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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Aphasia Awareness: Sweeping Cultural Change in the Healthcare Community and Aphasia.

By Tom Broussard, Ph.D.

I had a stroke and aphasia in 2011. I lost my language and could not read, write or speak well.

My experience (and that of many others with aphasia) at the hospital led us to understand why so many people with aphasia (PWA) and their families leave the hospital with little or no idea about this thing called aphasia even though 25-40% of those stroke survivors have aphasia too.

The Joint Commission (TJC) is a US-based nonprofit tax-exempt 501 organization that accredits more than 22,000 US health care organizations and programs.

There are 5,533 EDs (Emergency Departments/hospitals) in the United States with 2,446 (44%) stroke centers (Boggs, 2022). Stroke Coordinators (SC) coordinate the members of the stroke team at every accredited hospital.

These hospitals see their job as saving lives, stopping the stroke, and medically stabilizing the patient, physically. They are very good at it but discharge is the end of their stroke-related responsibilities.

At that point, PWA go to either inpatient rehab or to their home where they wait for weeks or months to get to their first outpatient rehab and speech therapy (Shipley et al, 2019).

During the interval, PWA and their families attempt to learn more about aphasia on their own but it is still quite difficult given that few or any educational materials about aphasia are provided from the hospital.

As a result, there is no continuity of care for PWA. The sending and receiving entities work well within their siloes, but there is no communication between them. Neither entity extends the care needed to the PWA who are lost in the middle.

Cultural change is always a hot topic. Organizations ride on the cultural bedrock which is the shared consciousness of the organization or community.

Change will only come when a critical mass of individuals within the environment feel the need and move in that direction.

Essentially the culture is stimulated by activities felt by the people within the group. Cultural change certainly

marches to its own tune and nowhere it is more evident than in the healthcare world.

The culture resides within an intricate system of values—some explicit, many more implicit—held collectively by its people. And changing the culture is not something that can be shaped directly.

It cannot be touched. It cannot be "scheduled." It cannot be directed to move from *here* to *there* on demand. Activities directed at aphasia awareness must address the *environment* within which these actions occur.

The sport of curling provides a useful analogy regarding the physics of cultural change.

In curling, a forty-four-pound stone is shoved (it would be hard to say that it is *thrown*) to the other end of the ice. Once it has been launched there is no way to alter its direction except by what is called *sweeping*.

Sweepers (the people doing the sweeping) use brooms to sweep the ice along the path of the stone with sufficient force so as to melt the ice (however slightly) and "draw" the stone in the direction of this newly melted sheen of ice.

It is illegal to touch the stone in any way. The only way to influence the path of the stone is to sweep. The harder one sweeps, the more the ice melts and the slicker the swept area becomes in relation to the surrounding environment.

In this way, the stone is then "pulled" in the direction of the smoother ice.

In an analogous way, culture cannot be "touched" directly. That is not to say that culture can't change over time or that it cannot be influenced. But when cultural change does occur, it is not in response to a push, but a pull.

Therefore, policies that demand action without considering the gravitational pull of culture, risk failure (Simmons-Mackie et al, 2020). Those activities are trying to lay a hand on the cultural stone rather than influence what lies in its path.

Policies with the expressed goal of *changing the culture of aphasia* must be directed at changing the environment, and education is the greatest catalyst for that change.

When that happens, it does so because it *wants* to. Yet even the individuals involved may not notice that things are changing. In much the same way as the curling stone, they may simply be *drawn* that way.

One of the mottos of TJC is "we support the change, but don't drive the change." Team Aphasia Nation is driving the change and expect that TJC can support it.

Stroke coordinators (SCs), speech language pathologists (SLPs), and people with aphasia (PWAs) are the *sweepers* for the team.

PWA need to contact the hospital's SLPs and SCs and discuss the actions needed to educate stroke/aphasia survivors and the wider public about aphasia.

The next step is to present to the hospital stroke committee about the gaps in the hospital's communication infrastructure (website, literature, discharge materials, database and community education) about aphasia.

It is never as easy as all of that, but whoever said sweeping cultural change would be easy!

Signed: *Johnny Appleseed of Aphasia Awareness*

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