

SCIENTIFIC FORUM: COMMENTARY

The World Report on Disability as a blueprint for international, national, and local aphasia services

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Abstract

This commentary aims to extend the debate of the lead article authors (Wylie, McAllister, Davidson, and Marshall, 2013) by translating the nine recommendations of the World Report on Disability into a plan of action for the aphasia community. Solutions for the advancement of aphasia science and services are presented at international (macro), national (meso), and local (micro) levels. Implications for speech-language pathologists and aphasia service delivery are discussed. An overarching call to action is the need for speech-language pathologists to support a strong and vibrant aphasia community at all levels, so that the voices of people with aphasia can be heard.

Keywords: *World Report on Disability, World Health Organization, aphasia, consumer organizations, access to services, communication disability.*

Introduction

This commentary on the lead article by Wylie, McAllister, Davidson, and Marshall (2013) agrees with, integrates, and expands on the authors' reflections on the World Report on Disability (World Health Organization and The World Bank, 2011). Specifically, we have sought to translate the nine recommendations of the World Report on Disability into a plan of action for the aphasia community at an international (macro), national (meso), and local (micro) level. To do this, we have assembled a team of aphasia researchers whose pre- or post-doctoral research is conducted in relevant areas. Collectively we have brought our own aphasia-specific recommendations to the fore.

A major feature of the World Report on Disability is its emphasis on hearing the voice of people with disability. The slogan "Nothing about us without us" is reflected throughout the report. The voice of people with aphasia has not been heard in the literature until recently. In this commentary, we wish to emphasize research that has sought to understand the perspectives of people with aphasia. The implementation of our recommendations will require a strong, vibrant, well-resourced aphasia community who can walk

beside us as equal partners in change. It is this challenge that continues to plague progress in aphasia rehabilitation. Therefore, our overarching recommendation is for the targeted capacity building of aphasia consumer organizations.

Recommendation 1: Enable access to all mainstream policies, systems, and services

Howe, Worrall, and Hickson (2008a, b) have documented the multiple barriers that prevent people with aphasia from accessing mainstream policies, systems, and services. The majority of the barriers involve other people in the community, through lack of knowledge about aphasia and negative attitudes or communication behaviours. Several physical barriers have also been identified including inaccessible written information, forms, and signs. Finally, many societal barriers exist such as systems requiring mandatory verbal communication and a lack of services for providing social opportunities for people with aphasia. To date, improvements in access for people with aphasia have clearly lagged behind those for people with physical disabilities. The aphasia community can use the impetus of the World Report on Disability to

address this disparity at local, national, and international levels.

At the local level, speech-language pathologists can ensure that their own clinical service is accessible; for example, by providing aphasia awareness training to clerical staff and developing accessible appointment letters and reports. Speech-language pathologists can also work with aphasia groups to promote better communicative access to local services such as public transportation (Ashton, Aziz, Barwood, French, Savina, & Worrall, 2008; Cruice, 2002) and cultural organizations (Duchan, Jennings, Barrett, & Butler, 2006). At the national level, the aphasia community can advocate for the implementation of a professional interpreter service (Larsson & Thorén-Jönsson, 2007) and communication disability training for key service providers (Togher, Balandin, Young, Given, & Canty, 2006). At the international level, consumer and professional organizations can be supported in campaigns to increase public awareness of aphasia and communication disability in general.

Recommendation 2: Invest in specific programs and services for people with disabilities

People living with aphasia have reported that they have not received sufficient specialist aphasia rehabilitation (Worrall, Sherratt, Rogers, Howe, Hersh, Ferguson, et al., 2011). However, there have been no studies to evaluate these unmet needs or to establish current access to services across the continuum of care.

Persistent patterns of health inequity exist in Australia (New South Wales Government, 2007). Groups who have been shown to be more likely to experience difficulty accessing health services and to show poorer health outcomes include indigenous people and those from rural and remote communities, as well as those with a mental health disorder, sensory, physical or intellectual disabilities, people from different cultural or linguistic backgrounds (including refugees), prisoners, and homeless people (New South Wales Government, 2007). These groups are put at additional risk when they also have aphasia. To date there has not been sufficient effort to make services accessible to these isolated populations.

In Australia, a disproportionate geographic distribution of speech-language pathologists impacts significantly upon access to aphasia services. A 2002 labour force survey found that only 4.5% of speech-language pathologists were employed in moderately accessible, remote, or very remote regions (Lambier, 2002). For the one third of Australians living in regional, rural, and remote areas (Australian Bureau of Statistics, 2004) this significantly impedes their access to communication rehabilitation services.

Not only should Australia aim for a higher target of speech-language pathologists in non-metropolitan areas, but greater effort could be made to provide outreach services (O'Callaghan, McAllister, & Wilson, 2005a, b; Verdon, Wilson, Smith-Tamaray, & McAllister, 2011; Wilson, Lincoln, & Onslow, 2002). Where appropriate, consideration may also be given to other non-specialist models of communication rehabilitation, for example computer-based therapy.

Despite research establishing that service delivery models such as group therapy (Elman, 2007; Lanyon, Rose, & Worrall, 2012), computer-based therapy (van de Sandt-Koenderman, 2011), telerehabilitation (Hill, 2008; Theodoros, 2008, 2012), and the use of rehabilitation assistants or other people as therapists (Meinzer, Streiftau, & Rockstroh, 2007) have the capacity to extend the reach of speech-language pathologist-led aphasia services, models of individual therapy continue to dominate (Rose, Ferguson, Power, Togher, & Worrall, submitted; Verna, Davidson, & Rose, 2009). There is a need for aphasia rehabilitation to be refocused so as to provide efficacious, timely, accessible, and person-centred services to people with aphasia and their families.

Recommendation 3: Adopt a national disability strategy and plan of action

The World Report on Disability calls for a national disability strategy and plan of action to be adopted—a long-term vision which moves disability science and services forward. Until recently, it has fallen to clinicians and researchers to guide the development of aphasia services in Australia. It is a process often conducted in isolation, lacking co-ordination and risking duplication of effort. Of greatest concern is the absence of a strong consumer voice. The questions are: Who should take responsibility for co-ordinating a strategy and plan for aphasia science and services in Australia? Are there economies of scale to be gained by developing aphasia action plans at an international level as well?

At a local level, aphasia services after stroke are being audited annually by the National Stroke Foundation, with evidence–practice gaps highlighted in publically available online reports. The National Stroke Foundation in collaboration with local stroke services is seeking to narrow the evidence–practice gap through its Strokelinek service—a team-based quality improvement program designed to help health professionals maintain or improve stroke care. While this process of audit and feedback from the National Stroke Foundation will have some benefits for aphasia services at a local level, the recommendations for aphasia rehabilitation in the stroke guidelines are limited. This raises the question of how likely it is to deliver improvement in aphasia services.

Within Australia, the Centre for Clinical Research Excellence (CCRE) in Aphasia Rehabilitation (www.ccreaphasia.org.au) has taken up the challenge

of designing a strategy for aphasia rehabilitation across the continuum of care. The Australian Aphasia Rehabilitation Pathway is being designed in close collaboration with speech-language pathologists and consumers with the aim of translating knowledge into best practice. A Knowledge Transfer and Exchange (KTE) (Power & Worrall, 2011) plan also details how the Australian Aphasia Rehabilitation Pathway could be implemented for maximum effect.

Internationally, Aphasia United (www.aphasiaunited.org) has recently been created to explore solutions to develop a global action-oriented strategic plan for aphasia. As an overarching body for the global aphasia community, Aphasia United aims to co-ordinate an international direction for aphasia. There is a need for a more detailed aphasia-specific plan of action at the local, national, and international levels.

Recommendation 4: Involve people with disabilities

People with aphasia and their family members have voiced their desire for greater involvement in rehabilitation and healthcare (e.g., Brown, Worrall, Davidson, & Howe, 2011b; Worrall et al., 2011). In order for this need to be met, communication support for people with aphasia must be embedded within healthcare settings at the local level. There is a growing body of evidence for strategies that improve the involvement of individuals with aphasia. For example:

- Providing communication partner training to health professionals (Simmons-Mackie, Kagan, O'Neill Christie, Huijbregts, McEwen, & Willems, 2007);
- Identifying communication needs and addressing barriers to communication within healthcare settings (O'Halloran, Grohn, & Worrall, 2011a; O'Halloran, Worrall, & Hickson, 2011b; see also recommendation 1);
- Providing aphasia-friendly health information to ensure individuals can make informed choices (Rose, Worrall, Hickson, & Hoffmann, 2011, 2012);
- Rethinking goal-setting processes used in rehabilitation to make goals SMARTER (Shared, Monitored, Accessible, Relevant, Transparent, Evolving and Relationship-centred) (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012); and
- Providing appropriate methods for consumer feedback so that people with aphasia are included in quality improvement cycles (Pearson, Worrall, & Brown, 2012).

For each individual with aphasia, active involvement is important not only to ensure the relevancy of services, but also to protect their right to autonomy.

Active involvement must also extend beyond health to services including education, legal services and community living. Part of the World Report on Disability's recommendation for involving people with disabilities is to also provide capacity building and support to consumer organizations. Capacity building of aphasia organizations (such as the Australian Aphasia Association), both at local and national levels has the potential to increase consumer power to drive changes in policies, laws, and services. The benefits of aphasia organizations also include: emotional, informational, and practical peer support; a sense of belonging and purpose, and the opportunity to help others (Brown, Worrall, Davidson, & Howe, 2010, 2011a; Legg, Stott, Ellis, & Sellars, 2007). Training and supporting people with aphasia to become leaders of conversation groups or "befrienders" offering one-to-one support to others are other ways that speech-language pathologists can encourage active involvement of individuals with aphasia based on principles of equality and mutuality (Pound, 2011).

Recommendation 5: Improve human resource capacity

In building human resource capacity, it may be more effective to shift focus to the wider societal networks of people with aphasia rather than to rely on under-resourced direct clinician-driven models of service delivery. Direct care models, often medically oriented, are a source for dissatisfaction for people with communication impairment (Worrall, 2006) and clinicians (Byng, Cairns, & Duchan, 2002). Investing in a wider human resource potential requires that we build capacity in communication partners. This human resource partnership must involve the immediate social network of the person, such as family and friends (Togher, McDonald, Tate, Power, & Rietdijk, 2009). It is also important that we work with rehabilitation, community, and government agencies that provide services to individuals with communication difficulties (Togher et al., 2006; Ylvisaker, Feeney, & Urbanczyk, 1993). We need to refocus our current direct clinical service delivery models to increase the provision of resources and training to people who participate directly with the person with communication disability in actual communicative exchanges.

To achieve a more fundamental shift in attitudes and support capacity, rehabilitation, and other professionals require training *within* their professional education degrees. Investing in human resource capacity building at the 'front end' such as training nursing students to communicate with people with aphasia (Welsh & Szabo, 2011) may result in changed attitudes and support capacity. This is the focus of a joint project between The University of Sydney Nursing School and the CCRE in Aphasia Rehabilitation. In training speech-language pathologists,

we need to modify curriculums to skill students in training communicative partners and in reaching out to rehabilitation and service-based community organisations.

Recommendation 6: Provide adequate funding and improve affordability

The current focus of funding for speech-language pathology services for people with aphasia is in the acute and sub-acute care stages. It is in these stages that people with aphasia are said to make the most gains, given the potential to retrain and re-route neurons during periods of greatest neuroplasticity (Gentleman, 2001). However, communication impairments are life-long and it is often not until adults are discharged from hospital-based stages of care that the degree of communication limitation becomes apparent. It is at this time adults with communication impairments request services, yet none are available (O'Callaghan, McAllister, & Wilson, 2009). The decision to focus services on specified groups or stages of care is an ethical challenge. In the case of services for adults with communication impairments it seems value judgements are being made that it is more important to care for patients with higher immediate risk than those whose quality-of-life will be affected in the long-term (Body & McAllister, 2009). When funding within a mixed economy of care is in part dependent on the ability of service users to be active, entrepreneurial agents asserting their rights (Needham, 2011), we need to ask who speaks out for people with aphasia? A co-ordinated approach to advocacy across all stakeholders is required to fill this role.

Recommendation 7: Increase public awareness and understanding of disability

Raising public awareness about aphasia is important. Low public awareness of a condition is associated with less research funding, fewer services, and less public understanding and empathy for people with the condition (Elman, Ogar, & Elman, 2000). This last point is critical for people with aphasia as their ability to participate in conversation improves when their communication partners have the awareness, knowledge, and skills to communicate with them (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). Recent international surveys indicate that the public's awareness of aphasia is low. For example, only 10–18% of people surveyed in English-speaking countries were reported to have heard the word *aphasia* and only 2–8% had any basic knowledge of aphasia (Code, 2010).

Public awareness campaigns can be directed at many different levels. Two important groups are the immediate social network of the person with aphasia and service providers in the community. To raise

public awareness amongst the person's immediate social network, people with aphasia and their close significant others must know the word *aphasia*. Health professionals continue to use both *dysphasia* and *aphasia* to describe the same language disorder. This confuses people with aphasia as well as health professionals. One distinct term should be used by all. Aphasia is the most recognizable and universally used term. Only when people with aphasia and their immediate social network know the term *aphasia* will they be able to find the excellent resources, services, and supports that are available through websites such as the Australian Aphasia Association (<http://www.aphasia.org.au>), National Aphasia Association (<http://www.aphasia.org>), Connect (<http://www.ukconnect.org>), and the Aphasia Institute (<http://www.aphasia.ca>).

Different methods of promoting public awareness of aphasia are relevant for service providers. One strategy is through the promotion of aphasia-friendly services (Snyder, 2011). Scope in Victoria has developed a Communication Access Symbol (Communication Resource Centre, 2011), similar in purpose to the internationally recognized disability symbol, to promote services that are communicatively accessible for all people, including those with aphasia. Before a service can display the Communication Access Symbol, people with complex communication needs, including those with aphasia, rate the service for its communicative accessibility. Not only does displaying the symbol promote public awareness about the need to accommodate people with communication disability, the involvement of people with communication disabilities also serves to shift public awareness from an idea to a reality.

Recommendation 8: Improve disability data collection

Prevalence and incidence statistics inform funding and policy decisions and have direct implications on service provision across the continuum of care. Accurate data collection on aphasia, however, has a number of potential barriers. The first difficulty lies in the construction of a universal definition of aphasia. McNeil and Kimelman (2001) discussed the controversies and challenges of describing such a multidimensional concept. Historically many definitions have existed, the majority of which have focused on describing impairments that impede language function. In recent times, the International Classification of Functioning, Disability, and Health (World Health Organization, 2001) has broadened attention from a purely impairment-based focus to include the consequences of aphasia on social functioning and quality-of-life (Martin, Thompson, & Worrall, 2009).

Accurate data collection for aphasia also requires the use of appropriate clinical tools to ensure

accurate diagnoses. Aphasia is reported to occur in between 21–38% of stroke patients (Pederson, Jorgensen, Nakayama, Raaschou, & Olsen, 1995). Clinical tools must be time-efficient and sensitive in screening prospective patients for the presence of aphasia. Accurate diagnosis of aphasia, however, is complex, as distinctions between aphasia and other conditions can be subtle (Butler & Zeman, 2005). Poor public awareness of aphasia may also result in people not identifying themselves as having aphasia on self-report or census surveys. Indeed the nature of aphasia as a communication disorder makes accessing language-based data collection resources (such as surveys) inherently difficult without appropriate support. This may result in deceptively low reports of the prevalence of aphasia in data collection systems.

The Australian Stroke Clinical Registry (<http://www.auscr.com.au>) is a national initiative designed to improve the quality of healthcare through the collation of data on hospital stroke care management. The registry has limited information on the diagnoses of stroke sequelae such as aphasia. Collecting data on aphasia through such registries must be a national priority in Australia.

Recommendation 9: Strengthen and support research on disability

Research has a fundamental role in improving outcomes for people with aphasia. It provides an evidence-base to service delivery and supports professional accountability. Research generates new perspectives on health issues and guides policy development and priorities for change (Davis, Gross, & Clancy, 2012). The World Report on Disability calls for disability research to be strengthened through focused investments in a human and technical capacity. It challenges us to forge international research links and to conduct research about disability in consultation with consumer organizations (World Health Organization and The World Bank, 2011).

The National Disability Research and Development Agenda (Disability Policy and Research Working Group, 2011) echoes this call and sets out national priorities, focus, and direction for disability research in Australia. At the heart of the Agenda is the need for research to be inclusive. For people with aphasia it is the very nature of their disability which often underlies their exclusion from research participation (Dalemans, Wade, Van den Heuvel, & De Witte, 2009). At the local (micro) level, the solution is 2-fold. Research must be structured to allow people with aphasia to contribute in a genuine and meaningful way—avoiding tokenism. Second, we must engage in the capacity building of people with aphasia to arm them with the skills and confidence to actively influence the direction of aphasia research and services. At a national (meso) level, consumer,

research, and professional organizations must work together to ensure that research answers the questions that can bring about change and progress for people with aphasia (World Health Organization and The World Bank, 2011). At an international (macro) level, a co-ordinated global research agenda can direct the combined resources of the global aphasia community. This may be a possible role for Aphasia United.

Conclusion

This commentary has responded to the challenge by Wylie et al. (2013) to use the World Report on Disability to improve services for people with communication disabilities. The most frequently recurring theme in this commentary is the need for capacity building of consumer organizations. This could include local aphasia support groups, the Australian Aphasia Association, and Aphasia United at an international level. Speech-language pathologists may contribute to capacity building by referring people with aphasia and family members to local aphasia groups or the Australian Aphasia Association. They may also encourage people with aphasia to engage in leadership training through programs such as the Leaders for Tomorrow program (http://www.fahcsia.gov.au/sa/disability/progserv/people/Pages/leaders_4_tomorrow.aspx). Currently, many speech-language pathologists donate their professional skills and time to aphasia groups and support organizations. Employers should be encouraged to view these activities as crucial components of rehabilitation; recognizing that active, well-resourced advocacy and support organizations benefit all. Allowing staff to routinely commit paid working hours to the capacity building of local, national, and international aphasia groups will enable speech-language pathologists to provide people living with aphasia with the tools to find their own way forward.

A second call to action is the need for speech-language pathologists in the Minority world (such as those in Australia) to develop programs that extend the reach of aphasia programs into geographically isolated and under-served populations. Research into the needs of these populations is an aphasia research priority.

Finally, the World Report on Disability lists many recommendations and actions that have the potential to improve aphasia services locally, nationally, and internationally. We hope that all speech-language pathologists will take a moment to raise their heads above local issues and consider the global issues for aphasia that are discussed in the report. They may just find plenty of fuel to fire their imagination for solutions at their local level as well.

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References

- Ashton, C., Aziz, N. A., Barwood, C., French, R., Savina, E., & Worrall, L. (2008). Communicatively accessible public transport for people with aphasia: A pilot study. *Aphasiology*, 22, 305–320.
- Australian Bureau of Statistics. (2004). *Measures of a knowledge-based economy and society, Australia. Information and Communications Technology Indicators*. Available online at: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/2f762f95845417aeca25706c00834efa/52f0148708e41d17ca25719600173dad!OpenDocument>, accessed 8 October 2004.
- Body, R., & McAllister, L. (2009). *Ethics in speech and language therapy*. London: John Wiley & Sons.
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology*, 24, 1267–1295.
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011a). 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. (2011b). Living successfully with aphasia: Family members share their views. *Topics in Stroke Rehabilitation*, 18, 536–548.
- Butler, C., & Zeman, A. Z. J. (2005). Neurological syndromes which can be mistaken for psychiatric conditions. *Journal of Neurology, Neurosurgery and Psychiatry*, 76, 31–38.
- Byng, S., Cairns, D., & Duchan, J. (2002). Values in practice and practising values. *Journal of Communication Disorders*, 35, 89–106.
- Code, C. (2010). The public awareness of aphasia around the world. *Aphasia Corner*. Available online at: <http://aphasiacorner.com/blog/experts-talk/aphasia-public-awareness-489>, accessed 30 September 2010.
- Communication Resource Centre. (2011). Communication access for all. Available online at: http://www.scopevic.org.au/index.php/cms/frontend/resource/id/988/name/Communication_Access_for_All_Booklet.pdf, accessed 13 May 2012.
- Cruice, M. (2002). *Personal communication. Tackling public transport: Making it easier for people with aphasia*. Queensland, Australia: Disability Services Queensland Access and Awareness Grant Funding Program.
- Dalemans, R., Wade, D. T., Van den Heuvel, W. J. A., & De Witte, L. P. (2009). Facilitating the participation of people with aphasia in research: A description of strategies. *Clinical Rehabilitation*, 23, 948–959.
- Davis, M. M., Gross, C. P., & Clancy, C. M. (2012). Building a bridge to somewhere better: Linking health care research and health policy. *Health Services Research*, 47, 329–336.
- Disability Policy and Research Working Group. (2011). *National disability research and development agenda*. Sydney: Disability Policy and Research Working Group.
- Duchan, J., Jennings, M., Barrett, R., & Butler, B. (2006). Communication access to the arts. *Topics in Language Disorders*, 26, 210–220.
- Elman, R., (Ed.). (2007). *Group treatment of neurogenic communication disorders* (2nd ed.). San Diego, CA: Plural Publishing.
- Elman, R., Ogar, J., & Elman, S. (2000). Aphasia: Awareness, advocacy, and activism. *Aphasiology*, 14, 455–459.
- Gentleman, D. (2001). Rehabilitation after traumatic brain injury. *Trauma*, 3, 193–204.
- Hersh, D., Worrall, L., Howe, T., Sherratt, S., & Davidson, B. (2012). SMARTER goal-setting in aphasia rehabilitation. *Aphasiology*, 26, 220–233.
- Hill, A. J. (2008). The assessment of acquired neurogenic communication disorders in adults using a telerehabilitation application. (Unpublished), The University of Queensland, Brisbane, Australia.
- Howe, T. J., Worrall, L. E., & Hickson, L. M. H. (2008a). Interviews with people with aphasia: Environmental factors that influence their community participation. *Aphasiology*, 22, 1092–1120.
- Howe, T. J., Worrall, L. E., & Hickson, L. M. H. (2008b). Observing people with aphasia: Environmental factors that influence their community participation. *Aphasiology*, 22, 618–643.
- Lambier, J. (2002). *Membership Survey Part A*. Speech Pathology Association of Australia. Available online at: <http://www.speechpathologyaustralia.org.au>, accessed 8 May 2012.
- Lanyon, L., Rose, M., & Worrall, L. (2012). *The efficacy of community aphasia groups: A systematic review*. Manuscript submitted for publication.
- Larsson, I., & Thorén-Jönsson, A. -L. (2007). The Swedish speech interpretation service: An exploratory study of a new communication support provided to people with aphasia. *Augmentative and Alternative Communication*, 23, 312–322.
- Legg, L., Stott, D., Ellis, G., & Sellars, C. (2007). Volunteer Stroke Service (VSS) groups for patients with communication difficulties after stroke: A qualitative analysis of the value of groups to their users. *Clinical Rehabilitation*, 21, 794–804.
- Martin, N., Thompson, C. K., & Worrall, L. (2009). *Aphasia rehabilitation: The impairment and its consequences*. San Diego, CA: Plural Publishing.
- McNeil, M. R., & Kimelman, M. D. Z. (2001). Darley and the nature of aphasia: The defining and classifying controversies. *Aphasiology*, 15, 221–229.
- Meinzer, M., Streiftau, S., & Rockstroh, B. (2007). Intensive language training in the rehabilitation of chronic aphasia: Efficient training by laypersons. *Journal of the International Neuropsychological Society*, 13, 846–853.
- Needham, C. (2011). *Personalising public services: Understanding the personalisation narrative*. Bristol: Policy Press.
- New South Wales Government. (2007). *Future directions for health in New South Wales – Towards 2025*. Gladsville, NSW: New South Wales Department of Health.
- O'Callaghan, A. M., McAllister, L., & Wilson, L. (2005a). Barriers to accessing rural paediatric speech pathology services: Health care consumers' perspectives. *Australian Journal of Rural Health*, 13, 162–171.
- O'Callaghan, A. M., McAllister, L., & Wilson, L. (2005b). Consumers' proposed solutions to barriers to access of rural and remote speech pathology services. *International Journal of Speech-Language Pathology*, 7, 58–64.
- O'Callaghan, A. M., McAllister, L., & Wilson, L. (2009). Sixteen years on: Has quality of care for rural and non-compensable traumatic brain injury clients improved? *Australian Journal of Rural Health*, 17, 119–123.
- O'Halloran, R., Grohn, B., & Worrall, L. (2011a). Environmental factors that influence communication for patients with a communication disability in acute hospital stroke units: A qualitative meta-synthesis. *Archives of Physical Medicine and Rehabilitation*, 93, S77–S85.
- O'Halloran, R., Worrall, L., & Hickson, L. (2011b). Environmental factors that influence communication between patients and their healthcare providers in acute hospital stroke units: An observational study. *International Journal of Language and Communication Disorders*, 46, 30–47.
- Pearson, C., Worrall, L., & Brown, K. (2012). *What did you want? What did you expect? What did you get? Consumer satisfaction and feedback in aphasia rehabilitation*. Paper presented at the Speech Pathology Australia Conference, Hobart, Australia.
- Pederson, P. M., Jorgensen, J. S., Nakayama, J., Raaschou, H. O., & Olsen, T. S. (1995). Aphasia in acute stroke: incidence, determinants, and recovery. *Annals of Neurology*, 38, 659–666.
- Pound, C. (2011). Reciprocity, resources, and relationships: New discourses in healthcare, personal, and social relationships. *International Journal of Speech-Language Pathology*, 13, 197–206.
- Power, E., & Worrall, L. (2011). *Better pathways to living successfully with aphasia. Translating a national aphasia rehabilitation research program into clinical practice*. Paper presented at the Clinical Aphasiology Conference, Florida, USA.
- Rose, M., Ferguson, A., Power, E., Togher, L., & Worrall, L. (submitted). *Aphasia rehabilitation in Australia: Current practices, challenges and future directions*.

- Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2012). Design preferences of people with aphasia for written stroke and aphasia information. *International Journal of Speech-Language Pathology, 14*, 11–23.
- 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.
- Simmons-Mackie, N., Kagan, A., O'Neill 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.
- Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, L. (2010). Communication partner training in aphasia: A systematic review. *Archives of Physical Medicine and Rehabilitation, 91*, 1814–1837.
- Snyder, D. (2011). SCALE's Aphasia Friendly businesses to expand services for people with aphasia. Available online at: <http://aphasiacorner.com/blog/living-with-aphasia-2/scale%E2%80%99s-aphasia-friendly-business-campaign-working-with-businesses-to-expand-services-for-people-with-aphasia-1239>, accessed 1 May 2012.
- Theodoros, D. G. (2008). Telerehabilitation for service delivery in speech-language pathology. *Journal of Telemedicine and Telecare, 14*, 221–224.
- Theodoros, D. G. (2012). A new era in speech-language pathology practice: Innovation and diversification. *International Journal of Speech-Language Pathology, 14*, 189–199.
- Togher, L., Balandin, S., Young, K., Given, F., & Canty, M. (2006). Development of a communication training program to improve access to legal services for people with complex communication needs. *Topics in Language Disorders, 26*, 199–209.
- Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (2009). Training communication partners of people with traumatic brain injury: Reporting the protocol for a clinical trial. *Brain Impairment, 10*, 188–204.
- van de Sandt-Koenderman, W. M. E. (2011). Aphasia rehabilitation and the role of computer technology: Can we keep up with modern times? *International Journal of Speech-Language Pathology, 13*, 21–27.
- Verdon, S., Wilson, L., Smith-Tamaray, M., & McAllister, L. (2011). An investigation of equity of rural speech-language pathology services for children: A geographic perspective. *International Journal of Speech-Language Pathology, 13*, 239–250.
- Verna, A., Davidson, B., & Rose, T. (2009). Speech-language pathology services for people with aphasia: A survey of current practice in Australia. *International Journal of Speech-Language Pathology, 11*, 191–205.
- Welsh, J. D., & Szabo, G. B. (2011). Teaching nursing assistant students about aphasia and communication. *Seminars in Speech and Language, 32*, 243–255.
- Wilson, L., Lincoln, M., & Onslow, M. (2002). Availability, access, and quality of care: Inequities in rural speech pathology services for children and a model for redress. *International Journal of Speech-Language Pathology, 4*, 9–22.
- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva, Switzerland: World Health Organization.
- World Health Organization and The World Bank. (2011). *The world report on disability*. Geneva, Switzerland: World Health Organization.
- Worrall, L. (2006). Professionalism and functional outcomes. *Journal of Communication Disorders, 39*, 320–327.
- Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., et al. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology, 25*, 309–322.
- Wylie, K., McAllister, L., Davidson, B., & Marshall, J. (2013). Changing practice: Implications of the World Report on Disability for responding to communication disability in underserved populations. *International Journal of Speech-Language Pathology, 15*, 1–13.
- Ylvisaker, M., Feeney, T. J., & Urbanczyk, B. (1993). Developing a positive communication culture for rehabilitation: Communication training for staff and family members. In C. J. Durgin, N. D. Schmidt, & L. J. Fryer (Eds.), *Staff development and clinical intervention in brain injury rehabilitation*. (pp. 57–81). Gaithersburg, MD: Aspen.