Aphasia United - A Unified Voice for Aphasia

Abstract (100 words)

Aphasia United is a new peak international organization that aims to bring together the global aphasia community and represent its voice to the World Stroke Organization. The aim of this paper is to describe the processes of development and the strategic direction of Aphasia United, and its proposed process for developing an international research agenda. Initial discussions and a summit have prioritized capacity building of consumer organization, building consensus around best practice, raising awareness and creating a governance structure as well as developing an international research agenda for aphasia. Opportunities for involvement are outlined.

Background

About 15% of the world's population, or over one billion people, live with some form of disability, and a global increase in the aging population suggests further increase in the number of people living with disability (World Report on Disability, 2011). The World Health Organization's *International Classification of Functioning*, *Disability and Health* which has been incorporated into the United Nations' *Convention on the Rights of Persons with Disability*, provides a framework for considering the factors that may serve as barriers or facilitators for those living with disability. Barriers can include inadequate policies and standards, lack of provision of services, inadequate funding, lack of consultation and involvement, and lack of data and evidence (WRD, 2011). International societies that provide opportunities for knowledge exchange and collaborative research efforts across national boundaries can expedite the improvement of services and resources available for those with a disability (Wensing, Grimshaw & Eccles, 2012). The sharing of knowledge, skills and resources across diverse populations creates a forum for development of new perspectives and innovative approaches to improving the lives of people with disability (Freshwater, 2006).

For the communication disability of aphasia, there have been limited opportunities for international exchanges although there are a number of national organizations for those living with aphasia (e.g. National Aphasia Association in the US, Speakability in the UK, Australian Aphasia Association). The *Association Internationale Aphasia* (AIA) represents aphasia consumer organizations at an international level and consists predominantly of European nations. There are also a number of national organizations for professionals and researchers with an interest in aphasia (e.g. British Aphasia Society, Aphasiology Society of Australia). At an international level, the International Association of Logopaedics and Phoniatry (IALP) has an Aphasia Committee, and the Academy of Aphasia represents published researchers in the field.

For the aphasia community as a whole, there is a need for an organization which links consumer, research and professional organizations world-wide. For the aphasia community to be

heard within an international health and disability agenda, the organization needs to have strong links with existing advocates for aphasia at a global level. The World Stroke Organization (WSO) is the world's leading organization in the fight against stroke. The World Health Organization (WHO) has approved WSO as one of their non-governmental organizations (NGOs) in official relations.

To meet the needs of the combined stakeholders at a global level, a new organization, Aphasia *United*, has been established to network existing aphasia organizations and develop a focused agenda. Aphasia United is aligned with the WSO.

Aphasia United's goals are to increase visibility of people with aphasia, create formal global networks that connect people living with aphasia and the clinicians and researchers who support them, set a global research agenda and strengthen international research partnerships, and encourage best standards of practice in aphasia care. *Aphasia United* seeks to foster collaboration between consumer, professional and research organizations throughout the world through a strategic plan and shared vision. (Figure1)

This paper aims to:
 1. Describe the processes underlying the development of Aphasia United
2. Outline the strategic direction of Aphasia United
3. Propose a methodology for setting an international research agenda.

Methods

 The concept of a global organization was initially introduced to stakeholders in various countries. Subsequently representatives from other stakeholder groups and world regions were recruited. A website was created (www.aphasiaunited.org) and invitations extended to participants for a summit. The inaugural summit was held on October 11, 2012 in Melbourne, Australia with representation of researchers, clinicians and consumers. The summit's purpose was to discuss and begin to develop a mission statement and strategic goals for advancing aphasia science/service. A discussion paper was written and posted to the Aphasia United website and related organization sites i.e., ANCDS , NAA, etc. A paper was published in the January 2013 ASHA Leader "World Beat" column .

Results:

At the Summit the following areas were identified as the initial strategic direction of Aphasia United**:**

- **Building capacity among consumer organizations.** The World Report on Disability emphasizes the need for people with disability to play a central role in decisions that affect them (WRD, 2011). It is essential that people with aphasia are comprehensively and

authentically involved in the process of advocacy. Aphasia United will direct efforts to build capacity in aphasia consumer organizations to support involvement at an international level.

- **Building consensus about best practices for aphasia.** No formal evidence-based clinical guidelines exist for aphasia rehabilitation. Nor is there consensus on what constitutes a rehabilitation pathway for people with aphasia. In order to promote best practice in aphasia care, Aphasia United will work towards establishing consensus in these areas.
- **Awareness raising and governance.** To achieve financial sustainability Aphasia United was endorsed by the WSO (www.world-stroke.org). There is a need to work closely with the WSO in its awareness campaigns and advocacy roles. Developing a governance structure within Aphasia United that facilitates this is also needed.
- **Setting an international research agenda.** Clinical research can be facilitated by combining existing knowledge, developing processes for transferring knowledge across cultural and national boundaries, and identifying research need areas that can be productively addressed by the international community. Aphasia United seeks to combine the perspectives of researchers, clinicians, and consumers in determining international research priorities.

Each priority area has a task force that selected some key deliverables that would be achievable within a six month time frame.

Setting an International Research Agenda

A research agenda that has input from clinicians and people living with aphasia along with researchers is likely to be more relevant to all stakeholder groups (Ahmed & Palermo, 2010), and thus can be an efficient use of public research resources. Incorporating the views of people with aphasia is consistent with the World Report on Disability, which has emphasized the need for people with disabilities to participate in decisions that affect them (WHO, 2011). A recent study demonstrated the feasibility of using Nominal Group Technique as a method for eliciting the views of people with aphasia about aphasia research needs (Hinckley, Boyle, Lombard, & Bartels-Tobin, in press). A Delphi method is a related technique that would provide the means for eliciting and combining the perspectives of all stakeholder groups to generate research priorities for aphasia. The Delphi method asks respondents who are sent a survey to rate the importance of each item in terms of a percentage. Percentages are then averaged across all items to determine a ranked order of items of importance. Aphasia United will employ these techniques to solicit input on international research priorities from clinicians, people living with aphasia and researchers.

Discussion

In summary, *Aphasia United* is a new international "peak" organization representing multiple stakeholder groups across the world. The many tasks/ challenges that lie ahead include development of a governance structure and criteria for membership, engaging organizations to

participate, funding, and implementation of strategic plan. The intent of task forces created at the Summit is to expand interest in Aphasia United and establish discussion groups. There will be opportunities to be involved in Aphasia United through its task forces and activities such as the Delphi exercise for establishing an international research agenda. Future summits will occur in affiliation with existing conferences (e.g. IARC, CAC, Speaking Out) in order to involve various stakeholder groups.

References

Ahmed, S. M., & Palermo, A.-GS. (2010). Community engagement in research: Frameworks for education and peer review. *American Journal of Public Health, 100*, 1380-1387.

Freshwater, D., Sherwood, G. & Drury, V. (2006). International research collaboration: Issues, benefits and challenges of the global network. *Journal of Research in Nursing, 11,* 295-303. DOI:10.1177/1744987106066304.

Glickman, S. E., McHutchinson, J. G., Peterson, E. D., Cairnes, C. B., Harrington, R. A., Califf, R. M., & Schulman, K. A. (2009). Ethical and scientific implications of the globalization of clinical research. *New England Journal of Medicine, 360*, 8.

Hinckley, J.J., Boyle, E., Lombard, D. & Bartels-Tobin, L. (in press). Towards a consumer-informed research agenda for aphasia: Preliminary work. *Disability & Rehabilitation.*

Wensing, M., Grimshaw, J. M., & Eccles, M. P. (2012). Does the world need a scientific society for research on how to improve healthcare? *Implementation Science, 7,* 10.

World Health Organization and The World Bank. (2011). *The World Report on Disability.* World Health Organization: Geneva, Switzerland. Available at: www.who.int. Accessed 20 May 2012.