

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 3- *Speech Language Pathologists*

By Tom Broussard, Ph.D.

This is the next in a series of *The Keys to Raising Aphasia Awareness Nationwide*. Aphasia Nation, Inc. (ANI) is assembling a team that includes stroke coordinators, people with aphasia, speech language pathologists, and others to help build the public-facing infrastructure of the healthcare system to show the public about aphasia, a widespread language disorder, typically from a stroke, *that most people have never heard of.*

I had a stroke and aphasia on September 26, 2011. I was an associate dean at The Heller School at Brandeis University when I fell down on Main Street, Waltham, MA. I lost my language and could not read, write or speak well.

Once I got better, I started studying the recovery process and began to

see some of the gaps in the stroke/aphasia care continuum. The less-than-smooth handoff of patients from one siloed system to another has potholes in the middle. The systems communicate fine but aphasia isn't in the playbook.

Doctors, nurses, therapists and staff are all very good at what they do and are heroes to us. They have helped heal us from the start. But there are system-level problems that, if fixed, can make it easier for the heroes to succeed with less

effort in the endless procession of people in need.

But fish can't see water and conventional hospitals can't see aphasia. It isn't because they don't know about aphasia. They know what aphasia is. The problem is that their own patients have aphasia but won't hear about it or learn about it while still at the hospital.

Some hospitals provide information about stroke to the patient and family at discharge but with little or no info about aphasia even though a huge percentage (25-40%) of the stroke patients also have aphasia. That is why it can't be seen. It is unknowable to the system.



The culture of many systems hardens over time and eventually becomes part of the woodwork.

Today, stroke center hospitals stand for safety, stabilization and speed. The rehabilitation community stands for practice, pathways and possibilities towards recovery. The shuttling patients appreciate the benefits of both but can see what is missing between the two systems.

This isn't about preventing more strokes or needing more therapists, although that is very important too. The problem is the missing link between the two.

The dearth of information about aphasia (website, materials, education) is the connective tissue that is missing, and the speech language pathologists (SLP) are an important part of raising aphasia awareness.

SLPs are heroes in the eyes of people with aphasia (PWA) too. They ask questions tirelessly, they have the patience of Job, and the empathy of understanding the perspective of others who live with aphasia every day. They have always been advocates for aphasia awareness. It is in their blood.

As a result, we have invited them to take on new responsibilities in partnership with stroke coordinators and PWAs to bring "aphasia" into the mainstream of the stroke/aphasia care continuum.

The SLPs can help prime the pump by asking the following:

1. Is your hospital a stroke center? If so, what kind? Who is your hospital's stroke coordinator?
2. Does your hospital provide information about aphasia on their website?
3. Does your hospital provide materials about aphasia to the patient/family at the hospital or at discharge?
4. Does your hospital provide education to staff (nurses, doctors, etc.) or to the community about aphasia?
5. Does your hospital collect info about stroke/aphasia codes in the database/Electronic Health Record and use it in the hospital/statewide stroke system?

For example, if the hospital does not provide much information about aphasia on their website, the local PWAs can note that and connect with the resident SLP and together can meet with the hospital's stroke coordinator and lay out a plan to increase aphasia information on the website and submit it to the regular stroke screening committee for consideration.

The same consideration can be said for materials, literature, staff education, database records, and more.

But the first and obvious step towards aphasia awareness is reviewing the website. If there are no hits about aphasia in the hospital's search box, then that is the first target. You can't aim at something that isn't there to begin with!

Aphasia is an invisible language disorder that can't be seen, understood, or even acknowledged and will remain that way until the word "aphasia" is exposed to the light of day that everyone can see.

The purpose of the Aphasia Nation team (stroke coordinators, PWAs, SLPs, and others) all have the same vested interest, helping them to provide the public-facing infrastructure (website, materials, education) at every hospital which then allows stroke *and* aphasia education (e.g., *The ABCs of Aphasia: A Stroke Primer*) to flow seamlessly downstream and into the public domain.

Signed: *Johnny Appleseed of Aphasia Awareness*

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

