



Show Notes
Episode #1 – An Interview with Kathryn Shelley
Premiered on October 12, 2016

Welcome to the inaugural episode of Aphasia Access Conversations! This series will provide practitioners with the latest information and inspiration to help.

Our four topics will include:

- Insights from the Trenches: Aphasia experts share their most significant “Aha!” moments
- Engaging Your Community: Essential tips to market and sustain your services
- Great Ideas: Tried-and-true ideas for innovative care
- It’s Good for Business: You’ll learn about the best practices of exceptional leaders

We have four amazing Aphasia Access members who will serve as interviewers for these episodes:

- Dr. Katie Strong, Central Michigan University
- Dr. Nidhi Mahendra, San Jose State University
- Dr. Janet Patterson, Martinez VA Medical Center
- Ellen Bernstein-Ellis, California State University, East Bay

In *this* episode, Dr. Katie Strong speaks with Kathryn Shelley, current Board of Director President for Aphasia Access. Kathryn shares her own journey in aphasia care and some “a-ha!” realizations behind the creation of Aphasia Access.

You’ll learn:

- Three W’s that start and sustain an aphasia program
- Four ways that Aphasia Access differs from other aphasia organizations
- Five aphasia access avenues designed to save you time
- One thing you can do today to improve your network

What happens in your life that made you passionate about aphasia advocacy?

Well, aphasia advocacy isn’t something I had planned for my life. Since I’m not in the communication disorders field, aphasia isn’t something I had ever heard of ... I certainly didn’t know that over 2 million people in the U.S. cope with it.

Initially what happened is that I saw the extreme losses and unwanted changes that happen to a person with aphasia when I watched my dad’s world fall apart. He suffered a massive stroke and acquired aphasia at age 70. He had always been an “in-charge” person - he has leadership roles in his business life, he was opinionated and never minced words. However, all of that changed after his stroke. He was no longer able to reliably say his own name, he couldn’t read the newspaper, and he couldn’t carry on a meaningful conversation with anybody. It was hard to watch and I felt powerless and didn’t know what to do.



Can you give me an example of not knowing what to do?

My usually in-charge father became so fearful when a hospital worker came to transport him for a medical test ... not because my West Point-graduate dad was afraid of medical tests, but because neither the hospital worker nor I had visuals to show him what was about to happen. Neither of us had the strategies to have a meaningful interaction with a communication-impaired person.

I knew these struggles weren't unique to me or my city; people struggle with providing 24/7 care all over the country.

In rehab, there was structure and professionals my dad adored. But knowing there was nothing else, I wanted a better life for my dad - something different than a 24/7 isolating life watching TV while the rest of the world marched on without him. But, the thought of me trying to work, weary of our failed attempts to communicate and thinking about years of no support for either of us was nothing but dismal.

You've certainly been an advocate for your dad, but you've also become an aphasia advocate as one of the founders of the Aphasia Center of West Texas. What's the most important thing that helped you get the Aphasia Center up and running?

Early on, a very respected professional from our local hospital told me it was essential to gather the three essential W's: wisdom, wealth, and workers. You can accomplish this in a number of ways: you could start a short-term task force, an advisory council, or a carefully constructed board of directors - that's what we did. We wanted a diverse board that would provide us with critical information and help extend our program's reach and fundraising capacity. Our members included: a top real estate agent, a financial planner, a media guru, a physician, and a city official.

Once that first group of movers and shakers understood the massive losses and the plight of people with aphasia and the solution we wanted to create, they stepped up: They opened and *continue* to open doors to grow awareness and sustainability for our services.

On the programming side of things, discovering the life participation approach to treating aphasia. I learned about it by reading Dr. Roberta Elman's book, *Group Treatment of Neurogenic Communication Disorders* and by going to training at the Aphasia Institute in Toronto. I also had a well-respected CNA who had worked in nursing homes and had worked with people with aphasia, a community philanthropist who traveled with us, and a highly-skilled speech pathologist. Once there was a solution, it was easier and easier to speak up about aphasia advocacy.



As I understand it, you were there on the ground floor of Aphasia Access. Could you share with us the story of that ‘aha’ moment that brought about the creation of Aphasia Access?

That’s true, I was there for the vote to create Aphasia Access, but the ‘aha’ moments began before that.

One of those moments was back in 2010 when Mike and Elaine Adler brought around 20 Life Participation Approach professionals together in Maywood NJ. Although Mike Adler has passed away now, I’ll never forget the passion behind his parting words to our group: He said, “You must do more. Places to get help need to be everywhere.” Those won’t easy words for someone with aphasia to say, so you could feel his passion and his heart. I think we all left energized that weekend realizing just as Mike and Elaine Adler yearned for more environments where people with aphasia could heal and find each other. As professionals, we yearned for an ongoing formalized support system to help us network, sustain and grow Life Participation Approach services.

Then, by 2013, that vision continued. West Texas leaders from the Permian Basin Area Foundation, the FMH Foundation, along with an endorsement from the Aphasia Center of West Texas staff and Board, made it possible for basically that same core group to get together again in Midland, Texas.

Did you know when you gathered that you’d become a new association?

No. I clearly remember, after an energizing two days of discussion, presentations, and debate, the moment finally arrived to vote. There was Dr. Audrey Holland, Roberta Elman, Nina Simmons-Mackie along with a room full of other professionals at the helm of innovation within their own spheres of influence. I imagined the spirit of my dad, Mike and Elaine Adler, along with the thousands of people with aphasia helped by this group of movers and shakers.

I don’t mean to sound overly dramatic, but that vote was *not* taken lightly. This group in particular knew how difficult it would be to start and sustain an upstart organization. But we also knew how great the need was and how much more effective our collective efforts would be if we mobilized. So, clearly the vote was to create Aphasia Access.

What is the overall mission of Aphasia Access and how is that different from other organizations?

The name speaks to our mission. Aphasia Access is about having professionals know how to help people with aphasia access their world from the moment of a 911 call all the way to ongoing care after the onset of aphasia. Our mission is to grow a network of healthcare, business and community leaders to advance lifelong communication access for people with aphasia.



How is Aphasia Access' mission different from other organizations?

Aphasia Access IS intentionally different. We know that no organization can be everything to everybody and still fulfill their mission well. There are already aphasia consumer organizations there to serve individuals and families coping with aphasia's impact. There's also professional aphasia organizations made up of clinicians and researchers who study the language problems of people with neurological disorders. Yet, there has been no go-to resource focusing help to the growing number of healthcare facilities trying to make their environments communication accessible and speech-language pathologists trying to incorporate Life Participation Approach values and strategies into their acute, rehab, university or community-based programs. Aphasia Access is the hub to bring it all together.

How can our listeners become a part of this mission?

One of the most compelling ways to be a part of this mission is to start by sharing with others how gratifying it is to help people with aphasia. Everybody has their own reason for entering this field. Aphasia Access has already created some video tools to make it very easy to share the Life Participation Approach in your community. There are free, downloadable six to ten minute videos - one features Dr. Roberta Elman explaining the Life Participation Approach. Another one is by Dr. Nina Simmons-Mackie explaining a framework for outcome measurement. There's also one from Dr. Leora Cherney where she explains what aphasia-friendly healthcare could really look like.

And, of course, it's easy to become a member at www.AphasiaAccess.org. We've made that membership flexible with options for an individual, a student or a group - memberships for 5 to 20 people within institutions who want key teams of employees to have their own 24/7 support.

How does Aphasia Access fit into the framework of healthcare in general?

Because Life Participation Providers are delivering a holistic service approach that considers a person's environment, their life situation, their identity, their attitude and feelings - in addition to their language impairment. Aphasia Access fits perfectly within healthcare's growing emphasis on holistic healthcare. Also, Aphasia Access professionals are providing the underlying foundation critical to delivering healthcare in a way that a person with a communication barrier can understand. We know that the techniques that help people with aphasia can go a very long way in helping people with other language barriers.

Also, as discussed in the book, Supporting Communication for Adults with Acute and Chronic Aphasia, a communication support approach places the work of speech language pathologists squarely in laws developed around the world that support communication rights. In the United States, the law states that health care facilities *must* provide accommodations to facilitate a patient's participation in their own health care if a communication disability is present.



Of course, healthcare is also about emotional health.

That's right. There are a number of studies that point to the fact that people with social ties fare much better with illness. So, helping a person have meaningful conversations will help them with their health and happiness.

Aphasia Access has a Leadership Summit. I attended the inaugural Summit in 2015 and it was a phenomenal experience. Can you tell us more about the Summit and share any plans for this year's event?

Sure! The Aphasia Access Leadership Summit is a condensed opportunity to network face-to-face with people who are making environments more communication accessible, a chance to speed up learning by immersing yourself with leaders in the trenches of hospital-, community- and university-based programs, a place to find experts creating innovative products, and educators teaching the next generation.

The 2017, the March 16-18 Leadership Summit will be held at the University of Central Florida. The theme is, "Pathways to Meaningful Outcomes." We'll have lively discussions about intervention, reimbursement, education, and research, and of course creating and sustaining programs for people with aphasia. In addition to Keynote presenters and panel discussions, there will be Posters, Share & Care quick idea presentations, and Roundtable Guided Discussions – lots of opportunity for learning, in-depth exploration, and networking.

We have working committees and task forces where people can volunteer for short-term or longer-term projects. There is a real spirit of generosity as volunteers share their expertise in all kinds of ways. Aphasia Access is a hub of innovation – it's a true home for professionals in the trenches of aphasia care to channel their knowledge and find holistic support!

If you had to pick only one thing we need to achieve urgently, as a community of providers/professionals, what would that ONE thing be?

As a community of professionals, we need to develop the actions and attitude of a "convener." That's the word Aphasia Access has adopted as our guiding concept. We want to empower speech language pathologists who are often working hard in isolation with the tools they need to satisfy insurance guidelines and the needs of the patient. Then, there are clinical directors, executive directors, and stroke unit coordinators who are often overwhelmed trying to keep up with regulations that influence their ability to offer top-notch care. And, so often, speech language pathologists haven't had a seat at the table to help the entire healthcare team to deliver care in the way that a person with aphasia can understand.

The ideal scenario is to empower any healthcare worker who interacts with a person with aphasia with communication access strategies, so that families are mentored before they leave care.



The urgent thing is that large-scale improvement at the local or national level will require educated, empowered professionals delivering integrated care in a communication accessible way.

What's one thing that we can do to help with that large-scale improvement?

Invite people in your community to Aphasia Access! I know that sounds like a sales pitch, but we all know how hard we work and we also know that it takes a village of professionals adept at communication techniques to truly make a difference. Imagine how improved the lived experience of people with aphasia would become if everybody - starting with the 911 call - knew the strategies on how to interact with someone with aphasia. And, Aphasia Access is the place with the tools, information, and resources so that none of us have to go it alone.

For too long professionals have been working very hard in isolated, independent ways trying to implement services on a shoestring, or fearing that sharing resources would undermine something. The urgent thing is to realize that large-scale systemic improvement in aphasia care will require lots of diverse entities pulling up a seat at the table.

We encourage current members to invite other healthcare professionals – OT, PT, speech therapy teams within the spectrum of care in your own community. In order to realize a world where all people with aphasia participate fully in life, we want to convene a robust alliance with more corporations and academia, funders and agents of change from diverse settings – The time is ripe to convene numerous people who dream of communication access being the norm rather than the exception. We need and must encourage an atmosphere of professional inclusion.

Were there any other 'aha' moments for you in the actual creation of Aphasia Access?

Later, in an out-of-town hotel room, I pulled an all-nighter while helping a loved one recouping from a back procedure. Typically early to bed me was wide awake, completely riveted reading a book by Nina Simmons-Mackie, Julia King, and David Beukelman. The book was Supporting Communication for Adults with Acute and Chronic Aphasia. It was as if I talked all night with a wise friend, full of practical examples that showed what acute care, nursing and assisted living environments, community-based aphasia programs, and communities in general could look like if they implemented Life Participation Approaches. I finally understood that impairment model approaches in aphasia care weren't at odds with social model approaches. An apt analogy in Chapter 2 from Dr. Simmons Mackie was from physical therapy when a person with hemiplegia is given aids to support safe walking, like a walker or cane, while also participating in therapy to restore muscle strength, coordination, and tone. A similar approach is appropriate in the management of communication. It was an entire night of aha moments thinking about my dad, the long road we had traveled, and now the power of so many visionaries gathering into one professional organization. That following days, the first draft of the business plan for Aphasia Access was created. By May of 2014, Aphasia Access was granted 501 (c)(3) status.



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Any final thoughts you'd like to share with us about Aphasia Access?

I'd encourage listeners to explore AphasiaAccess.org. There are free downloadable videos to use as teaching tools in the classroom or the boardroom. There's a guide to peer reviewed articles, archived newsletters and foundational videos explaining the Life Participation Approach and the history of its origin and evolution. If you chose to become a member, you'll find time savers like the programming resource exchange, a Membership Directory and to me one of the greatest helps - a peer-to-peer network to post a question anytime. AphasiaAccess truly is like having a professional mentor and skilled colleague always nearby.

Kathryn, this has been an absolute pleasure. Thank you so much for sharing your insights with us about how AphasiaAccess came to be and how our listeners can become involved in this organization.