



Show Notes

Episode #6 – Engaging your community In conversation with Maura Silverman

Premiered on April 27, 2017

Today, Dr. Nidhi Mahendra (San Jose State University) interviews Maura Silverman. Ms. Silverman is the Executive Director of the [Triangle Aphasia Project](#) in Cary, North Carolina and is also the inaugural recipient of the [Aphasia Access Innovator Award](#).

In today's episode, you will:

- Identify practical and strategic methods for increasing awareness of aphasia programming and supports within your community;
- Learn how to describe methods to engage and mobilize individuals with aphasia, along with their families and partners, in order to widen the service provision options available
- Identify stakeholders and determine how their objectives (and your LPAA provision goals) can be aligned for improved services.

Dr. Nidhi Mahendra

When you were invited to do this podcast on the topic of combining awareness and engaging with the larger community, what was the first thing that crossed your mind?

Ms. Maura Silverman

Of course, I was honored. That's something that I'm sure everyone feels when they're asked to share what is personally relevant, professionally motivating, and what you're passionate about.

I also thought about how Aphasia Access really makes sure that every voice is heard and that every message really counts. Your input has value! Regardless of whether or not you're a small community group in a hospital or you're in a large university setting, your input as a provider to people with aphasia is valued by Aphasia Access. They seem to take their role as a knowledge broker very seriously. I'm excited to be able to share what we're doing here at [Triangle Aphasia Project](#) (TAP) and how it relates to the mission of Aphasia Access.

I want to get things started by asking you about this topic of raising awareness about aphasia and its characteristics. We have made huge strides in raising awareness about aphasia and how it profoundly alters a person's functioning and quality of life. Yet, I know that we're often also circling around this idea that we have a lot more work to do. I'm curious about what you think as far as how you would say that we're doing overall when it comes to raising awareness about aphasia.



I think I'm really proud of the strides we're making. There are more and more people who understand what it means to have aphasia. They understand that your intellect is not impaired and that your language is really the barrier. But, the reality is that you care about something when it impacts you. When my father was diagnosed with esophageal cancer, I had certainly

heard of it, but I didn't really understand it until it became part of *my* life. When it becomes your passion, it's unthinkable that other people aren't as excited about getting the word out. So, getting the word out about aphasia has obviously come a long way but giving it a name and giving it representation is huge.

I remember that we had a consult from somebody in the nonprofit world who wanted to help us and we were so thrilled to get advice from them. And the first comment was, "I love what you're doing! Triangle Aphasia Project! But, you know, nobody really knows what that word 'aphasia' is. Why don't you just get rid of that from your title and we'll call it something else?" And, of course, I was aghast. Calling it "aphasia" is what helps us define it and giving it a name is huge. I think we've come a long way but we certainly need to have people recognize the relatability to it.

You're absolutely right. We are making strides and yet we have to keep making strides to really get that message out there. I'm reminded of a conversation with my dean recently who was very surprised that somebody in their 30's or 20's could also have aphasia. So that just speaks to how much more we have to keep doing that.

We have one group that the average age is 47 - that includes people who are 21 and in their 30's. Some of them are in the middle of their prime raising children. It's important that people see that it is not just a disease that affects older individuals.

You have all this experience as both a speech language pathologist and also as a program director. What do you think are currently some of the most important considerations our listeners should be thinking about when they are planning to raise awareness about aphasia?

It's really a great question. When I started TAP, I literally spoke anywhere, any place, anytime, with anyone that asked me to. I realized that showing up at health fairs and at every opening of anything to share information about aphasia was great because it helped raise awareness. However, I find that your energies need to be very strategic. We all want to engage and mobilize but we need to think about the audience: who do we need to educate and how can we get them involved?



The other thing I realized is that I was out there *giving* information, but I wasn't really *asking* for information. More recently, I believe we've grown our program because we started to listen more. We partnered with other non-profits and community providers and said, "What do you need?" When you start to listen, then you can find out what information they need.

I know through your work with TAP that you think it's very important to meet the long term needs of people with aphasia. How did you consider these long term needs in both developing TAP's programs and also planning aphasia awareness activities in your own community?

All people serving individuals with aphasia **should** go to the definition of it. We hear that it is chronic - which really means that aphasia is persistent and unabating. When you think about that chronicity of a disorder, people don't see the hope and the engagement that is there. I think that one of the things that happened initially with TAP is that our referrals came too late. Individuals had gone through the acute rehabilitation process and they had gone through outpatient rehabilitation. Oftentimes, they were going back on their third or fourth try with outpatient therapy and somebody would say, "Hey. You should see about this community program." So, I would really encourage all of the speech pathologists and providers to look at the words we use. Words like "re-engagement" and "re-integration". Those words assume that a person is disengaged. And it's very true. That's why social isolation is such an issue with individuals with aphasia. If we are going to look at life participation approaches and think of the person's life goals and their concerns, we can't come in at a time when they're already disengaged.

We also have this parallel now with more knowledge about neuroplasticity. We know that the intensity and repetition of therapy matters. Saliency matters. I think that when we look at long-term needs, we have to think about the changing roles that an individual has throughout their life. We have to look at their life when we meet them and see some of their barriers. We need to excite and engage them. We have to coach individuals with aphasia to really own this

rehabilitation process early on. When we started that, what we started seeing is that our referrals weren't coming when a person was at the end of the continuum of care, but rather they develop this partnership with us earlier on. This provided them with a connection in the community and they were able to address some of their return to social activities and their return to volunteer activities or work environments in a really supported way. So I think that long-term needs can be addressed by kind of coming in a little earlier and partnering with the providers on the beginning end of the continuum.



I'm sitting here just listening to you thinking about how much intuitive sense that makes. That approach would probably make the person's whole trajectory proceed much better. Having that message of hope and continuity of care right from the start makes a lot of sense.

I don't want to be the first person to tell them about hope. I want them to hear that message from the beginning and, if they do, then they'll hear this empowering message about living in their world with aphasia.

I have to say that there is something quite inspiring when you meet a person with aphasia that's gotten all the right kinds of support and care from the start. You see that they have hopes and dreams and it's very empowering to see that.

There's this link between the services that we design and the communities from which our clients are coming. In your experience, what have been some challenges that you have faced in your own community when marketing the services that TAP offers?

I think one challenge that a lot of people will be able to relate to is that we are really spread out in North Carolina. There's a lot of rural communities between Charlotte and Wilmington. Driving two hours to spend a couple of hours with people with aphasia may not always be the best option, so maybe we should look to serve people in a different way.

The "hub and spoke" model that TAP has developed and utilizes really looks to build networks and provisions where the person lives and connecting individuals to each other. I think the providers that are out there are all coming together and forming this seamless continuity of care and making the connections early on. People are ready for training often when they are long gone from an acute rehab or from an outpatient program, so we need to have those connections early. One of the things that we've really tapped into is getting education and training through other creative modes. When my mom had her stroke, the first thing we did was set up a [CarePages](#) account. Those type of internet-based communication systems like [CaringBridge](#) (even Facebook pages) are a great way to start to educate people. Our partners in the rehabilitation world have really embraced this and many work on having their clients update their own CarePages account. Through sharing photos of the person in rehab, they start to create a group of people who are willing and able to be active communicative partners and interact in this person's world.

Switching gears a little bit, I want to go back to this concept of developing aphasia programs. We know that aphasia programs take a long time to initiate, develop, and market to our communities. TAP has had tremendous success over the last 13 years. My sense is that the long-term sustainability of aphasia programs really hinges on pairing together this trifecta of understanding communities, aligning resources, and strategic marketing. Would you agree with that?



Absolutely. I think that really engaging people and getting them to mobilize has a lot to do with sustainability. It goes back to identifying who you are impacting. Who are your stakeholders? They're not just individuals with aphasia. It's also their families and their children - which is why we have a children's program to train individuals of people with aphasia.

We also have our partners. We have speech pathologists in rehab and people in home care. We have doctors, nurses, physical therapists and aides that might be working with individuals. We have to look at how all of our partners can be invested in our success - that goes back to

listening. How do we create a win-win situation with the stakeholders finding out what their needs and barriers are and how our program might help?

I think it's also important to really realize that our partners are not just in the rehab world. One of the best things that we've done is to recognize that it's important to collaborate with the arts and adaptive sports. Think of your life and what you do on a daily basis. Those are the things that people are missing out on when they have aphasia, so they can create isolation. So, we look at altruism and volunteerism and really connect with some community programs. That's a really neat opportunity to learn about your community. Also, grant writers will tell you that the best thing you can do to support grant money and funding for your program is to collaborate. That's really been helpful to us.

Your work in North Carolina has been a huge inspiration to lots of people - myself included - and that has been largely because of your advocacy on behalf of persons with aphasia. I want to ask you about what steps you took as TAP's executive director to sustain TAP's impact over the long duration that it has had in your region. Could you provide us with some specific examples so that our listeners will be able to take this into their practice settings?

It's not just going after the funds. Yes, we raise money to fund programs, but what we really want to do is sustain our impact. We want to make sure that our stakeholders - donors, clients, family members - see the relevance to themselves. Many aphasia programs have book clubs. One of the ways you can engage the community is get in touch with regular book clubs that are in the community. For example, our newspaper did a story on book clubs and we put our information in there and it was an opportunity to highlight what we're doing.

The Garden Group is another really good example. There is a speech pathologist that works for us and she loves gardening. (She's actually receiving a master's in gardening.) So, she hooked up with other partners in the community that were serving food to people and our clients are now growing food for individuals and families that need food. This is putting our clients back in a very empowering role. I think finding out what people are struggling with and how you can help



them serve is a great idea. It goes back to that original idea of really just listening and finding out what the community needs from you.

I think it's sometimes easier to show a really simple example. My mom has a desire to pick out her own clothing. While a speech pathologist might be working on a lot of word finding and sentence production, all my mom really wanted to do was not wear navy blue with black! Creating a simple, low-tech AAC page that you can stick on a hook and say, "Help me pick out

my own clothes." And when you can do something like that, you see how empowering communicative access is. And, of course, it fits into the life participation model.

As we wrap up, I wanted to ask if there's anything else that you thought you might want to share with our listeners and Aphasia Access members today that you haven't yet had a chance to share.

I'm not sure I learned this more from my service to individuals with aphasia in a professional capacity or through my service to my mother in a personal role, but it's important to remember that people want to help. When you first have a stroke or brain injury happen and you have aphasia, support starts pouring in. People are there with pies and meals wanting to do anything, but things die off if the people wanting to help don't feel that they have a purpose.

One of the things that I'd really like to share is this idea that we came up with here called a "communication support team". It's largely based on the model of "faith-based care teams" where if something's going wrong in a family that people really just get involved. This model really embraces the life participation approach. It also really reinforces the idea of what the Intensive Comprehensive Aphasia Programs (ICAPs) are doing. They're looking at applied neuroplasticity and saying that it's a really hopeful time to be involved in aphasia rehab and recovery. And in doing that we need to make sure that we allow everybody, regardless of finances or geography, the same intensity. We can do this by helping them develop a team in their own community that can help with their communicative interactions when they return home.

Some of our teams that are running have between six and 12 volunteers and they are there for an hour a week. They go out with the person to re-engage them in life and, at the same time, increase awareness of your own program as well as share information about aphasia. I really look at this communication support team as a potential avenue for people to get actively involved in their own recovery.