



Show Notes

Episode #11 – Engaging your community: In conversation with Esther Kim

Today, Dr. Nidhi Mahendra (San Jose State University) interviews Dr. Esther Kim. Dr. Kim is a speech-language pathologist, aphasia researcher, and Associate Professor in the department of Communication Sciences and Disorders at the University of Alberta in Canada. In addition to her research program examining treatments for aphasia and acquired reading disorders, Esther is the co-founder of the Alberta Aphasia Camp and has an interest in examining outcomes related to aphasia camp participation and LPAA programming in general. Beyond this, she also teaches an aphasia class and supervises graduate student clinicians.

In today's episode, you will learn about:

- The importance of utilizing multiple avenues for high impact when raising awareness about aphasia;
- The critical importance of recreational and therapeutic activities for people with aphasia with a special emphasis on offering these activities in a supportive communication environment;
- Program design with an eye to bringing people with aphasia together while also providing a rich training environment for speech pathology students.

Nidhi Mahendra

As you know, Aphasia Access has done some incredible work in commissioning a study that for the first time reveals that the real incidence and prevalence of aphasia is far greater than previously thought. I would like to get your thoughts on the public awareness of aphasia in Canada: What is it like and is it comparable to what we see here in the United States?

Esther Kim

I think I have a bit of a unique perspective on both the U.S. and Canada because I did my undergraduate training here in Canada and I did my master's, doctoral, and post-doctoral work in the United States. Since then, I've returned to Canada and I'm working here. I think that general awareness is comparable between the two countries. Canada is a very large country in terms of landmass but pretty sparsely populated, so most of the 35 million Canadians live in an area roughly the same as the state of California. I think there's also some regional discrepancies



across Canada. For example, Toronto has the advantage of being a major metropolitan center, but it also has the Aphasia Institute with Dr. Aura Kagan - that's really helped to make Toronto a place where people know and have heard of aphasia and are aware of what it is and what services are out there. I wouldn't say that that's the case across the board in all of the cities in Canada. One thing that I would say is that, because Canada's population is smaller, there seems to be more of a reach of some of the advocacy efforts. After living in Arizona, I was pleasantly surprised when I moved back to Canada that it seemed like almost all the clinicians I met at different conferences across the country had been trained or had attended the Supported Conversation for Aphasia training (SCA) offered through the Aphasia Institute. I found that that wasn't as prevalent when I was in the States.

I know that you have always been interested in aphasia advocacy and awareness. What have been particular avenues or strategies that you have found especially useful in Canada?

I think working in a university setting and having the enthusiasm of the students is something that we're lucky to have here. There's some grassroots kinds of things that we've done as far as increasing public awareness of aphasia in concert with our student group. They go out to the community then set up booths and demonstrations at places like recreation centers and farmers markets. They are just kind of spreading the word to the average lay person about what aphasia is as well as communication disorders in general. One of the other major fundraisers that our student group does is that they host a comedy night and a silent auction at a local comedy club. It's nice because it reaches a different kind of audience and the proceeds go to support our aphasia camp as well as the AAC camp that we recently started here.

In this day and age, you can't go very far without talking about social media. We have an Aphasia Awareness in Alberta social media account where we share articles of interests, information, resources and things like that. A lot of what I have personally learned about working with social media has come from our communications team here at the university. They have been really good at having ideas that will reach across different platforms and reach different audiences. For example, last year after our aphasia camp, we had a student volunteer write a blog post about her experiences volunteering at aphasia camp. Then that went out to the student blog and the student community got an interesting perspective. The communications team has also helped us facilitate interviews with local media featuring people living with aphasia where they talk about their experiences at the camp.



One of the cool things that we did last year was that we had posters at camp with “#AphasiaCamp”. People would then write or draw what it meant for them to attend aphasia camp. Then we took pictures of everybody holding up their signs and created a video from that. That’s up on our website and it got tweeted out in June for Aphasia Awareness Month. We also sent that video out when it was time to put out our registrations for camp. It’s also been sent to our funders who support the camp and so it’s a way for us to show that this is what you’re supporting when you are supporting our camp. Even if you don’t have access to a communications team, everybody has somebody within their social network who knows about marketing and are really good on different social media platforms. I’d say that you should take advantage of that kind of expertise because you can really expand your reach that way.

I know you were a co-founder of the Alberta Aphasia Camp - a weekend-long retreat-style camp for persons with aphasia. I still remember your really nice presentation about it at the inaugural Aphasia Access Summit. I wanted you to share more about the Alberta Aphasia camp and what your primary motivation was for helping to start it.

When I first came to the University of Alberta, I was volunteering with a committee called the Awareness Committee - which is a subcommittee of the Stroke Recovery Association of Alberta - Edmonton chapter. I met these two really stellar clinicians, Andrea Ruelling and Rhonda Kajner, who had been trying to develop a camp for the past couple of years. They approached me to help get it started. We recruited a couple of students and that kind of helped to get it off the ground. So, the camp itself is a weekend retreat that’s held at a rustic camp facility out in the wilderness. We’re actually moving to a new location this year, because we outgrew our previous location.

The motivation for the camp was to meet a variety of goals. First, we wanted to give people living with aphasia - both the people with the vision and any care partners - a chance to enjoy recreational and therapeutic activities in an environment where their communication is supported. The people there know what aphasia is, so they know how to communicate with people with aphasia. That allows for everybody to be themselves and do things that they enjoy doing and you can take that communication impairment out of the picture as best you can.

Another goal was to connect people living with aphasia to each other. In terms of LPAA principles, we really wanted to provide an opportunity for people with aphasia to grow their support networks. Finally, we wanted to provide a training opportunity for students in a nontraditional classroom or clinic setting. We have PT, OT, and SLP students - so, it’s also an



opportunity for them to get some interdisciplinary skills in working with each other in this kind of environment. It's been one of the most rewarding experiences in my professional career so far.

I'm curious about your thoughts regarding the link between program development (whether delivering research programs or clinical services) and the particular communities you are hoping to serve? How do you approach program development with due consideration for the communities you're targeting?

I'll talk about this in the context of developing the aphasia camp. When we first started out we were quite intentional about not trying to reinvent the wheel. We talked to several others who had already done this. So we talked to those people and asked: What's your model? How is it run? How are you funded? What does a typical schedule look like?

We also held some focus groups with stakeholders. We invited people with aphasia along with family members or care partners that would likely attend something like our camp with them. We then interviewed them about what they would like to see. Do they want the focus to be purely recreational? Do they want the therapeutic aspects? What kind of environment should it be? Since initiating the camp, we do ongoing program evaluation. This year, we've added an advisory board with people with aphasia and care partners who have been attending camp. They give us input on things that they like and the things they would like to see change. I think getting that input from the stakeholders is what's really important and useful.

Finally, we partnered with [March of Dimes Canada](#). They are a nonprofit organization that works to fight for disability rights in Canada. They were already doing aphasia camps in other regions of the country. We're fortunate to get their input and expertise because they had run similar things before. They help us with the fundraising part of it and working with these like-minded individuals. So, even if it's not a large nonprofit group like March of Dimes Canada, it would be helpful for everybody to find other clinicians or volunteers who have the same mindset and goals. I think it's important to find those partnerships and work together.

This type of camp programming is clearly inspired by the LPAA framework, but it's also different than other Aphasia Center-type programming because it's only a single weekend. I'm wondering about the kinds of outcomes you're seeing and what you might expect to see from this type of weekend programming.

We've actually done some research around measuring outcomes and we've used the A-FROM model to frame what domains we're looking for. Definitely, as you might expect from this type of programming, we've seen some changes in activity and participation domains and a lot of that



stems directly from participation in specific activities at camp. So, for example, a gentleman had tried adaptive yoga and that was something that he never thought he would be able to do - but, at camp, we had an instructor teach a yoga class where there were chairs and a lot of adaptations. When he went back into his community, he sought out a chair yoga class and that is something that he continues to do. That's probably not something that would have happened without his exposure at camp.

We see a lot of change in terms of personal factors (like increased confidence) that comes from decreased isolation. It's really great to see people with Aphasia and their care partners exchanging contact information. In terms of environmental factors, before care partners come they've probably been told how to communicate with their spouse, child, or parent. But, there's just something about actually observing those techniques and seeing their person with aphasia being successful in communicating with students or with total strangers. When they go home, maybe that care partner will try some different techniques.

We were using the Assessment for Living with Aphasia that really looks at all of these different domains. The one domain that we probably don't expect to see changes in is the impairment domain. When we look at the research, we don't see any significant change, but anecdotally, we had some stories, e-mails, and phone calls from people saying that they really noticed that there were some changes in fluency, speech, grammaticality, and things like that. I had an SLP who referred a woman with aphasia to the camp. When she saw her client again after the camp, she said, "I could be wrong about this, but I'm seeing some real improvement in fluency." If you think about it, using the principle of neuroplasticity, these people sometimes don't have a lot of communication partners - perhaps they even live alone. So, they're not talking to a lot of people and then they come and spend a weekend where they are surrounded by people and direct communication partners. They get a lot of mass practice in a very salient environment. I think that there could be something there as well in terms of the impairment domain.

What would you say have been some best practices that have worked for you as you have connected with the community through the marketing of your aphasia camp and through your research programs?

I think that it really is kind of a multi-pronged approach and so it's important to lay that foundation for why LPAA is important. You should start with your students because they are going to be your future clinicians and credible advocates. So, empowering those students, giving them opportunities to see LPAA actions through things like aphasia camp, as well as empowering clients and clinicians in the community is a great way to create the advocates and ambassadors you need to increase awareness of aphasia.



We've had examples where clients came to an aphasia camp and then they wanted to continue meeting and getting together. So, we encouraged them to start their own sort of coffee club or lunch club where they could get together and basically have conversations and meet once a month without necessarily being facilitated by a clinician. We've had students who had come to aphasia camp who go back to other parts of Canada and are really empowered or inspired to start something similar in their own communities. They've reached out to us about trying to start something like this and have asked for give advice about how we went about it.

Lastly, you can have an impact on people that you might not expect. At our first camp, we had a camp counselor that worked at that location who was from the UK and she had never met anybody with aphasia before. She didn't know what it was. After spending the weekend with her campers, she actually went back to the UK and decided to go back to school to work with stroke patients. That was a really interesting impact and something that we necessarily wouldn't think or expect.

As we wrap-up, do you have any final thoughts or takeaways that you'd like to share?

Start small. For us, we started with the aphasia camp and we have seen some natural growth from that. Our next step is that we're trying to start a center or program. I don't think I could have just jumped into that right off the bat. We definitely learned the lessons from starting small and we're kind of building our market. I should also mention that the resources available to me through Aphasia Access and its members are so incredibly helpful. I encourage everybody to take advantage of what an amazing resource Aphasia Access is.

Resources

Alberta Aphasia Camp

<https://www.ualberta.ca/communications-sciences-and-disorders/alberta-aphasia-camp>

Alberta Aphasia Camp - Facebook Page

<https://www.facebook.com/Alberta-Aphasia-Camp-523435954458999/?ref=hl>

Kagan, A. Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., Threats, T., & Sharp S. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*.<http://dx.doi.org/10.1080/02687030701282595>