathology services and community aphasia groups. Services that provide communication aids can also be helpful. People with aphasia may need help finding services as well as assistance with travelling expenses to facilitate access to services. They may need individualised assistance in the classroom or in the workplace. Without appropriate supports, aphasia can result in costly complications for the person with aphasia, their carers, and subsequently funding bodies.

People with aphasia need adequate funding in their 'Improved Daily Living' budgets for speech pathology services. By ensuring that funding is included in an individual's plan early on for speech pathology and related community services, this can result in better value for money in the long term. Capacity building for aphasia aims to focus on supporting language abilities as much as possible, supporting the ability to communicate using remaining language abilities, and exploring other methods to communicate such as gestures, pictures, or electronic devices. Provision of capacity-building services in an individual's home and outside of the health setting can assist people with aphasia to improve their language processing and live with residual problems with appropriate support and direction. In addition to tangible capacity building, the role of the speech pathologist is also to provide support to the carers and family of the person with aphasia to create a communicatively accessible environment that facilitates participation. Ultimately, this may lead to a reduction in the intensity of assistance with daily personal activities.

*The Australian Aphasia Association is volunteer-led, and not for profit. It has a network of people who have had experience with the NDIS and aphasia who can provide independent support to all members. **Aphasia is a permanent disability. The disability may gradually reduce over time but is unlikely to completely disappear.***

Acknowledgements

Natalie Alborés, NSW

Michelle Attard, VIC

Linda Worrall, QLD

Deborah Hersh, WA

Frankie Banzski, VIC

References

Allina Health. (2006). *Understanding Stroke* (5th ed.). Minneapolis: Allina Health.

Bartlett, G., Blais, R., Tamblyn, R., Clermont, R., & MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *Canadian Medical Association Journal*, *178*(12), 1555–1562.

Brown, K., Davidson, B., Worrall, L. E., & Howe, T. (2013). “Making a good time”: The role of friendship in living successfully with aphasia. *International Journal of Speech-Language Pathology*, *15*, 165–175.

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010a). Exploring speech-language pathologists’ perspectives about living successfully with aphasia. *International Journal of Language and Communication Disorders*, *46*, 300–311.

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011). Living successfully with aphasia: Family members share their views. *Topics in Stroke Rehabilitation*, *18*, 536–548.

- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2012). Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members and speech-language pathologists. *International Journal of Speech-Language Pathology*, *14*, 141–155.
- Caporali, A., & Basso, A. (2003). A survey of long-term outcome of aphasia and of chances of gainful employment. *Aphasiology*, *17*(9) 815-834.
- Code, C., & Herrmann, M. (2003). The relevance of emotional and psychosocial factors in aphasia to rehabilitation. *Neuropsychological Rehabilitation*, *13*, 109–132.
- Cruice, M., Worrall, L., & Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology*, *20*, 1210–1225.
- Flowers, H. L., Skoretz, S. A., Silver, F. L., Rochon, E., Fang, J., Flamand-Roze., & Martino, R. (2016). Poststroke aphasia frequency, recovery, and outcomes: a systematic review and meta-analysis. *Archives of Physical and Medical Rehabilitation*, *97*(12), 2188–2201.e8.
- Fotiadou, D., Northcott, S., Chatzidaki, A. & Hilari, K. (2014) Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology*, *28*, 1281-1300,
- Gialanella, B., Bertolinelli, M., Lissi, M. & Prometti, P. (2011). Predicting outcome after stroke: the role of aphasia. *Disability and Rehabilitation*, *33*, 122-129.
- Goodman, W. K., Geiger, A. M., & Wolf, J. M. (2017). Leisure activities are linked to mental health benefits by providing time structure: comparing employed, unemployed and homemakers. *Journal of Epidemiology and Community Health*, *71*(1), 4–11.
- Graham J., Pereira, S., & Teasell, R. (2011). Aphasia and return to work in younger stroke survivors. *Aphasiology*, *25*(8), 952-960.
- Grohn, B., Worrall, L., Simmons-Mackie, N., & Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: A longitudinal qualitative study. *Aphasiology*, *28*(12), 1405–1425.
- Hilari, K. & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, *20*(1), 17-36.
- Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R., Chataway, J., Ames, D. (2010). Psychological distress after stroke and aphasia: the first six months. *Clinical Rehabilitation*, *24*, 181-190.

- 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*(Suppl. 1), S86–S95.
- Holt-Lunstad, J., & Smith, T. (2012). Social relationships and mortality. *Social & Personality Psychology Compass*, *6*(1), 41-53.
- International Communication Project. (2014). Universal declaration of communication rights. Retrieved from <https://internationalcommunicationproject.com/get-involved/sign-the-pledge/>
- Kauhanen, M. L., Korpelainen, J. T., Hiltunen, P., Maatta, R., Mononen, H., Brusin, E., et al. (2000). Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovascular Diseases*, *10*(6), 455–461.
- Lam, J., & Wodchis, W. (2010). The relationship of 60 disease diagnoses and 15 conditions to preference-based health-related quality of life in Ontario hospital-based long-term care residents. *Medical Care*, *48*(4), 380-387.
- Nätterlund, B. (2010). Being a close relative of a person with aphasia. *Scandinavian Journal of Occupational Therapy*, *17*(1), 18-28.
- Northcott, S., Moss, B., Harrison, K. L., & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, *30*(8), 811-3.
- Parr, S (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, *21*, 98-121.
- Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). Talking about aphasia: Living with loss of language after stroke. Buckingham, UK: Open University Press.
- Sarno, M.T. (1997). Quality of life in aphasia in the first post-stroke year. *Aphasiology*, *11*, 665-679.
- Sjöqvist Nätterlund, B. (2010). A new life with aphasia: Everyday activities and social support. *Scandinavian Journal of Occupational Therapy*, *17*(2), 117–129.
- Street, G., James, R., & Cutt, H. (2007). The relationship between organised physical recreation and mental health. *Health Promotion Journal of Australia: Official Journal of Australian Association of Health Promotion Professionals*, *18*(3), 236–239.
- Thomas, S. A. and Lincoln, N. B. 2008. Predictors of emotional distress after stroke. *Stroke*, *39*(4), 1240–1245.



United Nations (2006). Convention on the Rights of Persons with Disabilities. Retrieved from:

<https://www.humanrights.gov.au/convention-rights-persons-disabilities-human-rights-your-fingertips-human-rights-your-fingertips>

Vickers, C.P. (2010): Social networks after the onset of aphasia: The impact of aphasia group attendance. *Aphasiology*, (24)6-8, 902-913.

World Health Organization. (2001). International classification of functioning, disability and health: ICF. Geneva: World Health Organisation.

Worrall, L. E., Sherratt, S., Rogers, P., Howe, T. J., Hersh, D., Ferguson, A., & Davidson, B.

(2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, 25(3), 309–322.

Zemva, N., (1999). Aphasic patients and their families: Wishes and limits. *Aphasiology*, 13(3), 219-224.