Show Notes - Episode #21
The Future of Aphasia Care and how Aphasia Access is Leading the Way, A Conversation with Ruth Fink, President of Aphasia Access

Here is another podcast episode focused on ***"Insights and 'Aha Moments' about Aphasia Care".*** Dr. Katie Strong (Central Michigan University) speaks with Aphasia Access President Ruth Fink about her career and the vision and initiatives of Aphasia Access. Ruth shares how her career has been a magical time.

Ruth Fink, MA, CCC-SLP is a co-founder and retired Clinical Director of MossRehab Aphasia Center, and Scientist Emeritus of Moss Rehabilitation Research Institute. A founding member of Aphasia Access, she currently serves as Board President. After 20 years as a clinical SLP, she joined the Moss Rehabilitation Research Institute as a Research Associate where she served as Co-PI and Project Director on treatment research in the areas of sentence processing, word retrieval, and computer-assisted applications in aphasia rehabilitation. She is a co-developer of MossTalk Words®, a computer-assisted treatment for word retrieval disorders and has participated in research on MossTalk Words and SentenceShaper software.

In today's episode you will:

- Hear Ruth share about how her career followed the course that a client might follow and about how magic happens in aphasia groups
- Learn three tips for how to transition from a clinician to a clinician researcher
- Hear about Aphasia Access' vision to advance lifelong communication access for people with aphasia
- Learn how you can become a volunteer with Aphasia Access

Note: These show notes have been edited and condensed.

Ruth, you've had a very interesting career with several distinct phases. As we get started, I was hoping you could walk us through your career and highlight a few of the 'aha' moments you have had along the way?

When I looked at my bio, I realized that I actually followed the same trajectory that our patients follow. For example, I started off in acute, rehab, home care and outpatient settings (which many of our patients do) and when therapy ran out I searched for programs to get involved with when patients were discharged because I knew that the need for continued intervention was really strong. I was always grateful to find a research project or a university setting. After I did clinical work, I actually got involved in research and, after that, I was fortunate enough to be able to establish an aphasia center where I could incorporate everything I learned through practice, research, and the Life Participation Approach to Aphasia (LPAA) into a program that would address the long-term needs of people with aphasia.

My very first “a-ha!” moment occurred when I got involved in research. I had been working at home care and with some clients who also happened to be involved in research at (University of Pennsylvania) Penn with a researcher by the name of Dr. Myrna Schwartz. These people had agrammatic aphasia - they could barely put a sentence together and were very hesitant with single word phrases. But, Dr. Schwartz was giving them these complex, passive, object cleft sentences in which they had to underline “who's doing what to whom” based on a series of questions as a precursor to what's referred to as ‘mapping therapy’. So, Myrna and I got to talking and I was really impressed with what she was doing and it turned out that she got a grant to study mapping therapy and was looking for a speech pathologist to run the grant. So I volunteered myself and that's when my career in research started.

So I moved from home care to Moss Rehab where she was then moving with her grant. It was a three or five year grant multi-site grant and I learned every aspect of putting a grant together and executing it. Thankfully, I didn’t have to write the grant myself. That was my introduction to research and I have to say that my experience in working as a clinical researcher was absolutely a perfect opportunity to grow my professional skills. As a clinician, we’re generalists - we need to know everything about neurogenically-based communication disorders. When you're in research, you focus on one thing at a time and you study it intensely. For me it was the best thing to going back to school without actually having to take any more classes.

What was different about research treatments was that I found that I love doing literature reviews - they’re time intensive and clinicians don’t have a lot of time for that. But being paid to do that was just amazing. I loved being of a valued part of a team where developing treatment protocols and outcome measures were critical and feeling that my clinical experience had a lot to offer the brilliant researchers who had a more theoretical background than I had, but not as much practical experience.

Also it was an opportunity to create aphasia-friendly consent forms and instructions and to train graduate students or research assistants on how to interact best with people with aphasia. I also got to work with patients which is my favorite part of the job. It was a win-win situation and it was really a career growth opportunity. Interestingly, for me, the hardest part for me as a clinician was actually sticking to the protocols because I was so used to moving according to what the patient did and how they responded. In a research protocol you really need to stick with the protocol and follow the procedures and the instructions so everybody who followed the protocol does it the same way.

The 10 years that I was a research associate led me to developing a bunch of different focused treatments. That included research in mapping therapy and verb-focused treatments with Myrna Schwartz and then contextual priming treatment with Nadine Martin. Then we were actually able to study some software we developed. We also developed MossTalk Words which unfortunately is out of date, but the most important part for me about MossTalk Words was the study that we did with a group of people with aphasia. We found that those patients with aphasia who worked independently and those who worked partially independently made similar gains. So, if someone saw a clinician three times a week using MossTalk Words and someone else worked independently and were monitored once a week by research assistants to make sure they were doing it right, we saw very similar gains in both groups. That encouraged me to believe that people with aphasia could continue to practice with computers after being discharged because as we know there's lots of drill and practice opportunities on the internet now. It also pointed out to me that any part of training with people with aphasia - whether its outpatient or at an aphasia center - individuals will benefit from supportive personnel. Whether it's a helper that just helps with the technical aspects of the program or identifying which program they should be using.

I participated in research on Sentence Shaper and, while I have no financial interest in Sentence Shaper, I wanted to mention it because it's really a life-changing software program for those who can use it. It’s referred to as a communication aid (some people refer to it as a processing prosthesis). The user can record a chunk of speech and then, after they record it, they can listen to it. If they like what they hear, then they can drag it to an area of the screen where it can be ordered into a sentence or into a longer narrative. If they don't like it, they can delete it. It provides memory support because recordings can be played back and also the replaying enables people to evaluate the accuracy of their speech and in the research there is some evidence that shows that people who use Sentence Shaper produce better aided speech - meaning that it’s much better than when they produce speech spontaneously. The research also shows that some people see subsequent improvement in spontaneous speech because they rehearse so much and listen so much to their final product.

The magic of Sentence Shaper is the final product which can be played back as a recorded speech. For example, the thing that sticks in my mind is a woman who wanted to speak at her husband's retirement. So, she recorded a speech on Sentence Shaper and they played it at his retirement dinner - and there was not a dry eye in the house because no one had ever heard her put a sentence together since her stroke.

These are some of the things that I had the honor of being part of. At some point, when the grants were over, the participants who were in our studies kind of came to us and said, “Okay. What now? You know we've finished our therapy. We finished with research. We need more. You need to do more here at Moss Rehab.” So, my next kind of “a-ha!” moment was when Myrna and I looked at each other and realized that we’ve got to get this amazing research into the clinic. Myrna convinced our administration that we needed to set up a separate Aphasia Center program which we called the Advanced Clinical Therapy Program. We needed a place where we could do these innovative evidence-based treatments that we were developing and that were coming hot off the press from other conferences that we were attending. We knew we couldn't get it into the whole hospital, so they carved out a very small program for us and allowed our clinicians a lower productivity requirement. Then we gathered a group of people with aphasia and called in the troops from the Aphasia Institute to have a big meeting with us. It was our first gathering of people with aphasia. And I think at that time Aura (Kagan) from the Aphasia Institute which was originally called the Pat Arato Aphasia Center. We got some donors and then we were able to actually open our Activity Center which is the heart of the Aphasia Center today at MossRehab and what you see growing around the country. That's the heart that has all of our conversation groups, our book club, our computer lab, our women's group, a men's group… it was just a magical time.

I'll bet we have many listeners who are interested in hearing your experience working as a clinician researcher. Could you share a bit about this?

Obviously networking with researchers in your area would be really helpful and getting to know their research projects. Find out if there's an opportunity to volunteer or to have your center involved in any of the research - that would be a great way to understand.

My job was to help create the protocols treatment goals and to actually write instructions for executing the protocols. I also got to teach research assistants how to implement the protocols because often it's not just the speech pathologist sometimes we have to either graduate level or undergraduates who spend a year or two as research assistants before they go on and decide what they want to do with their lives.

In fact, we had one speech pathologist who, before deciding to go on and get her Ph.D., actually took off one afternoon a week from her job and volunteered one afternoon a week from her job to participate in research with the institute. Some of the activities might include coding responses. As a clinician I would sit there doing check marks on a piece of paper to see how many responses individuals were doing. It could be transcribing utterances. I was never one who did the actual statistics; we always had someone else that did those. So my main focus was in data collection and then, of course, in dissemination - also, I did a lot of help in writing up results. After awhile, I was able to write my own small grants. My institution gave us opportunities to apply for innovative grant funding or small research grants. Without a Ph.D., I didn't think that I would have much luck with NIH funding, I was able to develop the skills to actually write my own grants and with the assistance of my mentor, Myrna Schwartz.

It sounds like it was just really a career changing experience that helped you to move forward to develop the Moss Rehab Aphasia Center.

Absolutely. That was the last 15 years of my career and that was probably the most fun and the most magical time.

When I look at quotes from different people with aphasia from the different centers, all of the quotes are almost exactly the same: Everyone needs a place of understanding. Everyone talks about social isolation. Everyone talks about friends leaving them. Everyone talks about needing an opportunity to continue their rehabilitation in a supportive environment. And all of the aphasia centers meet those goals. That's why Aphasia Access is so critical.

My third “a-ha!” moment was when the Adler family invited about 20 of us to the Adler Aphasia Center in Maywood, New Jersey for a meeting. That meeting for me was like what aphasia centers are for people with aphasia. I found a support group. I found like-minded people. I heard about their programs, how they develop them, how they sustain them, and what their activities are. It was just so amazing and then that meeting was followed by a meeting at the Aphasia Center in West Texas where we continued to talk about what how we can make this happen with a wider audience and to bring this Life Participation Approach to more people and to make it part of real life in all through the United States. At some point, we decided that we would create a formal non-profit organization that would be committed to doing that.

Our mission through Aphasia Access - to grow this network of health care, business, and community leaders to advance communication access for people with aphasia - has really taken off and I think that Aphasia Access has been a part of being able to accomplish that.

You're currently serving as our Aphasia Access President. Could you share with us about the vision for the organization for the next two years?

Broadly our vision is to strengthen the state of aphasia care in North America by bringing people together and giving them the tools and the strategies to integrate communication access and Life Participation Core Values in treatment at every stage. We also want to grow this network of health care, business, and community leaders to advance lifelong communication access for people with aphasia. The newest focus for 2018 is expanding our community and our initial outreach has been with the health care team.

We decided to reach out to health care teams after having some discussions in a process called “audience mapping” where we realized we really couldn't reach out to everyone as an organization initially. For this year, we're focusing on the health care team and we put on our first virtual conference called “Maximizing Communication Access for People with Aphasia: An

Interprofessional Approach Across Settings”. So, the focus is on communication access and on professional practice - it takes a team to do all of this work. It’s important to think “across settings” because we believe that the Life Participation Approach can be implemented from acute care to outpatient care in many ways. There's no reason for a person with aphasia to be discharged from the hospital without having the ability to communicate with a trained partner. We wouldn't send someone home without a wheelchair if they needed it and we should not be sending people home without communication access tools.

I can't tell you how frustrating it is when I go to the doctor's office myself and I see the paperwork that's in front of me. There’s so many questions and there's absolutely no accommodation for people with communication impairments on a routine basis. Hospitals are mandated to fix this. Anyone with a communication impairment has the right to be able to understand what's going on and to participate in their health care. It just happens that people with aphasia are more challenged.

There's still lots of work to do in that area.

Let me tell you about Aphasia Access’ major initiatives. The Virtual Conference is the primary emphasis for the start of 2018. Also, before the end of the year, we’ll have five academic modules fully developed available. These modules have been created to help faculty bring LPAA curriculum into their coursework. There are PowerPoint slides, instruction guides, and references. Three are currently up and the rest will be by the end of the year. After that’s completed, we're going to be looking at making sure that the dissemination is going as we hoped and we’ll solicit feedback so we can make these guides even better.

We want to build the Aphasia Access membership with clinicians and students. We recently had a student membership drive to support student memberships. We’ve now distributed over 130 student memberships, so the next generation of clinicians can have these complimentary memberships and get involved in Aphasia Access early on in their career. At Moss Rehab, we were always fortunate because we got a student practicum into our activity center, but most students don't have that opportunity. They either go to inpatient or outpatient. Until they actually step into an activity center, they don't really see the difference that these groups and interactions can make. So involving Life Participation early in their career through academic curriculum and through all the videos on the Aphasia Access website that are now available is really important.

Our podcasts are going to continue because they’re so popular. The last number I saw was over 12,000 downloads since launch about 19 months ago. My understanding is that we want to start reaching out to guests even outside of Aphasia Access that can provide us with some relevant and engaging topics.

I also don't want to forget to mention the State of Aphasia Care report that is out now and being widely disseminated. I want to tell everyone that it's been presented at numerous conferences so the word will get out at ASHA, ACRM, and other places. I want everyone to know that the Executive Summary is available free to all members, but to get the most out of it I'd encourage listeners to purchase the actual reference guide because the larger document.

Is there anything else you'd like our listeners to know about Aphasia Access?

It definitely takes a village to make this organization successful. As I mentioned, we have a lot of members that have volunteered to be on standing committees or working groups. But I guess I would like people to know that if they would like to volunteer for a committee they can just email us at info@aphasiaaccess.org.

There are a lot of webinars and videos on the Aphasia Access website that you can immediately use for staff training and in-servicing. I am reluctant to name names because I'm going to obviously leave somebody out but there are some great videos on there from people like Leora Cherney, Nina Simmons-Mackie, Roberta Elman, Aura Kagan and the staff at the Aphasia Institute. I would really encourage people to take a look at the website if they haven't. Give yourself an hour a week and you'll be pleasantly surprised at the content that's on there.

If you had to pick only one thing we need to achieve urgently as a community of providers and professionals who support the LPAA, what with that one thing be?

That is tough to come up with one thing.

The first thing that comes to my mind is to make sure that all people with aphasia are discharged with a referral to either an aphasia center or a group and that they know about research opportunities in their area. As I said before, magic happens when people with aphasia enter these groups. It's up to us as professionals to make sure that they have the information that they need to continue to participate in rehabilitation and that the information given to them is in an aphasia-friendly manner. They also need to hear it over and over again because I constantly hear from patients that they haven't heard about it before. Also, make sure that materials are in an aphasia-friendly format - that's very important if we want to continue to reach people.

Another wish is to make communication access training part of required annual competencies for all health care workers. We're going to have these videos that we developed for our virtual conference and I know that the information in our virtual conference will give people some of the tools and arguments they need to bring to their administrators about how important this is. If it's part of an annual competency, then they have to watch the video. If people have ideas about how to make that happen or have successfully done that at their institution, please reach out to us and share how you did it.

I can't stress enough about our need for more research on LPAA programs and protocols. If you go to any of the conferences, you mostly see imaging studies (which are critical), but we really need more research that's disseminated on LPAA program and I'm hoping that in the future we can help facilitate that.

For more information on Aphasia Access and to access our growing library of materials, go to www.aphasiaaccess.org. If you have an idea for a future podcast series or topic, email us at info@aphasiaaccess.org.

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