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More Than 2.4 Million Americans Live With Aphasia, According to New White Paper

New Estimates Are More Than Double Earlier Numbers; White Paper Includes Recommendations for Healthcare Administrators, Nurses and Others in Healthcare

MOORESTOWN, NJ -- March 27, 2018 -- More than 2,400,000 Americans live with aphasia, a potentially debilitating speech and language disorder, according to a new white paper from Aphasia Access, the nation's leading organization focused on providing aphasia care resources to healthcare professionals. The white paper also estimates that more than 166,000 people in Canada struggle with aphasia.

The new estimates represent marked increases in the prevalence of aphasia, according to the white paper's author, Nina Simmons-Mackie, PhD, CCC/SLP, BC-ANCDS. Prior estimates from other organizations have all been much lower and possibly outdated, ranging from one to two million.

The new data from Aphasia Access suggest that the estimate of 2.4 million people in America living with aphasia is conservative. The actual number could be as high as 4.1 million. One of the major variables in this range is the wide range of potential incidence of aphasia from traumatic brain injury (TBI) -- anywhere between one percent (nearly 65,000 people) and 19 percent (1.2 million).

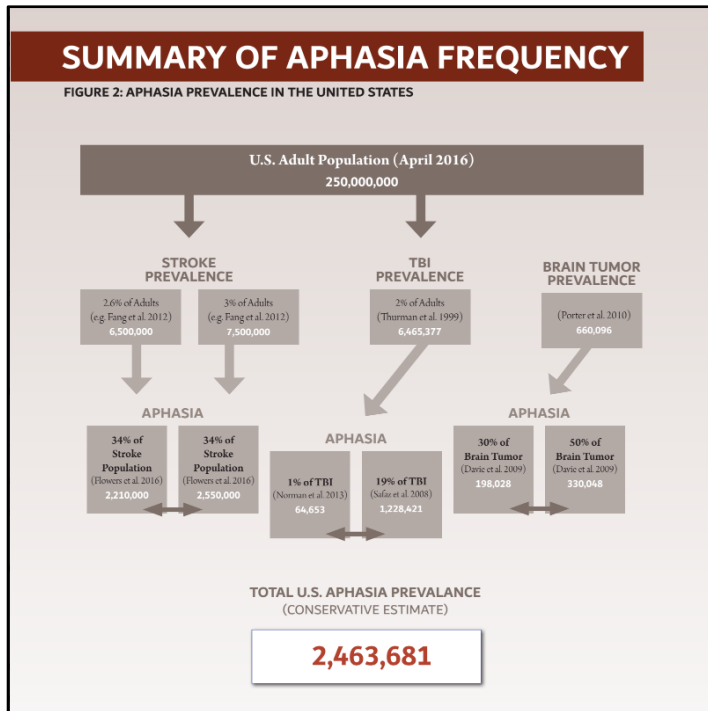
Most prior research into aphasia often only examined stroke as the primary cause of aphasia; the new white paper from Aphasia Access also included traumatic brain injury (TBI) and brain tumors as causes of aphasia. The paper also highlights that there is no definitive way to track aphasia, so all estimates -- such as Medicare data or ICD codes -- require an extrapolation from existing data sets.

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“This new report breaks the silence,” says Dr. Simmons-Mackie. “We hope that it can begin to pave new ways for understanding just how common aphasia is -- and how to tackle it effectively.”

“Nearly thirty years ago, America broke down the barriers for those with physical disabilities by implementing the landmark Americans with Disabilities Act. Now, we must do the same for those with communications barriers. For people with aphasia, there is a broken system at every level. For decades, a large population of people have been marginalized within healthcare systems that fail them because they do not understand them.”

The executive summary of the white paper is available for free at www.aphasiaaccess.org. The full white paper -- primarily intended for healthcare professionals who treat people with aphasia -- is available for purchase on the website, as well.



Definition and Impact of Aphasia

The new data dramatically illustrate the challenges that people living with aphasia face, as well as those faced by those who care for them, including family members, nurses, speech language pathologists, rehabilitation professionals and healthcare administrators.

Aphasia is a neurological disorder that impacts language production or processing. This language disruption affects speaking most obviously, but other language functions — speech comprehension, reading and writing — are also affected to varying degrees.

Most importantly, for people with aphasia, core intelligence and other mental functions are not diminished.

The inability to understand and communicate through language, despite having inherent intellectual competence can create extreme frustration, depression and dramatic social disconnects. **A 2010 study cited in the white paper, aphasia was reported as the largest**

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negative impact on health-related quality of life out of 60 diseases and 15 health conditions in a large cohort of individuals living in long term care. For instance, people with aphasia may not be able to read a bedtime story to their children, or fear the loss of a job, due to an inability to communicate efficiently (studies show that more than 75 percent of people affected by aphasia do not return to employment).

Aphasia also takes a toll on family members and others who care for people with aphasia; prior studies have shown that family members supporting people for stroke and aphasia are more adversely affected than those caring for patients with stroke alone. They often report a significant loss of freedom, financial instability, poor health and increased stress.

For healthcare systems, addressing aphasia appropriately can have significant cost and care implications. Compared to those with stroke alone, patients with stroke and aphasia had approximately double the number of physician visits and overall healthcare costs per year and were associated with higher hospital readmission rates.

Recommendations for Healthcare Providers

Like many long-term conditions, aphasia can impact the delivery and cost of care across the spectrum of healthcare settings and providers. However, two important groups of healthcare professionals can have a significant impact on the quality of care for people with aphasia: healthcare administrators who set policies and allocate resources for patients and nurses, who are on the front lines of care and often have the most contact with patients and their families.

Setting	Administrator Recommendation	Nurse Recommendation
Hospitals: Emergency Departments and Acute Care	Set hospital-wide policies and procedures for aphasia diagnosis and communication. Allocate time and resources for training staff on adaptive communication techniques.	Evaluate stroke and TBI patients for language and communications symptoms to identify aphasia. Take time to communicate with family members about aphasia.
Rehabilitation: Inpatient and Outpatient	Implement procedures to empower frontline staff to empower patients and families for ongoing life with aphasia and allocate staff time to ensure adequate interventions.	Maintain intensive interventions and stay alert for indications of depression among patients with aphasia. Focus interventions on participation in day-to-day activities, not just communication abilities.

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Long-Term Services	Train long-term care staff on communication support methods so they can feel more comfortable communicating with those with aphasia.	Include people with aphasia into important social interactions, including games, activities and events.
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Detailed recommendations and assessment of current therapies are available in the white paper.

Moving Forward: Removing Communications Barriers for Millions

An improved understanding of the prevalence of aphasia is just one step in Aphasia Access’ goal of better integrating people with aphasia into their communities. Aphasia Access is hosting a virtual conference on May 4, aimed at providing healthcare professionals with the resources necessary to diagnose aphasia and enable people living with aphasia to participate in their lives.

For Dr. Simmons-Mackie, efforts to improve care for patients with aphasia can open doors to many others, too.

“The scope of this challenge is far greater than anyone in healthcare has recognized,” she says.

“If we can improve the diagnosis and treatment of aphasia across the continuum of care, we can open doors for millions of others who also have communications barriers, including dementia and non-English speakers.”

About Aphasia Access

Aphasia Access reduces the barriers created by aphasia by bringing the Life Participation Approach to Aphasia (LPAA) to people with aphasia, the clinicians treating them and patients’ families. Aphasia Access represents leading aphasia educators, healthcare providers, researchers, and community advocates - all visionary leaders passionate about the collective impact of long-term solutions to create a world where people with aphasia can communicate with the world around them.

For the latest in aphasia news, research and treatment, visit www.aphasiaaccess.org or on Twitter at [@aphasiaaccess](https://twitter.com/aphasiaaccess).

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