Show Notes - Episode #13
The State of Aphasia in North America with Dr. Nina Simmons Mackie

Today, Dr. Katie Strong of Central Michigan University presents an episode on The State of Aphasia in North America. She interviews Dr. Nina Simmons-Mackie about Aphasia Access' recent report on the State of Aphasia.

Nina Simmons-Mackie Ph.D., BC-ANCDS is Professor and Scholar in Residence at Southeastern Louisiana University in Hammond, LA. She is past president of Aphasia Access and serves on the current Aphasia Access board. She has received the Honors of the American Speech-Language-Hearing Association, the Academy of Neurologic Communication Disorders & Sciences and the Louisiana Speech-Language-Hearing Association. She received an Outstanding Clinical Achievement Award from the American Speech, Language and Hearing Foundation. Dr. Simmons-Mackie has many years of clinical, academic and research experience in neurogenic communication disorders and has published numerous articles and chapters in the area of adult aphasia. Interests include aphasia, qualitative research, and social model philosophies.

In today's episode, you will hear:

- The story that inspired the State of Aphasia in North America Report;
- A guided tour of the organization of the report;
- A few of Nina's highlights from the report including the Impact of Social Isolation and Services for Aphasia.

Note: These show notes has been edited and condensed.

Dr. Katie Strong
As I read through the report, I found myself alarmed with the statistics of frequency of aphasia in the United States alone - somewhere between 2.4 and 4.1 million people are living with aphasia due to stroke, TBI, or brain tumor. That's a conservative estimate. I was also empowered by the challenges and opportunities that faced those of us who were interested in aphasia advocacy efforts. Nina, as we get started, I'd love for you to share with us the story of how the need for such a report was identified.

Dr. Nina Simmons-Mackie
Let me start with a personal story. Sometimes we don't know what we don't know and, even after working in hospitals and rehab for years, I don't think I really appreciated the experience of aphasia until it happened to my mother. That was because of the way the healthcare system failed to deal with her communication problems. I knew from having worked in healthcare that

there were significant service gaps in issues, but my experience as a daughter of somebody with aphasia was something totally different.

I know I've shared some stories before about my mother's experiences with acute aphasia, but one of the most harrowing happened when I went home one night to get some sleep and arrived the next morning to find that her stroke had extended and her blood pressure had escalated during the night - it just didn't make sense to me that this had happened. So, after some investigation, I found that during the night she had gotten very agitated, removed her hospital gown, kept refusing to lie back down, and once the staff left the room, she tried to get out of bed - which set off the bed alarm. The response of the staff was to decide that she was a safety risk and they put her in full restraint. But, what was happening was that she had been trying to show the staff that she had a terrible case of hives on her back. In the end, the restraints exacerbated her physical discomfort - it terrified her and it caused her blood pressure to skyrocket. The staff clearly did not understand aphasia and, rather than take the time to communicate with her, they assumed she was incompetent and took a totally inappropriate action. I think these kind of experiences combined with lots of distressing stories from clinicians and families really hit home - we need to do something about the way our healthcare system deals with aphasia and, for that matter, many other communication disorders.

Around that time, some of my Aphasia Access colleagues were asking questions about services for aphasia and we started wondering about the service gaps in our system: were there any data on what's available and what are the needs out there? We started thinking about all the research that's spread all over the literature and the internet, but not readily accessible in one place. In my experience, it just takes so much time to dig out relevant statistics for advocacy, for grants, or to write a proposal to fund a new program. So, it seemed like pulling together information from a wide variety of sources just seemed like a good place to start. I really believe that change can only occur when we understand the breadth of the problem, understand it from the perspective of various stakeholders, and understand it based on evidence as well as passion. That was really the basis for launching this rather massive project.

Can you walk us through the layout of the report?

The report is presented in several sections. It begins with an executive summary which is basically a brief overview of what the report contains as well as recommendations for where to go from here. In fact, the recommendations are really the culmination of the whole report from the perspective of how we can all contribute to change. That section is followed by the frequency of aphasia in North America that you alluded to earlier. This pulls together data from a variety of sources in an effort to estimate aphasia frequency, not only from stroke, but also from traumatic brain injury and brain tumor. The third section addresses demographics and risk factors for age and, again, includes stroke, TBI, and brain tumor - as well as information on primary progressive aphasia. Next is a section on the negative impact of aphasia and covers the

person with aphasia, the family, as well as society at-large. The fifth section addresses communication access in health care and in the community - a topic that we talk about a lot, but not much has happened in the area of implementing system-wide change. So, this section includes lots of data to support things like advocacy, grant writing, student projects, and systems change. A last section addresses services for aphasia in North America - including identifying gaps in each step along the continuum of care with lots of supporting data. Also, each section includes relevant real life vignettes or quotes followed by a summary of research in statistics. I think it gives you a nice subjective window followed by objective data.

Could you highlight a couple of sections that you were particularly drawn to?

For me, the most interesting section to write was on the impact of aphasia. Even though I thought I knew a lot about this, I was amazed at how much data is out there to really drive home the potentially massive consequences of aphasia. These data are what we need to make others aware of why services are so critical and why some of those services need to change. For example, one study reported that major depression increased from 11 percent at three months to 33 percent at 12 months in people with aphasia. The report is a goldmine of statistics like that for grant writers or others. Here's another example: Several studies found that people with aphasia are more likely to end up in long-term care settings and we quote research that shows that this is not only socially disastrous - imagine you end up around strangers who are unable to communicate with you - but, it's also associated with adverse events such as bedwetting, falls, medication errors, and so forth. So, the basic statistic about prevalence of long-term care placements really doesn't get at this constellation of secondary impacts.

Personally, the most interesting research in the document is related to the implications of social isolation. We all know that aphasia can result in loss of friends and shrinkage of social networks, but what does that mean for someone's life? Apparently, a lot. We report really interesting findings on how isolation is associated with premature death, a lower sense of well-being, higher risk of depression, and a higher level of disability. So, social isolation isn't just a sad situation, it's also a major public health issue and there's ample research to support this.

Something that really resonated with me relating to social isolation was that reduced social relationships should be considered a risk factor similar to obesity or alcohol abuse - and that reduced social contact is equivalent to smoking up to 15 cigarettes a day.

The other section that was eye opening for me was a section on services for aphasia, particularly gaps in services. For example, I was really surprised to learn from a North American survey that speech language pathologists reported only 13 percent of inpatient treatment time and 15 percent of outpatient treatment time involves participation-oriented intervention. Two small, separate studies showed that only two percent of people with aphasia in one study and

one percent of people with aphasia in another study were involved in any kind of aphasia or related services after discharge from traditional rehabilitation. In other words, once traditional rehab is over, the vast majority of people with aphasia are left to fend for themselves to learn how to live in a language-loaded society - and, based on that survey, most have not worked on the relevant skills. This cycles back to the issue of social isolation and loneliness being a long-term outcome for many people living with aphasia and that is possibly directly related to the types of services offered to them.

What would you like to see happen with the rollout of this report?

First of all, I would like to see lots of people read the report. I think bringing together a comprehensive set of recommendations for aphasia with supporting data is pretty unique and I think it can really focus our efforts to improve services and improve lives.

Let me give you an example: One recommendation is to promote interprofessional programs designed to prevent social isolation. I mention this one because it resonates with my earlier examples. Just think: We could join forces with social service professionals and others to see how we can prevent social isolation and aphasia. Why do we see so many goals focus on improving the naming of common objects and so few goals focus on reducing social isolation? What can we do in our intervention that really addresses this significant public health issue?

Another recommendation is to launch a strategic awareness program to build awareness of best practices with aphasia. Imagine if we could pull together a task force of multiple organizations and stakeholders interested in best practices so that we could get the word out. We could disseminate best practice guidelines across North America (or internationally). We could involve other disciplines and advocate for related best practices in their profession. Imagine if nursing included a statement about training in communications support in their practice guidelines - that could really push change in the system. I know that [Aphasia United](#) is an international organization that is certainly interested in this sort of campaign and I bet others would be interested in this kind of advocacy as well.

I think that once people read this document that they'll be energized to join together. Aphasia Access had the vision to spearhead this, but it's certainly not the purview of one organization alone. It's a wonderful opportunity for the entire aphasia community to pull together and collaborate to address needs and recommendations knowing that they are built on a review of evidence. So, I hope the paper creates collaborative action. I think the purpose is to provide a source of information, but also to help create change. Research and statistics need to be a springboard for better services and better lives for people living with aphasia and more satisfaction with work for clinicians. I think the contents and recommendations are a starting point - a call-to-action.

How can people get involved in this aphasia advocacy efforts?

It would be wonderful if people would really get on board. Aphasia Access plans to serve as a convener to help bring people together to take action, but it is something our organization can't do alone. It's critical to get input from stakeholders and then begin to identify key players in the efforts. Aphasia Access has created a dedicated email address specifically to gather input and ideas. That address is ideas@aphasiaaccess.org. If you have ideas or suggestions, email us. If would like to serve in a leadership role on a particular part, then email us. If you have contacts in other disciplines or other organizations that might be interested in these efforts, then email us. We want to get everybody involved. After that, the next steps will involve some sort of strategic planning to actually make things happen. The report has an excellent data source for grants, program proposals, research ideas, and so forth - but, we want it to be an impetus for change.