Show Notes - Episode 39

The Boston Community Aphasia Group, a 30 year perspective:

A conversation with Jerome Kaplan

Ellen Bernstein-Ellis, Co-director of the Aphasia Treatment Program at Cal State East Bay speaks with Jerry Kaplan about the history, structure, and future of the Boston University Aphasia Community Group.

Jerome Kaplan received his B.A. from the State University of New York at Albany and his M.A. from New York University. Now in his fiftieth year as a practicing SLP, Jerry has worked in academic, medical, rehabilitation, and research settings as well as in private practice. Founder of the Aphasia Community Group of Boston, now in its 30th year, Jerry has advocated for aphasia awareness and education through diverse and innovative programs, collaborating with noted actors, artists, filmmakers, and musicians. He has presented at the Academy of Rehabilitation Medicine, National Aphasia Association, and ASHA Conferences. He is the recipient of the Partners Health Care Community Service Award and Aphasia Access Innovator Award.

Listener Take-aways:

In today’s episode you will:

- Learn about the structure and flow of a monthly three-hour aphasia community support group
- Learn about four special events that are yearly highlights on an aphasia community group's calendar
- Discover some tips for preparing guest speakers to present to aphasia community groups

- Gain insight on how commitment and collaboration are key elements to starting an aphasia community group

Edited show transcript follows:
Ellen

Jerry, welcome, and thank you for being our guest today. I am so honored to be able to have this interview with you.

Jerry

Thank you so much, Ellen. And it's an honor and a privilege to be invited to share some of our thoughts and ideas with aphasia access, which is truly a splendid organization. I'm so glad you came along just at the third act of my career.

Ellen

I'm glad to be here today. We like to open with a fun question: “What motivated you to explore groups as part of your clinical setting?”

Jerry

I've been thinking about that and I have to say, my background and experience in doing a little theater and some stand-up comedy, really was the inspiration. I had sat in on a few small aphasia groups, here and there. But it seemed to me that groups and, let's face it, an audience in a theater is a group, are a natural bridge to facilitating communication and promoting a sense of comfort and safety. And often, especially with improv comedy, stand-up comedy and certain kinds of theater, there’s a lot of laughter, which promotes comfort and an ability to express yourself more openly. So it seemed to me that my background as an actor as well as a speech language pathologist, seem to be a kind of a way to utilize groups to further people with communication challenges to express themselves.

Ellen

I think you have done that extraordinarily well. Please tell us a little bit more about your group today. I'm just going to start with some impressive stats. Your monthly Aphasia community group has met continuously since March 1990. That's approximately 350 sessions, serving approximately 50 to 60 people per session, which doesn't count students or guest presenters, and serving roughly

17,000 people over the course of nearly 30 years. I feel that's quite remarkable. So why don't we back up for a moment and have you share the origin of your Aphasia Community Group-- the how and why you got started.

Jerry

It all started when I got a message from the Director of the Speech and Language Department at Spaulding Rehab Hospital in the winter of 1990. And a big tip of the hat to Nancy Lefkowitz, who was one of my mentors. Dr. Nancy Helm Estabrooks, renowned, legendary speech pathologist, was having a meeting in her living room to discuss the idea of starting a support group for people specifically with aphasia. And she thought, Nancy Lefkowitz, that I might enjoy participating. So the first unofficial meeting of the Aphasia Community Group happened on a winter day in Nancy Helm Estabrooks' living room.

Ellen

I think that's important-- these great ideas come from exchanges, informal and formal, with colleagues and see where they lead!

Jerry

Absolutely. I went into that little meeting with about 10 people. I didn't know what to expect or who would even be there. There were three couples living with aphasia. There was a neurologist, and there was Nancy Helm Estabrooks and myself, and I was listened to what they had to say and the hopes they had for developing a support group, specifically for people with aphasia and related disorders as well as spouse and partners.

Ellen

Well, before we dive too deep into the patient community group, please take a moment and explain how your group sits within the larger Aphasia Resource Center at Boston University.

Jerry

Sure, the Aphasia Community Group became part of the Sargent College Boston University Aphasia Resource Center 11 years ago, I think was 2008. The group had existed for 16 years prior to that and met monthly at Spaulding Rehabilitation hospital. But I quickly learned after running that group for a very short time that it couldn't nearly begin to meet the needs of people with aphasia at a once a month meeting. And so I reached out to the graduate programs in the Boston area that had Communication Science Disorders programs. And the dean at the time at Sargent College at Boston University, Dr. Gloria Waters, who was very interested, invited us to become part of their fledgling Aphasia Resource Center. So the Aphasia Community Group became and is sort of the foundation, if you will, of the Aphasia Resource Center, which offers semester groups every semester, three semesters a year, with graduate students as clinical interns. So The Aphasia Group is a monthly meeting that is part of the Aphasia Resource Center.

Ellen

Let's consider the many monthly aphasia community groups across the country, even if you're probably among the first. Please share a little bit more about what the typical composition of the group.

Jerry

The group is comprised of people living with aphasia, and they frequently often come with either a spouse or partner, perhaps a parent or perhaps a child, and sometimes a pet. So the core group is people living with this condition and a family member or significant other. We also have students, not only from Sargent College but from other area colleges who observe the session. And we also have at almost every meeting a guest presenter. So the group can range anywhere from 40 to 50 people to sometimes as many as 60, or 70, comprised of people with aphasia, family members, students and guest speakers.

Ellen

One thing that caught my ear about your group was that you meet on Saturdays. Why a Saturday? I'm impressed you can get students and professionals all there on Saturday. Tell me about that.

Jerry

There was a little bit of reluctance or pushback, if you will, at the beginning, when we were trying to find a day and time. We first we thought a late afternoon on a weekday, and everybody was saying, well, Boston traffic, which is legendary, would get in the way of that. And also, at the time, our home was Spaulding Rehab Hospital and they had limited availability for space. So I said, let's try a Saturday and see who shows up. And to my, frankly, surprise, quite a number of people came in those first six months, upwards of 20 to 30 people. Listen as word of mouth spreads, which is not so easy in the aphasia community, but as we did tell people that we exist, and through a network of SLPs around the region, we told them we existed. This was before internet. We also decided to send out postcards and ask people to tell their neighbors or anyone they knew that might be interested in this group. And so Saturday sort of stuck. It's become the tradition of having a Saturday group. Once or twice, especially in the winter, we have a snow date, and we will meet on a Sunday, but as a rule, it’s on Saturday and people make time for it. It's a priority to them at this point.

Ellen

Why don't you share with us the flow of the typical group?

Jerry

The group is basically three hours. We gather at about 11am. Some people show up early. And we run until 2pm. The structure is basically in three parts. From 11 to 12, the first hour, it's kind of more of an informal time of sharing, welcoming newcomers, inviting people to share anything they would like, about what they've been doing, their concerns, travel, family, anything that's important to them. It's kind of a sharing time for them to say what they need to say. And we also open it up to the group, to respond and to post questions or have follow-up information. It's also a time when people tell us about other things in the community that might be of interest to people living with aphasia.

Then in the second hour, we take a short break and then we typically will have a guest speaker, and over 30 years, you can imagine how many types of different topics speakers we have had. It can be anything such as an instructive session on new opportunities for research either at Sargent College or other area colleges or universities, or at the Aphasia Research Center, which sadly is no longer around, but it was over at the VA Medical Center, which was where Dr. Nancy Helm Estabrooks worked for many, many years. We also have different guest speakers on other concerns, psychosocial issues, driving, travel, travel for people with disabilities, I mean, the list is endless. I won't try to enumerate everything here, but we try to have a diverse presentation in that second hour.

Then in the third hour, we have what we call breakout sessions where we divide the group into at least two sometimes three or four subgroups, depending upon how many people show up. Family members meet separately, so they will meet in a separate space for an hour. The people with aphasia will meet separately so that we keep the group numbers under 15, ideally under 10. And these breakout sessions run for an hour, in which myself and our students help co-facilitate. So it gives them more of an opportunity in less of an overwhelmingly large crowd situation to share and reflect on anything that concerns them. Sometimes we might ask them for feedback about the presentation that they just heard. And sometimes we might go in other directions. So the structure is informal group sharing, speaker presentation and breakout sessions.

Ellen

I'd really like to know what guided your development of this format or approach to the group? Were there particular factors that contributed to this structure?

Jerry

Well, it was a number of things. I always asked, from the very beginning, for guidance from that core group and Nancy Helms Estabrooks. What do you envision this group to be like? And one thing everyone said, especially the three couples that were there, was that there needs to be a dedicated time just for caregivers. So that needs to be an essential component of whatever the support group is going to look like. And I think they said that there should be a separate time for the caregivers to meet by themselves. So that was I think the first thing on paper that said we will make our last hour a dedicated time for them. And then it sort of evolved that we would use the first part of the session for an informal care and share, bring and brag, whatever you want to call it. Time for everyone. And then the middle hour, we have guests from all professions and community activities. We would like to have them learn about aphasia and tell us how they could accommodate us in in their particular setting. We've had people from Access America sports, we've had people from various theaters, we've had events where actors have performed scenes from plays, including one play that dealt with aphasia. So the format sort of evolved into that structure. I hope that sort of gives you a sense of it.

Ellen

It does and I want to ask another question to help paint this picture. Do the breakout groups have a particular focus, or are they more of an open-ended support group?

Jerry

The students and I try to facilitate the breakout session with a structure. We always start by going around the room and asking folks to, as they're able, to tell us who they are, where they live, and when aphasia first afflicted them, whether it be by stroke, traumatic brain injury, or a progressive disorder. Some with more severe types of disorders need facilitation, so sometimes a family member or I, if I know the person well enough, will try to help fill in. We'll try to do some scaffolding to let them provide a lot of information, or at least the basics, that they live in a certain town. What's really lovely in that moment is that other people who live in the same town, they'll say, “Hey, I live in this town. Where do you live?” And there's a connection that's made. So the other times, and in addition to The Meet and Greet, we open it up and ask people to share a little bit about what they thought of the presentation that they just heard. Some people say they enjoyed it. And some people say things like, “Well, it was not very aphasia friendly”, or “The person spoke too fast. And I didn't understand what they were talking about”.

Ellen

Actually, I want to come back to that. But first, you mentioned the students participating in the breakout groups. Who runs the caregiver breakout groups for you?

Jerry

The caregivers themselves. This has been a topic that I visited many times. I always ask people if they wanted a facilitator, and they always consistently said no, they really want to have this time for themselves. We have the more veteran, experienced members of that group who've been coming the longest and who have been living with aphasia the longest, to informally be the group facilitator, but it's just that group of spouses and partners or family members that are in that group. They made it clear that they really don't want students or any outside professionals at that group. I and a couple of professionals did observe and they concurred that these folks know what they want and know what they don't want. And if it gets more individualized, or a person really goes off on a tangent about their specific issue, then we try to provide them with suggestions and resources because it obviously more needs more attention on a one-to-one basis. But they are really on their own during the breakout session of the family members.

Ellen

That’s an interesting model. You also mentioned students who help you run the program each time. How do you involve the students?

Jerry

We have student interns at the Aphasia Resource Center. We have anywhere from five to 10 students. They often will attend the group and help run, basically signing people in, directing traffic to what room they're to go to, especially in the third hour, and the more experienced students that have worked with this population or done some facilitation of our weekly groups will feel comfortable enough to co facilitate the breakout session. So, we have you typically a second-year student or two who will help facilitate each of the two or three breakout sessions.

We talk in advance about how run the group: How to manage if somebody is monopolizing the conversation or somebody is not saying anything, how to try to provide them access points to speak up or communicate, or give them some forced choice or Yes/No or other accessible questions, and also how to tactfully tell a person who may be speaking at length and monopolizing conversation, “Well, we get it, we are going to have to ask to ask you to hold it right there and we're going to go on to somebody else.” It's kind of an art, kind of a science to do that without stepping on any toes and be diplomatic about it.

Ellen

Absolutely a common challenge for many groups. In fact, your numbers, if they really run from 50 to 70 group members per session, how do you handle sharing in such a large group?

Jerry

In the total large group the first hour, they're obviously going to be some more verbal people and some less. I don't look at that first hour at a time when every single person is going to be invited to say something. Some people are natural talkers, even with their aphasia, and they like to come down or stay at their seat, but I prefer them to come down because it's sort of a lecture room. And if you're talking from the back, everyone in the front can't see you. I try to invite them, as they're able, to come to the front of the room. And we also have amplification so that they can be heard. I would say that maybe 25- 30% of the people in the large of 50 to 60 members in that first hour will contribute something. They may not say anything, but that doesn't mean they're not present and paying attention.

In the breakout session, when the number is ideally 12 or less, and the ratio of people with aphasia to student interns or SLP, like myself, is like 1 to 3 or 1 to 4, we have more time and fewer people so we can help encourage people to respond or initiate. In that (smaller) breakout group, there's a lot more conversational sharing with every single member of the group. In the general assembly, there's less of that, just by the nature of the size of the group.

Ellen

Sure, it's really two different formats within this group. Jerry, do you mind if I asked about funding? Do group members pay?

Jerry

I don't mind if you ask about funding. Funding is an ongoing challenge for all of us. We don't charge a membership fee or anything like that. We do have a donations basket and I often talk it up. We often have very generous donations. The group is basically funded by Sargent College in terms of, they donate the space. They pay for refreshments which we get through the college catering service, which is typically coffee, juice, water and cookies. We’re fortunate enough to have the support of Sargent College and the Aphasia Resource Center’s budget to help us fund the monthly group. Occasionally, we're blessed to have people with, shall we say, deep pockets who will make significant donations. We're very grateful to that but it's not mandatory. Also, through the Development Office of Sargent College, we have an annual donor solicitation letter and fundraising campaign, which is actually geared to asking people to donate to the Aphasia Resource Center of which the Aphasia Community Group is a part.

Ellen

It sounds like you think about sustainability by partnering with groups and collaborating-- drawing resources together.

I want to ask you, how does today's group look the same or different from how the group looked in your first five years as a community group? What I'm really asking, how has your group evolved over these 30 years?

Jerry

I've gotten much older. I was a mostly brown- haired, 40-year-old, thin person when I started the group. Now I look in the mirror and there's some white- haired 70-year-old. So I've changed. The demographics of the group have changed significantly. I don't have any hard data in front of me, but I can tell you, the group has obviously gotten much larger. Also the mean age has lowered. I think there are data reflecting that stroke and other neurogenic disorders of language and communication are hitting people a bit younger than they did in the 1990s or even prior to that. Also, as the Boston area becomes more ethnically diverse, we've had a much more multicultural presence in the group. Back in the early 90s, it was a smaller group of mostly suburban people, probably skewing to the 60 to 82-year-old range. Now, we have people from their 20s into their 90s. And we have more and more people that are from all ethnic backgrounds. I'm glad to see that we are reaching people in communities where they might not have access to services as much. And they come to our group. It's also a challenge to us, because if some people whose language native language was not English and have aphasia, the challenge of communication is that much more compounded. But the group has changed in terms of size, diversity, and age.

Ellen

You've given us a nice description of your group’s flow, but I also know that you have special events, throughout the year. Do you want to describe what they are?

Jerry

Absolutely, we have some parties or events. Let's see starting in March, which is our anniversary month, we have an anniversary party and we have a celebratory cake. When we hit 20 and 25 and maybe when we hit 30 officially, in a few months, we will have a special event. For our 25th, we had a banquet with some local comedians, and we had some performances, but usually our anniversary party is kind of a low key event with a cake. And there's a legendary cake that we got a few years ago where the baker instead of writing Aphasia Community Group, they wrote “A-F-R-A-I-D-I-A Community Group”. We took a picture of it and then we ate it. Raising awareness of aphasia comes in many different forms.

Ellen

Agreed.

Jerry

In the early summer and Aphasia Awareness Month in June, we started a few years ago, something I call a pizzaphasia party, which is simply an event where in that middle hour, perhaps in addition to or instead of a guest speaker, we will have 10 pizzas which we will eat. There's a lot of socializing during these special activities. That’s an important part of the connections that are made through food and cake and pizza and other things that aren't so good for you. But they're fun things to do.

And one of my fantasies is to have us established somewhere in the area an aphasia pizza parlor, where it's run by people with aphasia. I think there's a group somewhere in the Midwest that has a restaurant, run by people with Parkinson's or MS or some sort of identified community and that would be amazing. In the fall, we have an ice cream social, which is just what it sounds like. We have lots of ice cream and toppings. And then to sort of the top it all off in December, we have our holiday party, which I named our buffet-sia (bu-fay-zhia). Everybody groans. It’s a party where we have the aphasia chorus, which is one of semester groups, performs. We have a visit every semester from Santa Claus who suspiciously looks like one of our founding members and somehow manages to bring along about a half dozen elves, which strangely look like doctoral students. And we also have music performed by a local combo that had been with us for 20 years, Bo Winokur, who's been sort of an honorary member of the Aphasia Center since almost its inception. We have Santa speak to different people who decide to come up and they either get a nugget of coal, or a chocolate Apple. Everybody gets a chocolate apple.

Ellen

It sounds fun and festive. Did we cover all of your activities?

Jerry

Occasionally, and I'd like to do more of it, we have had some off-site events. I mentioned that I had a bit of an acting background. About 10 years ago, I was fortunate enough to play the lead in a classic play called *The Man Who Came to Dinner*. I spoke to the theater company in the Boston area about maybe doing a benefit performance to benefit the Aphasia Resource Center and the Aphasia Community Group. Long story short, we sold out the last matinee. I'd say two thirds of our group came over to the suburban town, a ways away from Boston, and we filled we filled the theater for that performance. I've also collaborated with some filmmakers and we had some benefit screenings at a local theater in Harvard Square.

Ellen

You've also had a variety of special projects. I had a display of some special postcards on my desk. Do you want to briefly tell us about some of those highlights? I wish we had two hours, but we don't.

Jerry

Mum's the Word was a project created by a local artists multimedia artist, a gifted woman named Ellen Driscoll. She had received funds from the City of Boston Arts Council to do a community awareness project. And she wanted to do something related to aphasia because her father had had a stroke and had aphasia. He had kept a journal graphic of sketches that he made during his recovery, and the initial sketches were very one sided because of his visual field loss. And then gradually over time, the images filled in as he recovered and learned to compensate. So Ellen, met with a dozen members of the Aphasia Community Group and fashioned images and a short text that started with the starter phrase “My mind is…” She would work with them and they would come up with a startling phrase like “*My mind is like a bicycle that goes round and round*” and she created these images with this single line of text. And we fashioned them into large banners, which were displayed at various conferences. For one summer, they were suspended on light poles across one of the bridges between Boston and Cambridge. There was also a companion postcard set, that's probably what you still have. That was a wonderful project that could not have been done without the efforts and talents of Ellen Driscoll

Ellen

Jerry, that's public art you've mentioned.

Jerry

In 2000, I got a small grant from the then national Stroke Association to do a public awareness project. And I called it *Faces of Aphasia*. And it was a performance where we featured a noted mezzo soprano who had had a stroke and to her own surprise, found that she could still sing quite well, despite a little bit of apraxia, while her aphasia was still severe. And she performed for the first time in public.

We also had a famous New York actor named Joseph Chaiken, come to Boston and he did a staged reading of a monologue about a gentleman who has aphasia, sort of an internal monologue. We had a performance by members of our group of an original piece called *The Voices of Aphasia*, which was culled from the experiences of many of our members. We also had a video of one of our members who had been a recorder player, like a half size of a clarinet recorder. After his stroke, he had a special recorder made for one handed fingering. And he performed. We had to do that on video because he couldn't attend the event. It was publicized by a theater and music critic of the local newspaper and all of the media came. It was a sold-out standing room house.

Then, many years later, I worked with a filmmaker to create a documentary called *After Words*. And then about nine years later, I did a sequel, where I used parts of that film and new footage to create a 15-minute piece about our community of people with aphasia. We were fortunate enough to have the involvement of some noted celebrities, such as the late actress Patricia Neal, who had had a number of strokes. We also had the wonderful Julie Harris who had had a stroke and was actually a patient at Spaulding Rehab Hospital. And Bobby McFerrin, of the song *Don't worry, Be happy*. We involved him because his father Robert McFerrin had had a stroke and communicated for the last few years of his life mostly through music. And we were able to incorporate them into the film.

Ellen

That's an incredible list of additional projects on top of the monthly meetings. I want to circle back for a moment to the guest speaker because that's an integral part to your group structure. I'm reflecting on some of the experiences I've had running groups at the Aphasia Treatment Program. How do you help your presenters be aphasia friendly? I found that, despite good intentions, sometimes the rate and complexity may not always be optimal for our aphasia group members. So how do you prep your presenters?

Jerry

Well, it's not always successful, despite all the steps one takes. I invite them and sometimes it happens, sometimes it doesn't, to come to a session prior to the session at which they're going to do a presentation so they can get to know the aphasia community, at least our segment of it, and get a sense of what aphasia is and what aphasia isn't. I will send them some basic tips on what facilitates versus what impedes comprehension and understanding. I try to send them bullet points of what is going to help your audience take the information in and retain their attention. Sometimes, despite my best intentions, people, especially from medical or research communities, they just either don't get it, or don't want to get it, and they think they're speaking to a medical audience. I look out at the audience and several have their eyes closed. Other times, people who had never heard of aphasia before, they bump up their volume, they slow their rate, they simplify their sentences, and yet they don't infantilize the audience. And that's a fine line to navigate, to simplify, but not infantilize. Sometimes they get it, and sometimes not so much, and sometimes people who I think should know better, don't seem to get it.

Ellen

I think it can be challenging. So thank you for sharing those tips.

Jerry

Yes, thank you. We do the best we can.

Ellen

That's all we can do, right? Jerry, you shared so many amazing things with us today. I was wondering what else do you hope to do?

Jerry

As I said I there are a few pure fantasies that I don't think, unless there's an influx of six to seven figures, could ever happen. I'm a fan of train travel. And I've traveled the country a couple of times by train, and I woke up in the middle of the night a few years ago with this. Maybe I got this phrase from the American Stroke Association *Train to End Stroke*. Wouldn't it be awesome to rent a private railroad car and go across the country with people with aphasia. We'd stop at local communities and unhook the car and just have an afternoon where it could be a drop in session. That's kind of a ridiculous notion because of the cost and logistics involved.

I would more realistically like to do at least one more film, or cinematic piece. I've worked on two documentaries. And I've talked to a couple of my colleagues about the idea of doing a feature film, in which it's a narrative. I'd like to make another film where education and entertainment are combined to raise awareness. I just watched a documentary last night on Turner Classic Movies called *Cinema Ability*. It was made by a filmmaker with Muscular Dystrophy and it was a very interesting piece, an hour and 45 minutes about how disability is represented through the last 120 years of film. Aphasia was not mentioned. There were a few people like Marlee Matlin who's deaf, and other people who had communication, mostly hearing, disabilities. I came away with, like I have from so many pieces that have good intentions, not having any insight given about the condition of aphasia. I think that's a huge gap that needs to be filled.

Ellen

Absolutely. We're always having to be mindful of how we can become better advocates for aphasia and raise awareness.

Jerry

Exactly, and mostly the efforts are well intentioned, but we're often preaching to the choir. We have to try to come in under other people's radar, so that they're being educated and also entertained at the same time. Otherwise, there's the pity piece or the barrier, “I don't want to see a movie about people who can't communicate. It's too depressing.” So we need to come through the back door.

Ellen

You’ve done some amazing work. It is truly inspirational to hear how you have brought such passion and talent to this whole endeavor.

I'm going to go back to one issue I skipped over earlier. I was just wondering if you keep any outcomes of group participation in your group or do you have any intake measures or criteria for group membership?

Jerry

I have to give a huge amount of credit to my colleague and mentor, Dr. Elizabeth Hoover. Elizabeth and some of the other clinicians and clients have given up their time to gather information and data on what the experience of coming to the Aphasia Community Group and the Aphasia Resource Center has meant to them. In fact, some of us did a paper lead by Liz at ASHA last November here in Boston, about the benefits of participating in an aphasia resource program. Liz and some of the other clinicians keep data like that. We go back and we interview or sit down with people, family members, as well as people with aphasia, and ask about the impact of these programs to them.

Ellen

So you really are capturing that.

Jerry

We're trying to.

I just want to give credit to Liz Hoover, Audrey Holland, and Nancy Helm-Estabrooks. They have been my inspiration over the years, along with Nancy Lefkowitz who first connected me to Nancy Helm-Estabrooks, although I had been to many of her presentations about starting an aphasia support group, way back in 1990. A big shout out to those to those four people--and Roberta Elman.

Ellen

That is a talented team lineup that you've just mentioned, for sure.

Jerry

There are others, but I'm not going to go into it because we'd be here all day.

Ellen

I agree. I'm looking at the time and I'm going to focus on one last question. Can you summarize your best takeaways from this experience or offer any advice for someone who wants to start a community group?

Jerry

You have to have a commitment. It has to be more than, “I really think I'd like to start a group of people with aphasia.” It sort of becomes a very well intentioned thought, but you really have to understand what's going to be involved. You're in it for the long haul. And by doing that, you will be rewarded and inspired by these people who are so brave and are my teachers and my inspiration. But, it has to start with a commitment and a core group. You can't do this alone. It has to be a core group of family members and students, if you're lucky enough to be in an academic or near an academic institution that has a CSD program. You also need administrative support of a facility that's going to help provide you with space, and hopefully, other logistical concerns. And you need a setting. Well, that's the space, but it could be a function room in a library, it could be a lecture room in a university, it could be an auditorium. Most hospitals have that. But you need the commitment. And you need to say, “Okay, you're going to be giving up whatever day and time and how frequently you meet for the long haul.” and if you have a team, then you have the luxury of sort of handing it off. So for me, you'll run the group and for June I'll run the group and that way it's shared, but there has to be the commitment. For me, it's the best thing I've ever done in my career, and it can be very inspiring. Sometimes you're sort of grumpy, because things don't work out. But that's part of the experience.

Ellen

Well, I couldn't agree with you more that collaboration makes any project better and stronger, and that your commitment to this ongoing community resource group is for me, also very inspiring. Jerry, I've watched you over my career and I've always felt inspired by your work.

I want to thank you again for sharing your expertise with our Aphasia Access members. On behalf of the Aphasia Access, we thank you for listening to this episode of The Aphasia Access Aphasia Conversations podcast. For more information on Aphasia Access, and to access our growing library of materials, go to www. aphasia access.org. If you have an idea for a future Podcast Series topic, email us at info at aphasia access.org and thanks again for your ongoing support of aphasia access.

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