The Committee Secretary
Senate Standing Committees on Community Affairs
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Parliament House
Canberra ACT 2600

To the Committee Secretary,

The Centre for Clinical Research Excellence (CCRE) in Aphasia Rehabilitation welcomes the opportunity to make a submission to the *Inquiry into the prevalence of different types of speech, language and communication disorders and speech pathology services in Australia.* This submission addresses the inquiry terms of reference with respect to the communication disability *aphasia.*

Background

Aphasia (also known as dysphasia) is a communication disability caused by damage to the language processing centres of the brain. The most common causes of aphasia are stroke and traumatic brain injury. Aphasia affects understanding, speaking, reading and writing. People with aphasia are affected in different ways and to varying levels of severity (for example, some people with aphasia experience mild word finding problems, whereas others completely lose the ability to understand and speak). Bilingual/multilingual speakers may find that they lose all or partial access to their different languages (Paradis, 2004). The onset of aphasia is also associated with significant and life altering psychosocial and financial consequences (including poor vocational outcomes, increased prevalence of depression, changes in relationships and social isolation) for both the person with aphasia and their family members (Code & Herrmann, 2003; Gainotti, 1997; Herrmann & Wallesch, 1993; Morris, Franklin, Menger, & D., 2011; Muller, 1999).

The CCRE in Aphasia Rehabilitation (www.ccreaphasia.org.au) is an Australia-wide research program, funded by the National Health and Medical Research Council. The program seeks to develop *the Australian Aphasia Rehabilitation Pathway*, a set of guidelines for person-centred aphasia services. With research, capacity building and community engagement as its foundations, the CCRE seeks to investigate principles of neuroplasticity as they apply to aphasia rehabilitation and translate best research evidence into best practice for Australians living with aphasia.

a-b) Incidence and Prevalence of Aphasia

Incidence and prevalence of aphasia in the developed world

In the developed world, the incidence of aphasia ranges between 0.02 and 0.06%, with a prevalence of between 0.1 and 0.4% (Code & Petheram, 2011).

Incidence of aphasia in Australia

Stroke is the most disabling health condition for Australians (National Stroke Foundation, 2010). The National Stroke Foundation commissioned report, *The economic impact of stroke in Australia* (Deloitte Access Economics, 2013) states that in 2012, 25 831 Australian males and 23 235 Australian females had a stroke. Aphasia has been estimated to effect approximately one third of first ever stroke survivors (Disability Policy and Research Working Group, 2011; Frattali, 2013). This figure was confirmed in a recent Australian study, which reported that 37.2% of acute stroke admissions to the Royal Perth Hospital over a ten month period had a confirmed diagnosis of aphasia (Godecke et al., In press). Based on an incidence of 37.2% it is estimated that in 2012, there were 18 253 new cases of aphasia in Australia.

Prevalence of aphasia in Australia

In 2012, 420 000 people (1.77% of the Australian population) were living with the effects of stroke (Deloitte Access Economics, 2013). Aphasia affects approximately one third of stroke survivors (Disability Policy and Research Working Group, 2011; Frattali, 2013), with 60% of this number still experiencing the effects of aphasia 12 months after their stroke (Engelter et al., 2006). Based on these figures, it is estimated that in 2012, between 93 744 and 156 240 Australians were living with the effects of aphasia.

It should be noted that these estimates of incidence and prevalence are based on stroke data alone (the most common cause of aphasia) and that figures would likely increase if other causes of aphasia (e.g. head injury, brain tumour) were included in this analysis.

c) The availability and adequacy of speech pathology services for people living with aphasia

Australian speech pathologists provide services to people living with aphasia (people with aphasia and their families and friends) in a range of settings including hospitals, rehabilitation centres, university clinics, private practice, aged-care facilities, and patient homes (Verna, Davidson, & Rose, 2009). Service delivery models include individual therapy, group therapy, communication partner training, community groups, computer-based therapy and tele-rehabilitation. Speech pathologists provide services which aim to not only improve language impairment, but also to reduce the wider impact of communication disability. It is important to note that as the effects of aphasia are wide-ranging there is no single treatment that can be applied to every person with aphasia (Brady, Kelly, Godwin, & Enderby, 2012). However, therapy to improve language or communication abilities in people with aphasia has been shown to be beneficial (Brady et al., 2012). Further, therapy models such as community groups that help to address ongoing psychosocial affects have also been proven effective (Vickers, 2010).

Speech pathology services are not equitably available for all members of the Australian population. Services for people with aphasia who speak English as their second language are restricted by a scarcity of bilingual speech pathologists, high demands on over-stretched health interpreter services and the lack of assessment and therapy resource materials across multiple language groups (Al-amawi, 2013). The geographic distribution of speech pathologists in Australia also forms a barrier to service access. Labour force survey results indicate that only 4.5% of speech pathologists work in moderately accessible, remote or very remote regions of Australia (Lambier, 2002). This creates inequities in service access for people living with aphasia in these regions and highlights the importance of investments in alternative service delivery models such as tele-rehabilitation.

Research indicates that people with aphasia want speech therapy that meets their needs at different stages of recovery, is relevant to their life, is more frequent, and continues for longer (Worrall et al., 2011). Yet people with aphasia report that they do not receive sufficient specialist aphasia rehabilitation to achieve these objectives (Worrall et al., 2011). During the critical early stages (4 weeks post stroke) one study has identified that people with aphasia can recieve as little as 11 minutes per week of therapy with some people with aphasia receiving no therapy at all (Godecke et al., In press). Once a person with aphasia has been discharged home from hospital, therapy services also continue to remain scarce with very limited servies provided to people with aphasia beyond 12 months post-stroke (Verna et al., 2009). A NHMRC funded research program analysed interviews with 50 people living with aphasia and their families and speech pathologists about what they want. This series of research studies found that people living with aphasia prioritise meaningful outcomes around improvement in communication, relationships, social and leisure areas (Worrall et al., 2011). A national survey of practices in aphasia management was conducted in 2013 and indicated that the desired models of therapy by people with aphasia are often under utilised (Rose, Ferguson, Power, Togher, & Worrall, 2013). Speech pathologists also frequently identify that there is a lack of adequacy in the provision of speech pathology therapy services, follow-up structures and community services to help meet these objectives (Rose et al., 2013).

d) Evidence of the social and economic cost of failing to treat aphasia

Humans are uniquely defined by their ability to communicate using language. Whilst humans use multiple modes to communicate (such as gesture and facial expression), language facilitates the communication of meaning with unparalleled scope, efficiency and flexibility (Fitch, 2010). Language facilitates the expression of complex ideas and feelings and as such is intrinsically linked to an individual's identity and relationships. Whether through paid employment, social relationships or basic activities of living; language and communication permeate daily life. The pervasive nature of language makes its impairment all the more devastating and a wide range of social and economic costs may result when aphasia is left untreated.

The evidence:

- Stroke patients with aphasia experience longer length of stays, greater morbidity, and greater mortality than those without aphasia (Ellis, Simpson, Bonilha, Mauldin, & Simpson, 2012) and therefore incur greater costs.
- Language and cognitive impairment have been found to be highly associated with difficulty communicating healthcare needs (O'Halloran, Worrall, & Hickson, 2012). The ability to communicate with healthcare staff is essential if patients are to receive adequate, appropriate and timely healthcare. People with aphasia are less able to communicate with healthcare staff and therefore less able to receive adequate, appropriate and timely healthcare in hospital.
- Patients with communication problems have also been found to be 3 times more likely to experience a preventable adverse event in hospital (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008). In a study by Bartlett and associates (2008) 57% of patients who experienced a preventable adverse required prolonged hospital stays (35%) or readmission to hospital (32%).
- Patients with aphasia have a higher incidence of depression (62% -70%) (Hilari et al., 2010; Kauhanen et al., 2000) than stroke survivors without aphasia. Caregivers of people with aphasia also have significantly worse caregiver outcomes than caregivers of non-aphasic stroke patients, with the increased risk of depression persisting over time (Bakas, Kroenke, Plue, Perkins, & Williams, 2006).
- People with aphasia are much more likely to lose friends after stroke (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Northcott & Hilari, 2011) and social exclusion has been found to be a common experience for people with severe aphasia (Parr, 2007). Loss of friendships post-stroke has been found to contribute to long-term psychological distress (Hilari et al., 2010).
- The impact of aphasia is not just limited to the person with aphasia. Research has revealed that family members of people with aphasia also experience changes to their functioning and disability as a result of their family member’s aphasia (Grawburg, Howe, Worrall, & Scarinci, 2013).

Summary

- Approximately 30% of stroke survivors experience aphasia. Aphasia persists in 60% of these people 12 months post-stroke.
- There is insufficient data regarding the incidence and prevalence of aphasia in Australia, particular where the aetiology of the aphasia is not stroke-related.
- There are a range of speech and language therapies and service delivery models which have been shown to be effective in the treatment of aphasia and communication disability.
- Hours of treatment currently provided to people with aphasia do not meet recommended levels. People with aphasia and their families also say that they are receiving insufficient treatment.
- Inequities in access to aphasia services exist for bilingual/multilingual and geographically remote populations.
- There are significant financial and psycho-social consequences for people with aphasia and their families and friends, when aphasia is untreated.

Recommendations

1. There is insufficient evidence regarding the incidence and prevalence of aphasia in Australia. These estimates are often based on stroke figures and there is little information regarding the incidence and prevalence of aphasia arising from other causes (e.g. Primary Progressive Aphasia). **Research into the incidence and prevalence of aphasia in Australia** and their trajectory through the health system is essential to allow for adequate resource allocation and the formulation of realistic projections of future demand on aphasia services.
2. There is insufficient research examining the cost-effectiveness of aphasia interventions. There is a need for research which examines **the most cost-effective approaches in the treatment of aphasia.**
3. There is insufficient research closing evidence-practice gaps. **Strong partnerships and research programs** linking researchers, practising clinicians, people with aphasia and

their families are required to ensure the effective **translation of research evidence to clinical practice.**

4. Consumer involvement is essential in the production of relevant and meaningful research. This requires an active and supported consumer organisation for aphasia. The Australian Aphasia Association requires **ongoing financial support** to remain operationally viable in the future.

Overarching recommendation

1. It is the overarching recommendation of the CCRE in Aphasia Rehabilitation that the National Health and Medical Research Council make a **targeted call for research into communication disability**.

This submission is made by Professor Linda Worrall on behalf of the CCRE in Aphasia Rehabilitation.

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