

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 1- Stroke Coordinators.

By Tom Broussard, Ph.D.

This is the first 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 therapy, other allied services, nurses, and physicians to name a few. The next article in the series will be *Part 2- People with Aphasia*.

I didn't know much about the position of Stroke Coordinators and their responsibilities until my local hospital's Stroke Coordinator asked me to speak at their first Hospital Medicine Symposium, *Stroke: Updates, Mimics and the Aphasia Patient Perspective*, Mid Coast Hospital, Brunswick, ME in May 2022 for Stroke Month.

I agreed and asked if we could do another presentation in June for

Aphasia Month given my work on aphasia awareness. The Stroke Coordinator thought that would be good too. She described the information that the hospital does to help stroke survivors and family.

At discharge, the hospital provides a “stroke packet” booklet (<https://www.mainestroke.org/stroke-discharge-rehabilitation>) to every stroke patient, but I was surprised to see that aphasia was mentioned just once in the glossary of the 61-page booklet. Clearly more needs to be done to include additional

information about aphasia while still at the hospital and at the point of discharge.

In my case, I was discharged after my first stroke and aphasia from a

Comprehensive Stroke Center with just a single sheet of paper including a list of brain diseases and disorders that included aphasia.

No educational materials of any kind about aphasia were provided to me or my family and no follow-up other than daily and then weekly calls asking about sleep, eating, blood pressure, coughs or temperature/fever until I started speech therapy a month later.



I also asked the local Stroke Coordinator if the hospital collects and analyzes patient data about the number of people with stroke and aphasia at discharge, types, destinations, etc. The hospital does record stroke and aphasia data and hopes to be able to report it in the future.

I further explained that many hospitals often don't use the lexicon of aphasia, don't describe it in their website or literature or provide any materials about it to their stroke patients even though *25-40% of stroke survivors have aphasia.*

We agreed that we have to do more to use the hospital's information to better understand stroke *and* aphasia prevalence in Maine and in their community. Mid Coast Hospital does provide good information about aphasia in their website but that is often rare at many hospitals (Broussard, 2019).

I have seen several state and regional stroke coordinator-type organizations around the country including one from Missouri called the Association of Stroke Coordinators (ASC) who "strongly believes in education for ourselves and the communities we serve." I contacted the ASC chair and she was very interested in hearing more about aphasia.

I did a Zoom presentation at the ASC last month to 30+ stroke coordinators and members scattered across several regional

hospitals and healthcare entities entitled, "Aphasia Awareness: Stroke Coordinators are the Key!"

One of their Board members said "any and all information about aphasia is greatly appreciated because there is so little of it!"

Several of the attendees asked for copies of "*The ABCs of Aphasia: A Stroke Primer*" as the first step towards building a partnership between Aphasia Nation, Inc. and the Association of Stroke Coordinators.

There are 5,533 EDs (Emergency Departments/hospitals) in the United States with 2,446 (44%) stroke centers (Boggs, 2022).

Aphasia Nation has started the process of working with stroke coordinators at stroke center hospitals to help rebuild the stroke care continuum and improve the lives of millions of people living with stroke AND aphasia.

Stroke coordinators work with various hospital departments to educate the public and staff about aphasia awareness including the hospitals' website, literature, discharge materials and community education -- but the activities themselves have to be built into the system.

Stroke coordinators are an important key in raising aphasia awareness nationwide; hospital by hospital and state by state.

But we need everyone on the team to make this happen, otherwise it will be a Sisyphean task, pushing the aphasia awareness rock up the mountain, only to have it roll down again tomorrow.

Thank you to all stroke coordinators for lending a hand...and a voice to those who are voiceless!

Signed: *Johnny Appleseed of Aphasia Awareness*

Citations:

Broussard, T. [July 2019, Vol 1, Issue 5–Aim High for Aphasia Awareness Campaign](#)

Boggs KM, Vogel BT, Zachrison KS, et al. An inventory of stroke centers in the United States. *JACEP Open*. 2022;3:e12673. 10.1002/emp2.12673

Learning About Stroke, Maine Medical Center, Neuroscience Institute (Maine Health, 2012).

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.

