

Aphasia Insights!

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“This paper serves as a call to action for those interested in increasing awareness and understanding of aphasia and ultimately improving the lives of those living with aphasia. It is time for more effective, targeted and collaborative aphasia awareness campaigns, or we risk the same disappointing aphasia awareness survey results over the next decade (pp 468).”

Beyond the statistics: a research agenda in aphasia awareness. Simmons-Mackie Nina, Worrall L, Shiggins C, Isaksen J, McMenamin R, Rose T, Guo Y, Wallace S. *Aphasiology*, 34:4, 458-471 (2020).

Stroke Educator, Inc. is committed to educating the wider public about stroke and the 50 state “*Aim High for Aphasia!*” Aphasia Awareness Campaign.

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Reading the Landscape of Aphasia, *Part 1*, *Aphasia Awareness*

By Tom Broussard, Ph.D.

Reading the Landscape of Aphasia (loss of language), is my understanding of speech therapy and recovery based on the last several years of my work written from the perspective of a person with aphasia (PWA). I have been using my experiences as tools to help other people with aphasia as well as speech therapists and allied clinicians.

There are three parts to *Reading the Landscape of Aphasia*:

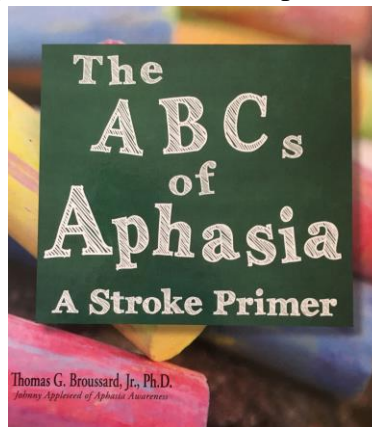
-Part 1, aphasia awareness points out that many hospitals do not utilize the lexicon (the language) of aphasia in their website;

-Part 2, aphasia therapy calls for higher education to study the relationship between patients, and their pre-stroke environment, and their post-stroke environment, and their recovery outcomes; and

-Part 3, aphasia recovery describes the changing roles of speech therapists and PWAs that share in an increasingly self-

directed approach to adult learning, lifelong learning, and long-term personal speech therapy. Part 2 and Part 3 will appear in subsequent articles.

Part 1, Aphasia Awareness: Aphasia in North America white paper (Simmons-Mackie, 2018) lays out the problem in great detail. What is needed now is a call-to-action regarding aphasia awareness. The paper describes the low percentage of people in the U.S. who are aware of aphasia as a language disorder.



I did a study of 23 hospitals in Northeast Florida and was awarded a “Brag & Steal” Presentation, *Aphasia, a national disease that no one*

has ever heard of: A Study in Public Awareness of Aphasia at 23 Hospitals in Florida at the 2019 Aphasia Access Leadership Summit in Baltimore, MD. Twenty (20) of the 23 hospitals in Florida provided NO information about aphasia anywhere on their websites.

I have spoken to several hospitals nationwide (including staff, leadership and volunteers) and have provided information, articles, and books in an attempt to secure commitments to educate the wider public about aphasia. The hospitals could be updating their

websites to include the lexicon of aphasia, but to my knowledge this hasn't been done.

Using the American Hospital Association (AHA) website as an example of what's missing, my search of "stroke" on the AHA website provided 170+ hits while a search of "aphasia" resulted in just two. A search of "aphasia" on the American Medical Association website came up with zero results.

Public education is the key that links stroke *to* aphasia. People who have never heard of it before have no idea what it means or what it is connected to, let alone how to pronounce it, 'aphasia' (uh-Fay'-zhuh).

The ABCs of Aphasia: A Stroke Primer (Broussard, 2020) is designed to be used by stroke survivors and their families *before* being discharged from the hospital to help them begin the journey towards recovery and this thing called *aphasia*.

The book outlines the basics of aphasia from the very start of the stroke, through the development of aphasia, and during the recovery process. It took me years to recover and many more years to create a book like this. I only wish that my family had this kind of a resource on day one.

It is not enough to preach to the choir where only 7-8% of the population are "aphasia aware." What is needed is a sustained, multi-year, national & international aphasia awareness campaign to raise aphasia awareness

substantially worldwide (Simmons-Mackie, 2020).

The American Heart and American Stroke Association provide good information about stroke and aphasia. The National Aphasia Association (and many others in the aphasia world) provide the needed information about aphasia.

Yet many other national organizations like the American Hospital Association and the American Medical Association provides little or no information about aphasia in their websites.

The problem is that all these organizations are silos and do not communicate about the issue of the missing linkages between conventional healthcare providers and the rehab providers regarding aphasia.

The next big step is educating the local populations about aphasia through the local hospitals' (and other local organizations') websites.

The websites can provide the link from stroke *to* aphasia. It doesn't help if hospitals' websites provide information about stroke without mentioning *anything* about aphasia at all, especially given that a huge amount of people with stroke (25-40%) *acquire* aphasia!

The only way to open the door to aphasia awareness is through local hospitals that can provide the information that links stroke *to* aphasia in their website before they hear it for the first time at their local hospital's Emergency Room.

Signed: *Johnny Appleseed of Aphasia Awareness*

References:

Simmons-Mackie N. *Aphasia In North America*, Frequency, Demographics, Impact of Aphasia, Communication Access, Services and Service Gaps. Aphasia Access White Paper (2018).

Simmons-Mackie Nina, Worrall L, Shiggins C, Isaksen J, McMEnamin R, Rose T, Guo Y, Wallace S. Beyond the statistics: a research agenda in aphasia awareness. *Aphasiology*, 34:4, 458-471 (2020).

Broussard, Thomas G. *The ABCs of Aphasia*. Stroke Educator, Inc. (2020).

The author is a three-time stroke survivor and aphasia. He could not read, write or speak well which took years to recover.

He is now Founder and President, Aphasia Nation, Inc., a non-profit organization whose mission is educating the wider public, national and international, about aphasia and plasticity, the foundation of all learning.

