AphasiaAccess
CONVERSATIONS

Show Notes
Episode #3 - Great Ideas in Aphasia Care Programming: In conversation with Aura Kagan
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This episode is the first in our regular “Great Ideas” series. Each episode will provide listeners with tried-and-true ideas for innovative care.

Our host this week is Ellen Bernstein-Ellis, director of the Aphasia Treatment Program at California State University - East Bay. She is speaking with Dr. Aura Kagan, a true LPAA champion and innovator. Dr. Kagan is a fellow of the American Speech Language Hearing Association and has developed innovate approaches to treating aphasia. Today, she is the Executive Director and the Director of Applied Education at the Aphasia Institute in Toronto. The Aphasia Institute is a non-profit teaching and learning agency dedicated to service, education, research, awareness, and advocacy on behalf of all of those living with aphasia and their families.

In today’s episode, you’ll learn:

- The value of a more impact-focused definition of aphasia
- How a conversational interactions approach guides programming
- The value of volunteers in your aphasia centers
- The importance of providing an introductory experience for people with aphasia and their families

A note from Ellen Bernstein-Ellis:
As Director of the Aphasia Treatment Program at Cal State - East Bay, I have shown the Aphasia Institute’s “Life is Larger than Aphasia” video every quarter for the last eight years. It’s one of the earliest aphasia advocacy videos. I encourage everybody to check it out.

What was the source for some of your original ideas at the Aphasia Institute?

My first job when I came to Canada was in home care and it was my first exposure to what was was actually happening for people with aphasia and their families *after* discharge from hospital-based therapies. Like many other people, I had no idea about what happened after we discharged patients and it was a real life-learning lesson for me. Then, I heard about a job in a small program that was located in a school classroom. I went to visit and I found a room with people sitting in several small groups around tables and the focus at that time was on workbook and reading activities. But, what captured my interest was something else and that was what was happening between activities. It was something I hadn’t seen before with people with aphasia. The person who started what is now known as the Aphasia Institute, Pat Arato, a family caregiver, came at things from a different angle and she knew it was essential to give people hope. Which unfortunately today is still such a needed message as so many people still receive the “no hope” message. And although she didn't really use these words at that time, she was really saying that it's possible to live successfully with aphasia. That was a huge initial inspiration for me.

I just read in one of your recent articles in *Clinical Rehabilitation* that over half of all persons living at home six months after a stroke report that their life is lacking some aspect of social, recreational, or purposeful activity. That just really struck me! You know how important it is for us to look at that and understand what that means.

I agree and I think those of us who have exposure to the daily lived experience of people with aphasia understand why we have recently redefined aphasia in a way that we think changes the aphasia narrative. I'm referring here to an article that I co-authored with Nina Simmons Mackie in 2013 published in the ASHA Leader. What we looked at was the idea of impact - really understanding that definitions are important because they imply a scope of practice. And so we felt there was a need for a *definition* of aphasia that focuses on its impact - how people with aphasia can live their lives without hope and how, after receiving their initial therapy, they are left without a way to get back to participating in their lives.

So, we need a definition that automatically expands our scope of practice beyond the fact that “aphasia is a language problem”. Our definition needs to include that aphasia masks inherent competence and that it has its most dramatic impact on conversational interaction. We are talking about talking--talking and understanding. We also understand that aphasia includes an impact on the ability to read and write, but the major impact is on this ability to participate in conversation because, without that ability, we know that every single relationship, every life role, and almost every life activity is at enormous risk. Now, when you add on the problems with reading and writing, the impact can be devastating.

How did you use this focus on conversational interactions to develop programs at the Aphasia Institute?

The idea of the centrality conversational interaction and the opportunity to reveal competence is at the heart of just about everything that we do. And you know part of that came about through an evolution of thoughts. You know one of them being the title of an article that I co-authored with Gillian Gailey many years ago: Functional Is Not Enough. Many of us were taught that our job is working on the impairment and, if that doesn't work, work towards functional. In many schools now, functional is included from the beginning but they’re working on a fairly narrow definition.

If you thinking about functional communication broadly, like someone like Audrey Holland does, that would be okay. But for many people, the idea of functional communication is: Can you do this task? Can you order items of a menu? Can you get a message across. That is very different than the ability to connect to people through conversations. So, functional work is important and, certainly at the Aphasia Institute, people have many opportunities to practice. They practice on an impairment level because they are actually practicing language skills but the biggest piece is this ability to connect with people in a community via conversation.

One of the ideas that I think is central is getting into exploring what we mean about “community” because many of us are in the community-run community programs. There are two ways of thinking of “community”: One of those is a “little C” community that you create. Once you have a group, you’ve actually created a small-level community. There’s also the bigger Community in the sense of all of us living in something that is larger than us just living within our own small circle of relationships, our own personal home--we all live in a bigger community where we have a lot of different roles. So, one of the ideas is to give people the opportunity to reveal competence through their interactions. This also gives them a chance to reveal their ability to take on community roles even if it's within something like an aphasia center. I'm talking about the natural opportunities to help other people, for example, through serving on a committee or being on a board. Those are things that kind of replicate what you can get in a big Community.

How would you say that these core values translate into a life participation aphasia program?

If you agree with our definition of aphasia with the centrality of conversation, then one of the must-haves is this opportunity for conversational interactions or conversation groups and having groups where a conversation actually is an activity the same as any of us do when we meet a friend for coffee or we go out for dinner. We don't do it for the purpose of actually having a coffee - we do it to meet and chat with someone. So, that is one element that I think is absolutely core. The second element would be education and support for people with aphasia. And, while some of us have the luxury of a dedicated education programs, it doesn’t have to be in a separate group. There is an opportunity for education and support for people with aphasia in any conversation group. These two elements are absolutely critical. Then, there are a whole lot of other things that are great to have, if you can. For example, having a larger community is very important. When you’ve got 40 people in there during the day - as opposed to four - then you’ve got what we all take for granted which is choice of association. So you might have small groups, but in a bigger center, during the coffee breaks you see all sorts of informal little groups happening in a natural way.

Also, family caregiver education is very important, Providing opportunities for people to be a giver and not only a recipient of service. This can happen within a small level within a group, but if you have the luxury of a bigger center, there are so many roles people can take on, volunteers, or as I mentioned earlier, sitting on committees or boards.

Also, exercise programs are important because all of the latest stroke and rehab research program demonstrates that when you can pair exercise with other simulation approaches, it really makes a difference. There is a lot of information about community-based exercise programs that I would encourage people to look into. There are all sorts of activities, where conversation is the lubricant instead of “the activity.”

Let’s talk a little about what the Aphasia Institute offers people. In addition to the conversation groups, you've expanded to exercise groups, book clubs, singing groups, art groups, gardening, Toastmasters, a creative writing group, and a creative expressions group that just has posted some marvelous videos. You have musical theater and peer leader training. Am I missing anything? What guides your decision-making when deciding what groups to put in place?

A lot of the inspiration for those come from our members with aphasia and really looking at what they want. We also look at what *any* of us wants for ourselves. Part of the message of the approaches we use, and it gets back to how the World Health ICF frames itself, we don't look at well people and sick people with two completely different paradigms. When you're looking at participation, we look at what we all like to participate in. So, if you think of the list of things that you mentioned, many of those are things that any of us like to do in our lives. That's often our idea. We also have to look at the very realistic impact of our resources - who is available to run a group? Sometimes a program will start or stop depending on if we have a volunteer or someone who has a particular talent or interest. What we do well at the Aphasia Institute is really making use of the talents of our volunteers.

One program that I think is important to mention is our outings program dedicated to getting people out into the larger community and ensuring that they are doing what people in the community are doing because it gives topics for conversation as well when people are participating in the same type of theater or sport activities.And I know that some of our staff are also interested in getting people meeting outside of the institutional setting as much as possible. Meeting outside in restaurants and facilitating families meeting and getting together in very natural contexts. So that’s another program idea.

Could you talk a little bit more about the role of volunteers at the Aphasia Institute?

I know that not every program uses volunteers. We do because we really believe that volunteers bring something very special. So, it’s not *only* cost effective. Actually, the truth is that having a good volunteer program requires quite an investment of time and resources. But, we think volunteers bring something that we can’t and their family members can’t. It’s a combination of two things. One is that they have no obligation to be there. Of course, we have an obligation to be there as professionals and the families have one, but these volunteers don’t. Also, they don’t know the person with aphasia prior to their volunteer experience - this allows the volunteer to accept them as they are now. Our volunteers have made a tremendous difference to hundreds and hundreds of people.

Why do you feel there is value in requiring people at the Aphasia Institute to enroll in an introductory course prior to enrolling in the communication groups?

We actually need to acknowledge the contribution that social workers have made. What we learned from social workers the importance of that concept of *front-ending* - how important the start is. We find a huge benefit to people with aphasia and families when people start off together because you're creating a natural social group. Having a group of people with the same start times really deepens that whole experience of going through the support and educational program.

And one of the unique features of our introductory program is that there's a completely parallel curriculum for people with aphasia and one for their families. The families actually follow the same curriculum as their family member with aphasia, but this time it's about them. The program is once a week for 12 weeks. There's a block in the middle of program that includes some sessions that bring the groups together for joint partner training and practice. When you look at the impact of a program, our before-and-after on this three month program is incredibly dramatic in the perception of people. That feel of really energizing people with possibilities is a very strong part of that program.

The program is once a week for 12 sessions. The whole program is predicated on a particular kind of what we call an “initial visit” which is very different from the usual kind of assessment. It's a conversational interview and it's done by a social worker and a speech pathologist. Part of this visit is done with the family together - husband and wife, for example - and then they split off and each one has their own chance to tell their story. And it's a very moving experience and it's actually, for some people, a life-altering experience in and of itself. And one of the things that often happens is the translation for the family member of what the person with aphasia is thinking. So, sometimes, it's the first time that the family member hears that their partner with aphasia is worried about *them*. It’s often quite an emotional session and it usually ends with people walking out very differently to how they walked in. That's the strategy of the introductory program.

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

I think one advocacy action that we could take on as a field would be to try and get conversational interaction listed as an essential activity of daily living in ADL like the more obvious self-care categories like being able to look up stairs or cook a meal. I know that many occupational therapists do feel like they look at communication as part of getting people back out to doing activities, but that's very different from having conversational interactions. I think it would change practice if conversational interaction was a necessary part of ADL. In other words, you can't discharge someone with aphasia, you can't discharge them home unless there's at least one person who knows how to have a conversation with them or there is some way to have support. So, I guess what I like about that is that you're not mandating how you do things because people have got so many different ways. But, I strongly believe that if you mandate an outcome you will change practice.

References and Additional Resources

Kagan, A. (forthcoming). Supported Conversation for Adults with Aphasia (SCATM). In J.S. Damico & M.J. Ball (Eds.), *The SAGE Encyclopedia of Human Communication Sciences and Disorders.* Thousand Oaks, CA: SAGE Publications, Inc.

Mayo, N. E., Anderson, S., Barclay, R., Cameron, J.I., Desrosiers, J., Eng, J. J., Huijbregts, M., Kagan, A., MacKay-Lyons, M., Moriello, C., Richards, C.L., Salbach, N.M., Scott, S.C., Teasell, R., Bayley, M. (2015). Getting on with the rest of your life following stroke: A randomized trial of a complex intervention aimed at enhancing life participation post stroke. *Clinical rehabilitation*, *29*(12), 1198-1211.

Kagan, A., & Simmons-Mackie, N. (2013). Changing the Aphasia Narrative. *ASHA Leader, 18*(11).

Kagan, A. (2011). A-FROM in action at the Aphasia Institute. *Seminars in Speech and Language*, *32*(3), 216-28.

Kagan, A. (2003). Aphasia centres and community: More than just a sum of parts. In S. Parr, J. Duchan & C. Pound (Eds.), *Aphasia inside out.* Berkshire, England: Open University Press.

Kagan, A., Black, S., Duchan, J. F., Simmons Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using Supported conversation for adults with aphasia: A controlled trial. *JSLHR, 44*(3)*,* 624-638.

Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners." *Aphasiology, 12*(9), 816-830.

Kagan, A. (1998). Philosophical, practical and evaluative issues associated with Supported Conversation for Adults with Aphasia: A reply. *Aphasiology, 12*(9), 851-864.

Kagan, A. & Gailey, G.F. (1993). Functional is not enough: Training conversation partners for aphasic adults. In A. Holland and M. Forbes (Eds.), *World perspectives on aphasia*. San Diego, California: Singular Publishing Group, Inc.

Aphasia Institute – Programs & Services . (2015). Retrieved from URL: http://www.aphasia.ca/people-with-aphasia-and-families/aphasia-institute- programs-services/

Aphasia Institute--YouTube. (2016) Retrieved from URL: https://www.youtube.com/user/AphasiaInstitute