



## Episode 14: LPAA Pioneers Discuss Core Values History & Tenets Premiered – December 2017

In this episode, Guest Interviewer Dr. Liz Hoover brings together three pioneers of LPAA, Dr. Roberta Elman, Dr. Aura Kagan, and Dr. Nina Simmons-Mackie, to share their perspectives on some of the early roots of LPAA and to offer insights about each of its five tenets. Enjoy this lively exchange about LPAA core values.

AA would like to extend a special thank you to Lyssa Rome, a new Cal State East Bay alumnus, who is not only a new SLP and AA member, but who kindly put her previous job skills as a radio producer to work in helping with this episode.

In today's episode, you will:

- **Get the insider view of the history of the LPAA Statement of Values from three members of the working group that published it in the ASHA Leader in 2000.**
- **Listen to a description of the five core LPAA values and their importance to providing patient-centered care**
- **Gain a greater understanding of how personal factors and the environment play critical roles within the LPAA framework**
- **Hear advice for the new clinician about how to make a limited number of speech therapy sessions "count"**

### **Aphasia Access podcast transcript**

**Elizabeth Hoover:** Hello, and welcome to Aphasia Access conversations. My name is Elizabeth Hoover, and I'm really excited to be sitting here with three pioneers of this approach, Dr. Roberta Elman, Dr. Aura Kagan, and Dr. Nina Simmons-Mackie. So why don't we start by going around and having each of you state your name and tell us a little bit about where you currently practice so that our audience can match the voice to the name. Why don't we start with you, Roberta.

**Roberta Elman:** Thanks, Liz. This is Roberta Elman, and currently I'm at the Aphasia Center of California in Oakland. I came to work at an aphasia center and starting an aphasia center inspired by the aphasia center in Toronto, actually. I met Aura Kagan quite a few years ago and decided to try to replicate some of what they were doing in California.



**Nina Simmons-Mackie:** And I'm Nina Simmons-Mackie, and I work at Southeastern Louisiana University. I spent many years as a clinician working in rehab and outpatient and home health, and got really interested. And now I'm in academia trying to get other people interested in this whole area. And have known these two wonderful women for quite a long time.

**Aura Kagan:** And I'm Aura Kagan, and I work at the Aphasia Institute, which is in Toronto in Canada. And it's been quite an exciting journey to see where we've come from when we first sat around talking about the ideas that informed LPAA.

**Elizabeth Hoover:** That's great. It's hard to believe that that initial paper, that position paper, was published in 2000. But I'm wondering if you'd each share a little about what was going on in your practice that inspired this revolutionary paper, this change in practice as we know it. Aura let's start with you this time.

**Aura Kagan:** The Aphasia Institute was actually started in 1979, as many people will know, by a person who was not a professional, just a regular person whose husband had aphasia. And she brought to it I think a real-world perspective and a belief that there was hope for people with aphasia. And starting off something in the way that she did, which was literally a group in her basement with volunteers who were family and friends, was really the seed of something that has developed over the years, and has taught us. So what I would say in terms of what was happening at the time, what we were seeing, was possibilities of people with aphasia enjoying what we all take for granted: being able to sit and do what we're doing now, having a chat and having a conversation in a normal way. For us, things happened in a very grassroots way, which was something else that happened, the whole idea of having groups arose probably for very practical reasons in the beginning, but once that did arise the benefits of it were obviously enormous and we saw changes that were not being captured in traditional approaches.

**Nina Simmons-Mackie:** I got interested in this area kind of progressively, because probably something like 30 years ago I was working in rehab, both inpatient and outpatient, and I started worrying about what was happening to the clients that I was seeing after they got discharged or even while they were in therapy, they would say things like, "In here, great. Out there, no way." That was such a... That kind of concept was very common. And I kept worrying about why was out there so "No way"? What's the difference and how do we make out there in the community be more palatable, enjoyable, satisfactory for people with aphasia? Also, around that time you all might remember all the work that was just starting on generalization. That was the big topic. But they were talking about generalization in terms of, learning a list of words and seeing if a list of words that they hadn't been trained on got better. And people weren't really talking about, so what does that matter? Are they able to talk to their wife? Are they able to talk to go back to their bridge club, and so I got really interested in that. And it was sort of a progression, trying to see if there were ways to make changes that were important in the community or that generalized to the community. And I got really interested in the whole idea of the social model. And so that's how I came into it, from that direction. And I can even remember—do y'all remember those conference calls we used to do? I can remember sitting in my sunroom and talking to Aura and Roberta, and I think Jon Lyon, because we were trying to share ideas about these new thoughts we were having. I can remember sitting there while an alligator was crawling up on the lawn. I wasn't even interested in that. This was so fascinating!



**Roberta Elman:** This is Roberta. I think one of the life-changing conferences I went to a conference where Nina and Jon were presenting and I was just in my doctoral program at the time. And I sat in the audience and thinking, oh my gosh, these people are talking about things that I've been thinking about for a long time and I'm not the only one who's having these concerns about traditional individual speech therapy. And so from that conference was really a turning point I think for me in my career. And then some of us started getting together informally with the conference calls that Nina was talking about and then we actually did some face-to-face meetings. And then in 1997 we had a conference that I helped to arrange in Yountville, in the wine country, where I think there about 22 people who came and presented ideas that they had or shared papers. I guess that was kind of the beginning of LPAA at that point. Because after that conference a smaller subset of us got together a couple more times. Once in England and then in Martha's Vineyard and it was really the Martha's Vineyard meeting that was the birth of LPAA and the publication that happened in the year 2000. And part of that was because there were people in the field and outside our field who were telling us that aphasia therapy was dead, that had really, that swallowing had really taken over the field and that people weren't treating people anymore with aphasia. And we felt so strongly that we really needed to have some kind of a position paper or a statement that would be an opposition statement for that and try to be a catalyst for treatments and ideas going forward.

**Nina Simmons-Mackie:** I think that at the Napa conference we were all so fascinated because we all reported on kind of these approaches we were taking and we realized that they weren't just parallel. They all had this core underneath them of shared values, and so then it was just a matter of putting that into some sort of form that made sense.

**Aura Kagan:** We did learn, though at that time, I think it as new for most of us, about the World Health Organization's ICF. And it was Linda Garcia, from Canada, because she was involved in the Canadian part of developing the ICF and we learned about that and that also helped to catalyze some of the thinking.

**Elizabeth Hoover:** That's a great story, and the perfect segue I think to start talking about what those core and shared values really are. So, for those who are unfamiliar with them, why don't you walk through them one by one. The first of course is that the explicit goal of intervention is enhancement of life participation. So let's start with that one. Aura, what does that tenet mean to you?

**Aura Kagan:** Well the phrase that I love to use is beginning at the end. When you make life participation your explicit goal, and I put in there, your explicit *end* goal, that's why the word "end" is in there, it really makes you think about what you should do at the start. All of us want probably the same thing for our clients, our patients with aphasia. We want them to have a better life. And nobody would say that doing their work with an end goal of having someone saying the sound "pa" or the word "cup" as an end goal. Everybody's idea is that is what will make a difference. So there's a treat and hope idea. What this value says is that you need to make it an *explicit* end goal. In other words, whatever work you are doing, because LPAA is not a—doesn't tell you exactly what you should do—but what you do need to do is explain how the work that you're doing will end up with that goal, it will achieve that goal. The word explicit is there. Those words are carefully chosen. That you have to be able to explain to yourself or to others why the work that you're doing is going to achieve that goal. Why, how, and the timeframe that you're looking at, is that possible.



**Elizabeth Hoover:** And what do you think life participation means?

**Aura Kagan:** I've actually kind of changed my mind, a little bit over the years, expanded, a little bit. So when you think of the way the World Health Organization developed the ICF, and what we've developed at the Aphasia Institute, the AFROM schematic, with different domains, what that's led me to believe, is that you can't think about life participation without thinking about the personal domain and areas there like identity, autonomy, and confidence. Those are two interacting areas. The one influences the other. The more you participate, there's all kinds of benefits on how you feel. And the better you feel, it has an impact on how you participate. And I'm going to say something that might be controversial. I don't really care what people do to get there. There may be things that I think work or don't work, and if it achieves that result, show me, that it's actually having an impact on people's real lives, on their relationships, their roles, the things that they do, on their identity and how they feel about themselves. I think we all agree we don't want to be prescriptive, but we need to leave an opening for saying that we don't always know exactly what gets us there. We've got some tried and true things that we know work, amongst the people doing this work, but there may be openings for a whole lot of other ideas for things that get us there.

**Nina Simmons-Mackie:** It seems like too, life participation is defined by the person, so the person with aphasia needs to work with the clinician on identifying what those things are that will make life more livable and enjoyable. So it's really personally defined, I think, by the client and family.

**Roberta Elman:** This is Roberta. You took the words right out of my mouth. I mean, really, getting back to participating in activities of choice, and I think we can't speak for our clients, or the people with aphasia, their families as well, getting back to doing whatever it is that's going to give them a better quality of life, and living successfully—more successfully—with aphasia.

**Elizabeth Hoover:** The next value, or shared value, that all those affected are entitled are entitled to services. Quite frankly it seems that that value should be a given, so can you talk a little about why that one needed to be explicit in this?

**Roberta Elman:** Are you asking me, Liz?

**Elizabeth Hoover:** Yes

**Roberta Elman:** So, I think there was a realization that with healthcare reimbursement, we had seen first-hand and were being told by others that family members and important people in the person's family and community weren't able to be addressed in therapy because it wasn't quote-unquote reimbursable. And so, what we wanted to make, again, explicit in the core values was that aphasia doesn't just affect the person, obviously, who had the stroke with aphasia, but it cascades outward from the spouse and family members and work colleagues and friends. And so, although there may still be challenges with health care in getting some of those things reimbursed, I think advocacy is needed and there are often important ways that one can include people in therapy and others in the whole family relationships and friends and family.



**Aura Kagan:** Interesting to me your introductory sentence, when you spoke to, when you asked Roberta the question and assuming that it was a given. You know it's not a given. It's wonderful to hear that you think it's a given, but even here, even today to a lot of people it won't necessarily be a given, this idea that aphasia actually happens to a family. It doesn't happen to a person. One of our clinicians at the Aphasia Institute, Lorraine, will often say, "You're not aphasic when you're by yourself. It happens when you're with another person." And it really does happen to a family. And when we see the trend in stroke with younger people being affected, you truly seeing the impact on family. Because it used to be couples with kids who'd moved out. And we'd be talking more about husband and wife, that sort of situation. We're now seeing a lot of parents with young children, so you'd better believe that it happens to a whole family. But I don't think that in healthcare that's accepted at all. That people are all deserving of service or will necessarily get service or there's reimbursement for the family actually having their communication issue dealt with.

**Elizabeth Hoover:** I see you nodding, Nina.

**Nina Simmons-Mackie:** I think that's really true. All the accreditation guidelines say that the family needs to be educated, they need to be included, but I think a lot of times what happens is that they're given information, so they really aren't listened to, they don't know what their concerns are, they're not taught to communicate with the person with aphasia or asked what they need.

**Roberta Elman:** I'm still finding that there are a number of SLPs in the audience and it seems like it's kind of new to them that we should be working with family and extended, and friends and the community. So, I think we still have some room to grow in that respect.

**Elizabeth Hoover:** I'm sure you're right. The next core value states: "Measures of success include documented life enhancement." Nina, what does this core value mean and how can we do this do you think in a systematic way?

**Nina Simmons-Mackie:** That really ties back to the first value, so it means that we don't only need to work towards goals that are meaningful and that improve life participation, but we need to be able to demonstrate that we've achieved that. And so if you don't demonstrate that you've achieved it, then how are people going to accept that it's a worthwhile approach? And so I really think that's critical in any kind of intervention to demonstrate that through some kind of measures or some qualitative documentation, some sort of way that you've achieved a meaningful outcome, that beginning with the end outcome that Aura was talking about. We have work to do on ways to measure that, but there's been some progress there. So you know there are measures that look at participation and personal outcomes, goal achievement scales, things like that, that show that people's own personal goal has gone from a zero to a one or whatever.

**Aura Kagan:** The LPAA values are very interconnected. They're actually inextricably connected. Because you can't talk about that, the value in relation to outcome measurement without tying it to life participation being the explicit end goal. So, you know if you don't understand that then you could be documenting success in something that is not necessarily related to full life participation.



So, the onus is on the researcher, within an LPAA way of thinking, to show that if you're documenting something that's a component, or you think it's a component of getting someone to that end goal, of really explicitly indicating how that happens. I think there's just this tacit understanding that you're measuring this and of course in the end if someone can do just a little bit more linguistically or syntactically even with conversation partner training, I would say, in the end it has to be tied to that goal of real life participation. It's very easy to demonstrate achievement or success on components without getting to that end part.

**Roberta Elman:** As Nina was saying, there's been progress made since the year 2000. We have some measures now that get at measuring life participation as an outcome. I think that when we first wrote the paper, that was the area that we maybe had the slimmest information about. And so it's really worthwhile to see where we've come. Much of that is due to the two ladies who are sitting next to me, Nina and Aura, who've put a lot of time into coming up with research outcomes and measures and making sure that measures they've come up with are sound measures. There's more room for progress in the future but we're a lot further along than we were when we first wrote this article.

**Elizabeth Hoover:** Okay the fourth value is that both personal and environmental factors are targets of intervention. So, Aura back to you, can you talk a little about how we go about this in practice?

**Aura Kagan:** For me, as you heard me say earlier, personal factors are very much tied to real-life participation as an end outcome in itself. And personal factors in the way that the ICF originally talked about it is very narrow. They are talking about gender and demographic type features, whereas what we were talking about with LPAA were different kind of personal factors, things like confidence, and autonomy, and things like that. So personal factors need to be taken into account because the interaction of those with real-life participation is essential and critical. And I look at that differently to the environment. To me impairment work and the environment work is a means to an end. It's work that you do not only for its own sake. It's not an end in itself to stay in that domain. Even the environment domain, which is a broadening from what many years ago was our focus, which was solely impairment. So the environment domain is interesting because we know that what it means for people is a move from this idea that it's the responsibility of the person with aphasia to get better. They need to work as hard as they can, we need to help them do that, but the onus is on them to really be the best communicator they can. Moving from that idea to one that says that things are, or should be similar to what it is for people with physical disabilities where you should be able to exercise and walk as you can if you have a physical disability. However, we take for granted that in society there are ramps and all kinds of physical aids to access when there are barriers. In the same way, in aphasia that was something that was a fairly new idea, I think, for us in terms of the role of the SLP, that was a change that our role broadened from only looking at the person to also looking at the environment. For our purpose now, I think that the biggest move and shift is that: the role of the speech pathologist—the kind of obligation, the opportunity to really broaden our role and say that it's ethically not okay if we ignore the environment and just send someone with aphasia out, particularly when the aphasia is severe.



**Nina Simmons-Mackie:** Yeah, I think that at the time we came up with the values, we were influenced a lot by disability movement at the time, so that whole social model of disability, where the problem isn't the person with the disability, it's society, that hasn't accommodated the person and supported them to do whatever everyone else is doing. So that, along with the ICF and along with a lot of the things we were observing in our own practices, just seemed really important to highlight. You can't just work on the language of the person with aphasia, or on compensatory strategies, or whatever. You've got to look beyond that to personal factors like confidence and self-esteem or to the environment where it supports communication.

**Roberta Elman:** I think being able to work on things, especially in the environment, for some people and for some situations, it's really been a huge benefit to people. I know when we do community outreach and community trainings in the community, and businesses or healthcare institutions realize that changing the signage or changing the dietary menu for the hospital will allow access for people with aphasia and all kinds of other people—people who are speaking ESL, or are illiterate, or whatever. It really brings it home to them. It's something that makes it understandable. It helps them understand the language barrier that aphasia causes. There's been a lot of activity in that area, and I think outcomes have been positive.

**Elizabeth Hoover:** Yeah, thank you. And the final value is that emphasis is on availability of services as needed at all stages. Nina, can you speak to this value for us, please?

**Nina Simmons-Mackie:** Yeah, that's probably one that in the U.S. healthcare system, and probably Canada too, is difficult to achieve because of the funding structure. But we really felt like and still feel very strongly that life continues after somebody is discharged from inpatient rehab. More and more research is showing that people with chronic aphasia can improve their communication. And so it's really important to look at that whole continuum of care over the lifespan and how we can develop services that support that so that people aren't just dropped off the cliff. When I was practicing that's really what happened. They reached this—what was called "the plateau." Which really means that the PICA showed that they weren't improving, and they just got discharged. And so now we recognize that it is, it's a chronic disability that needs to be addressed as needed for as long as needed. And there have been models that have come up now that my two colleagues here have really well developed and the aphasia center model that allows people to get services for a long period of time.

**Roberta Elman:** And that's kind of morphed into lots of other types of programs and models. But that's been a place that people can continue to get that kind of communicative support for as long as they feel that they want to be coming to that type of program or an environment. And I think for many people it's been a life-saver for them, both communicatively and otherwise. That they have a community where they feel that they're a part of and that they have a place that they get to vent their frustrations and share their joys. And it's been a very rewarding part I know of my life to be able to be a part of that.



**Aura Kagan:** Yeah, I've always liked to use the analogy of the fitness club. When we get told about discharge. And that really is the analogy. It's not—as many of us would probably love—to get fit and then never have to go again. That's not how it works. You need to keep going to benefit. You need to keep exercising to benefit. And you need to keep having conversations to have conversation. I think the emergence of aphasia centers has been absolutely monumental in changing the landscape. And what these values have done is provide an underpinning, a reference point. One of the differences between what happens in an aphasia center compared to what happens in a therapy room is you're not practicing something so that you can do it afterwards. It works the opposite way. You're having the opportunity to have the conversation and that in itself improves conversation.

**Roberta Elman:** And that's life.

**Aura Kagan:** It kind of flips the model on its head—training someone to do something so that they can go out and do it, which we know in many cases doesn't happen. Going back to your generalization comment, Nina, we know that there's often there's very little generalization from narrowly focused work to real-life participation. What we do know is that when you work from an LPAA values perspective, not only are you giving that opportunity, but you actually are improving communication ability.

**Nina Simmons-Mackie:** Another element of that value is that people with aphasia are just all of us. So they get divorced, their spouse dies, and at those critical times they may lose their primary person that sort of facilitated their participation in life and so what happens? It's not that at that point they can go back and be Medicare-funded therapy. Maybe a little bit, I don't know, as maintenance. But there needs to be resources for that. Depression—people with aphasia get depressed. So those are the kinds of things, that are the lifespan services that might be needed, and we may not be the ones that treat them for depression but we certainly need to figure out how that system manages that. And see if we can facilitate that. And I know in the centers, people will leave and then come back later.

**Aura Kagan:** The same way as any normal person does with leaving and joining any kinds of groups.

**Roberta Elman:** It's been interesting over the 20 years that we've been going. We actually have some people that have been there that entire time and many, as you say, they've left for a period and come back, like what Nina was talking about. We've had weddings, we've had divorces, we've had funerals. We've kind of walked beside people and they're beside one another in the community of the group. And it's really been the thing that's kept them stable, I think, that's been the one stabilizing factor sometimes in their lives. It's so important.

**Aura Kagan:** And it's not different to groups that happen for any of us. It's the identical mechanism, because what's being provided is the vehicle for doing it. Because it happens via conversation. And so when you enable that or you reduce the barrier, you can actually step back and let it happen. If you stepped into a conversation group at any of the aphasia centers on any day, you would see these themes. You'll see all of the values. You need to capture it and demonstrate it.



**Roberta Elman:** And make it available.

**Aura Kagan:** And make it available, yeah.

**Nina Simmons-Mackie:** Yeah. And that's the challenge now, is really looking at how we can make services available over a long continuum, make them sustainable, and address needs over a long period of time, as needed.

**Elizabeth Hoover:** So, you're talking about a shift in the way that aphasia is viewed and to look at it more like, if it has to be viewed in a medical model, perhaps more like in a diabetes management model.

**Nina Simmons-Mackie:** Yes.

**Aura Kagan:** Yeah, well nobody removes insulin at a certain stage.

**Roberta Elman:** We hope not.

**Aura Kagan:** That would be that analogy. And I think as we end off the conversation, the elephant in the room is that in a situation where there is funding crisis, we know that services are cut back. We're all concerned about what is happening. It's not that the LPAA values are then not relevant. It's that they are more relevant than ever. Because when you've got less resources now, what are you going to do with those precious few hours that you have. And if you use them in accordance with these values, you'll be doing a better job than without them.

**Roberta Elman:** Yeah. I think you really want to make those few sessions count. A lot of speech language pathologists are up against just a few sessions with someone with aphasia, or 10 sessions or 14 sessions, and you'd better really think about what's important to that person, and to the family, and what's going to make a difference in their life.

**Elizabeth Hoover:** What would you say to the young clinician who's starting out and is really afraid of making a mistake in those precious 14 visits? What words of wisdom might you have for that young clinician to stay on the right course?

**Roberta Elman:** Keep in mind, be client-centered, family-centered, relationship-centered. Really get to know as much as you can about the person and the family, and point your therapy sessions towards what's going to help them communicate, what's going to connect them with other people, what's going to move them forward with life as much as you can even in those 14 sessions.

**Nina Simmons-Mackie:** And connecting them with resources in the community. Either a referral to a university or whatever's available there so that they have some kind of system. Even what Pat Arato started out with in the 1970s, you know, where you get a system of friends and relatives if you're in a place that has no resources.



**Aura Kagan:** Yeah, I think if you're sticking with those values, you're not going to make a mistake, even things might be done differently to how you hope. And the example that you just brought up, Nina, is a good one, because the way that the activities that I saw on my first day when I first came into what's now the Aphasia Institute, is not what you would see now. Now you're seeing conversation groups that are adult conversation groups, but what I walked into were groups doing work sheets, reciting the alphabet, and doing that kind of thing. That was what was happening. Now in my mind now, that would be, in quotes, a mistake. However, when you get the group of people together and they are sitting around a table, what emerges is what happens in groups. And that was the magic that I saw.

**Roberta Elman:** And that's still the magic now.

**Aura Kagan:** It took me a long time to actually put my finger on what it was. We first used to call it the X-Factor. We used to call it the magic factor. We used to tell people "You have to come and see what it is. I can't explain it to you, but there's something different. It's just different. You have to come and see. I don't have the words for it." And it was only after reading and seeing videos, actually, from outside of our field, learning from ethnography and philosophy and sociology. Many people who understood more than we did, about what communication is and what the role of conversation is, that we really learned about what was happening in the groups that we were seeing and were able to articulate it. That's what we were looking at was interaction.

**Nina Simmons-Mackie:** Participation.

**Aura Kagan:** Participation, yeah. And so go for it.

**Roberta Elman:** Keep your passion. For the speech-language pathologists that are coming up. Sometimes I think that the environments that people are working in can be kind of soul-draining. The productivity standards and some of the other regulations that people are working under. But I think that if they maintain their focus on what brought them to the field to begin with, to help people improve their quality of life and be able to communicate better in activities of choice, and out in the quote-unquote real world. If they can keep that passion and the focus on that, as Aura said, the values that we articulated 16 years ago, they probably won't go too wrong.

**Elizabeth Hoover:** Thank you so very much.

**Nina Simmons-Mackie:** You're welcome.

**Roberta Elman:** Thank you, Liz.