



APHASIA IN NORTH AMERICA

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FREQUENCY
DEMOGRAPHICS
IMPACT OF APHASIA
COMMUNICATION ACCESS
SERVICES AND SERVICE GAPS



AphasiaAccess
Until Every Voice is Understood

APHASIA IN NORTH AMERICA

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INTRODUCTION & BACKGROUND

The State of Aphasia in North America

In cities across North America, healthcare systems, families and communities face one of the most pervasive communication disorders of our times. Until now, the silencing condition of aphasia has been underestimated in the number of people affected. Outdated and scattered data has undermined any large scale change to stop the epidemic marginalization of people coping with aphasia.

This report is designed to provide current, comprehensive information — information to empower people living with aphasia to take more control over their futures, information to enable health care providers to optimize services, information to support policy makers in efforts to create and fund services, and information to provide a comprehensive data source for aphasia researchers and students.

In addition, this report is a call to action! Each section of the report addresses a key topic associated with aphasia advocacy and services; an executive summary not only summarizes some of these key points, but also lays out core priorities and recommendations to initiate a far-reaching overhaul of aphasia services in North America. Now is the time to move forward, now is the time to move toward better lives for people with aphasia.

What is Aphasia?

Imagine waking up and finding yourself in the hospital. You desperately want to find out what has happened to you, but even simple words come out wrong. You can think, but you can't understand what other people are saying, and writing won't help because your writing doesn't make sense. This is a terrifying situation that has happened to millions of people who have suddenly experienced aphasia.

The National Institutes of Health¹ defines aphasia as “a neurological disorder caused by damage to the portions of the brain that are responsible for 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. There is a resulting critical impact on communication. That is, the give and take of information and viewpoints, and social connections that are essential to all human activities are often seriously disturbed.

¹ <http://www.ninds.nih.gov/disorders/aphasia/aphasia.htm> retrieved 6/9/16

Basically, aphasia is a language impairment; however, core intelligence remains intact in aphasia. Thus, the language problem masks inherent competence and can create the impression that the person is not mentally competent. People with aphasia are quick to point out that aphasia affects words, not intelligence! But aphasia is much more than the simple definition suggests. Aphasia disrupts communication – the core of our ability to develop and maintain relationships, take part in home and community events and project a public image of “who we are.” Communication is essential to almost all of our activities of daily living. “Without the ability to participate in conversation, every relationship, every life role, and almost every life activity, is at huge risk. When adding problems with reading and writing, the impact is devastating. This results not only in barriers to accessing stroke/healthcare services and information, but also inevitably leads to a loss of self-esteem and a profound sense of social isolation” (Kagan & Simmons-Mackie, 2013, p. 8). Imagine being unable to chat on the phone with friends, read instructions on a prescription bottle or explain a health problem to your doctor. Because of the pervasive impact on vital life activities, aphasia tends to create withdrawal and social isolation resulting in a host of secondary health and social issues for both the person with aphasia and for family members.

The onset of aphasia is typically sudden and incredibly traumatic for both the person with aphasia and for loved ones. The characteristics of aphasia tend to vary from person to person. For example, aphasia can range from virtually no ability to speak (severe aphasia) to occasional difficulty thinking of words (mild aphasia). Although it is primarily seen in individuals who have suffered a stroke, aphasia can also result from a brain tumor, infection, inflammation or head injury causing damage to language regions of the brain. Aphasia affects millions of people in North America, yet precise frequency statistics capturing the multiple etiologies of aphasia are not known. We know that aphasia affects a diverse population including both men and women, diverse ethnic groups, all socioeconomic groups and all age groups (with an increasingly younger population emerging). Aphasia is often a chronic condition. Although many people with aphasia improve, residual language problems often persist. In fact, there is a high frequency of long-term aphasia (e.g. Flowers et al. 2016). One exception to that pattern of improving symptoms over time is primary progressive aphasia (PPA); this rare disorder is associated with a progressive degeneration and worsening of symptoms.

Awareness of Aphasia

The public appears woefully ignorant of the answer to the question “what is aphasia?” Since people with aphasia tend to withdraw from social and community life, aphasia is often referred to as an “invisible disability.” Poor public knowledge of aphasia effectively exacerbates the hidden nature of aphasia.



In a survey of aphasia awareness, a nurse responded “I don’t want to get too technical... but in lay terms it’s ‘floppy.’”

(Simmons-Mackie et al. 2002, p. 840)

Public surveys of aphasia awareness attest to the lack of public knowledge of aphasia. For example, a public survey in Canada revealed that only 5.7% of those surveyed had some knowledge of aphasia (Patterson et al. 2015). In the US, public knowledge of aphasia ranged from 11.5% in California to 1.5% of people surveyed in Louisiana (Simmons-Mackie et al. 2002). Many likened aphasia to dementia or Alzheimer’s disease, revealing a common misconception that aphasia is a disorder of general intellectual processing. In a recent US survey by the National Aphasia Association, only

8.8% of respondents had heard of the term aphasia and correctly identified it as a language disorder (National Aphasia Association, 2016). A large number of respondents associated ability to talk with intellectual capacity (National Aphasia Association, 2016). These dismal statistics on public awareness certainly explain this quote by Carol Dow-Richards (the mother of a man with aphasia and founder of Aphasia Recovery Connection): “*It’s hard enough to deal with aphasia, but it’s even harder to go out in public and see how you’re treated*” (Pompilio, 2016). The importance of public awareness cannot be underestimated. Increased public awareness and understanding is likely to lead to greater acceptance and support for those living with aphasia and markedly improved life quality. Thus, awareness and advocacy are critical elements in improving services for aphasia.

In addition to poor public awareness, many health care professionals and physicians are poorly informed about aphasia. For example, people with aphasia report that they do not have the same medical access as people without a language disorder (e.g. doctors did not discuss their medical condition with them; many were not told they had aphasia; aphasia was never explained to them or their caregivers in the hospital; they were not told about resources, services, or outcomes (Welsh et al. 2009). Physicians tend to overestimate the language abilities of patients with aphasia (McClenahan, Johnston, & Densham, 1990). Many health care professionals are unaware of the long-term impact of aphasia, the potential for long-term improvement and the critical need for support services. In fact, many people with aphasia are unaware that their condition is aphasia, often worrying that they are mentally ill or suffering from a progressive disorder such as dementia.

Is There Hope for People Living with Aphasia?

The answer to the question “Is There Hope for People Living with Aphasia?” is an emphatic YES! Even though many people with aphasia have been mistakenly told that there is little hope for change or that they have reached a plateau in their recovery and should not look forward to future improvements (effectively eliminating hope) (Welsh et al. 2009), there IS hope for people living with aphasia. People with aphasia can improve and can learn to live successfully with residual communication issues. Research has shown that language and communication can continue to improve for many years after the onset of aphasia. These improvements are accompanied by new activity in the brain (National Institute on Deafness & Other Communication Disorders, 2015)². These changes in the brain relate to the concept of neuroplasticity – the ability of the brain to adapt and change in



Too many people are told or assume, ‘If I have aphasia, I might improve a little but after six months or a year, I’m done.’ That’s old science. New research shows the brain does have the ability to change and make new pathways...”

(Dow Richards quote in Pomilio, 2016)

response to stimulation and experience. Factors that affect neuroplasticity include the extent of brain damage, severity of aphasia, age and health, availability of rehabilitation and stimulation, and support from the environment. Increasingly, we are understanding more about what it takes to live successfully with chronic aphasia and continue positive change.

Rehabilitation can improve language processing and people can learn to live successfully with residual problems given sufficient support and direction. Treatment for aphasia aims to restore language abilities as much as possible, improve the ability to communicate using remaining language abilities, and use other methods to communicate such as gestures, pictures, or electronic devices. In addition to treatment directed at the person with aphasia, management of aphasia also includes attention to the communication environment around the person with aphasia – that is, creating a supportive and communicatively accessible environment that facilitates participation. Speech-language pathologists (SLPs) are the health professionals that are most qualified to evaluate and manage language and communication issues in aphasia. In addition, other professionals (e.g. counselors, occupational therapists) can contribute substantially to positive outcomes in aphasia. Services for aphasia over the long term are helping people re-engage with the community and connect with others.

To assure a bright future for people living with aphasia, rehabilitation, community programs and long-term support are needed. In spite of research indicating that people with aphasia benefit significantly from treatment and support for many years after onset (e.g. Allen et al. 2012), few services and support programs are available after the first few months. Without appropriate

² <https://www.nidcd.nih.gov/health/aphasia> retrieved 9/22/16

intervention, aphasia can result in costly secondary complications for both the person with aphasia and family members. This report provides a detailed review of research relevant to aphasia services and provides recommendations for advancing the field, and invites advocates to participate in critical change.



After my dad moved in, we felt stuck, afraid and just thrown to the wolves. I was preparing to quit my job to care for my dad full time. Everything seemed so hopeless. Then we heard about the Aphasia Center. Leaving the Center after our initial meeting, I remember the relief and hope I felt, realizing I would now have a way to return to my own life and goals – that my dad would have something to look forward to with friends who would understand and encourage him. I've watched my father evolve from depressed and isolated to being engaged in his own community.”

(Daughter of a man with aphasia from <http://www.aphasiawtx.org/our-stories/sarahgordon>)

EXECUTIVE SUMMARY

“The State of Aphasia in North America” describes research on the frequency and demographics of aphasia in North America, the enormous impact on people living with aphasia, the critical role of communication access, and an overview of current and needed services for aphasia. This comprehensive data source will aid health care providers, people with aphasia, their families, researchers and policy makers in identifying and advocating for needed services. The report offers critical recommendations for moving forward and creating hope for the future of aphasia services. It is time for all relevant stakeholders to come together to support the future of people living with aphasia.

Following is a brief summary of the major sections of the report:

Frequency Statistics

The frequency of a health condition impacts the resources, funding and services available; thus, inaccurate statistical estimates negatively affect those living with a condition such as aphasia and reduces the resources available for support or intervention. Due to the diagnostic reporting methods currently employed for aphasia in North America, the prevalence of aphasia has been underestimated. This report draws estimates of the frequency of aphasia from varied data sources on stroke, traumatic brain injury and brain tumor, - all potential causes of aphasia. The statistics do not include rare etiologies of aphasia or primary progressive aphasia. Based on data sources for stroke, traumatic brain injury and brain tumor, a conservative estimate of people living with aphasia has been revised upward from earlier estimates to approximately 2,500,000 people in the US and 166,000 people in Canada.

Demographics of Aphasia

Knowledge of risk factors and demographic patterns of a health condition help with primary and secondary prevention, as well as planning for services and funding needs. Data on the risk factors associated with aphasia due to stroke, traumatic brain injury, brain tumor and primary progressive aphasia are identified and described in this report and relevant statistics are cited. Although many factors are associated with stroke (the primary cause of aphasia), a few features constitute the highest risk of stroke such as: age (65 years or older), black or native American/First Nations race/ethnicity, residence in the stroke belt of the US (largely Southern States), family history of stroke, prior stroke, depression, history of transient ischemic attack(s), high blood pressure, diabetes and high cholesterol. The highest risk for traumatic brain injury includes factors such as age (elderly people or young males) and prior brain injury. Risk factors for brain tumor tend to vary with the type of tumor. Family history has been cited as a potential risk factor for primary progressive aphasia.

Impact of Aphasia

While much is known about the myriad social, health, psychological and communicative consequences of aphasia, these data are spread throughout an extensive aphasia literature, as well as a wider literature outside of aphasia. A single clear summary of these significant impacts (beyond the language disorder) on people living with aphasia is required in order to effectively advocate for needed services. In addition, an understanding of the implications of these consequences is critical to effective management. This report provides a thorough synopsis that details the pervasive and potentially devastating negative life consequences of aphasia including the enormous economic, social and psychological costs to people with aphasia, their family members, the health care system and society at large. Many consequences beyond the obvious communication disability are addressed in this section. Following are examples of the types of data found in this section:

- People with aphasia are less likely to be discharged home from inpatient settings than stroke patients without aphasia.
- People with aphasia participate in fewer activities than stroke survivors without aphasia.
- Working aged people with aphasia are less likely to return to their jobs than those without aphasia.
- Aphasia is associated with a high risk of depression, low mood or emotional problems; these often persist over time.
- Potential negative impacts on the health and emotional well-being of family members is a significant, and often overlooked, consequence of aphasia.
- Health care costs are higher for those with aphasia than for stroke survivors without aphasia. Moreover, costs to society such as loss of productivity are a consequence of aphasia.

Communication Access

Collier et al. (2012, p. 207) define communication access as “having the means, supports and opportunities to communicate effectively, meaningfully, accurately and authentically in order to get equal uncompromised access to goods and services.” A wide variety of international, governmental and professional statements and guidelines mandate that people with disabilities should have equal access to services. However, communication access to health care and the wider community has not been widely available to people with communication disabilities such as aphasia. Knowledgeable communication partners and communication aids are not generally available to people with communication disabilities in the community or in health care settings. In health care this results in serious consequences such as significant medical errors, safety risks, high vulnerability to secondary consequences (such as a second stroke) and problems understanding medical advice. In the wider community, poor communication access results in a range of serious consequences such as social

isolation, inability to manage day to day responsibilities, loss of employment or difficulty participating in community or leisure events and activities. In addition, depression, loss of confidence and damaged identity result from marginalization and misunderstanding by others. The negative consequences of poor communication access can and should be alleviated for people with communication vulnerabilities. This report provides a comprehensive summary of the risks of poor communication access and a crucial call for improvements in health care and North American society at large.

Gaps in Services for Aphasia

Service offerings around North America vary greatly, and it is often unclear what services are actually available and fundable. In fact, the general public, most medical professionals and even some families living with aphasia know little about aphasia and the options for aphasia management. Without a clear conception of the existing services, needed services, and gaps in aphasia services in North America, it is impossible to identify well-defined priorities for the future. Following is a summary of key gaps in aphasia services identified in this comprehensive review.

- Potential discharge from emergency room services for some people with aphasia without diagnosing aphasia and referring people with aphasia for follow-up evaluation.
- Markedly insufficient communication access for people with aphasia across the continuum of health care.
- Poor knowledge or understanding of aphasia by health care staff across the continuum of care.
- Markedly insufficient training/education of family or carers regarding aphasia and communication strategies. This is a particularly critical failure during acute stages.
- Markedly insufficient speech-language pathology services for aphasia during acute hospitalization.
- Insufficient attention to depression and low mood for people with aphasia across the continuum of care.
- Lack of a holistic approach to reintegration into the community.
- Lack of long-term services for people living with aphasia.
- Lack of services specifically for family members of people with aphasia across the continuum of care.

Recommendations

This report constitutes a “call to action” for all stakeholders interested in the future of aphasia services! Together we can and must act now to transform the lives of people with aphasia. Following is a detailed list of recommendations based on the “State of Aphasia” report.

- 1. Develop a reliable and valid mechanism for identifying the frequency of aphasia (across multiple etiologies) in the US and Canada.**
- 2. Launch a strategic awareness program including inter-organizational collaborations to build knowledge and awareness of aphasia and best practices to obtain meaningful outcomes.**
- 3. Increase sustainable funding sources for aphasia services.**
- 4. Improve services for people with aphasia (including attention to depression).**
- 5. Improve services for family members or caregivers.**
- 6. Improve communication access in health care and the wider community.**
- 7. Generate “audit” mechanisms to track key features of aphasia services.**
- 8. Connect across organizations and systems to identify “best available resources” suitable for aphasia and other communication disabilities.**
- 9. Promote inter professional programs designed to prevent social isolation.**
- 10. Increase research aimed at the consequences of aphasia.**

ABOUT THE PRINCIPAL AUTHOR



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Dr. Simmons-Mackie is a past-president of Aphasia Access, is a founding member of the Academy of Neurologic Communication Disorders and Sciences (ANCDS) and is board certified by ANCDS. She has over 100 professional publications and is an editor of “Supporting Communication for Adults with Acute and Chronic Aphasia.”