

Aphasia Insights!

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The *Aphasia in North America* white paper describes the first gap summary of aphasia awareness as:

“Insufficient awareness and knowledge of aphasia by health care providers and the wider public.”

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

Aphasia Nation, Inc. is committed to educating the wider public about stroke and aphasia and the *“Aim High for Aphasia!”* international Aphasia Awareness campaign.

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The Keys to Raising Aphasia Awareness Nationwide, Part 2- People with Aphasia

By Tom Broussard, Ph.D.

This is the second in a series of *The Keys to Raising Aphasia Awareness Nationwide*. This article is a call-to-action in support of aphasia awareness.

Aphasia Nation, Inc. (ANI) is building a team that includes stroke coordinators, people with aphasia, speech language pathologists, occupational therapists, other allied services, nurses, and physicians to help raise aphasia awareness. The next article in the series will be *Part 3- Speech Language Pathologists (SLP)*.

I had a stroke and aphasia in September 2011. Once I woke up at the hospital, I spent most of my time on the Neuro (Stroke) floor wondering why I was still there.

I could walk around the floor as much as I wanted. I would peer into any open doors looking at patients and seeing how damaged

they were compared to me. I would check my hands, my arms, my legs and my face on the mirror. After days of this, I started to think that I must have something wrong with my brain. I wished someone had told me that that was the case.

I met the speech therapist once. Other than that, there was no communication between me and the staff about any problems I might have had for the six days I was there.



“There were no additional conversations with the speech pathologist. I wanted to know more, but I had been informed more than once: physical injuries were treated at

this hospital; the next hospital would treat any additional neurological issues” (Broussard, 2015).

I was discharged without any information about aphasia other than a piece of paper with a list of brain disorders and a one-line description of aphasia. I had been assessed as a person with aphasia while at the hospital but didn’t get the report until two years later when I requested the hospital to mail my medical records to me.

It takes years for us to learn more about aphasia although we live with it every day. Unfortunately, there was no day-to-day use of the word “aphasia” while I was still at the hospital. None of the nurses or doctors at the hospital had told me that I had aphasia or tried to explain aphasia to me.

A friend of mine had the same problem:

“After a few years from my strokes, I wanted to explore what happened to my brain. After all, I had medical training and loved reading medical reports for my patients so I went to the hospital and got ALL of my medical records—pages and pages, piles and piles, box after box.

I was skimming through the report like the speech therapist taught me and saw the word “aphasia”. I then quickly thought “This wasn’t my records!” and verified my name and birthdate. It was!!! I was so shocked by the revelation I had aphasia!

I was curious about why did I now find out many years later, requesting my medical reports. Then I asked her at my next speech therapy appointment. I said “Why didn’t you tell me that I had aphasia?” Then she said “I thought you already knew. I thought somebody at the hospital told you” (Jennifer Kurnal, stroke survivor, personal correspondence - Essay, *How I found out that I had Aphasia*).

Unless you are a speech therapist, hospitals typically do not discuss aphasia with their patients, whether in their website, literature, few educational materials at discharge, or community educational activities. Considering that 25-40% of stroke survivors develop aphasia, this was very surprising to me.

It is time for us to explain more about aphasia and our recovery to the nurses, doctors and yes, even to our speech therapists.

Our knowledge about aphasia goes far beyond what we learned in the few hours we get from formal therapy, having spent thousands of hours of non-formal and personal therapy which are also highly therapeutic as well.

Stroke center hospitals are designed to stabilize stroke patients and prepare them *physically* for the next step towards recovery.

But those hospitals don’t think they *need* to educate the public about aphasia because they don’t *have* to.

The rehab facilities, not the hospitals, are the ones with the responsibility to care for the *communication* needs of people with aphasia. Both are very good at what they do, but a gap exists between the two siloed entities in the care continuum.

Approximately 2/3 of stroke patients are discharged to home while they wait for what comes

next, with many waiting for weeks or months.

Half of those who are discharged to home, *stay* at home based on a number of factors including: 1) limited or no insurance, 2) no transportation, 3) no family support, 4) lost employment, and 5) limited to no information provided to them about their condition or how to improve it.

Fortunately, stroke center hospitals can still build the bridge to the aphasia world and PWAs can help. We can train the staff at every hospital about the ABCs of aphasia. The various departments at the hospital can update their website, literature, discharge materials, and community educational activities *about aphasia, a serious language disorder that few people have ever heard of...until now.*

Signed: *Johnny Appleseed of Aphasia Awareness*

Broussard Jr., T. G., Stroke Diary, A Primer for Aphasia Therapy (Vol I). Stroke Educator, Inc. St. Augustine, Florida, 2015.

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 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.

