AphasiaAccess
CONVERSATIONS

Show Notes - Episode #20
Merging an LPAA Model and a Medical Model for Successful Aphasia Treatment: An Interview with Denise McCall

Janet Patterson (V.A. Northern California Health Care System) speaks with Denise McCall, the Program Director of SCALE at The League for People with Disabilities in Baltimore, Maryland, about their unique organizational structure.

Denise McCall is the Program Director of SCALE at The League for People with Disabilities. She co-founded SCALE back in 2008 and, in 2014, it merged with The League and has turned into a specialty program there as part of their medical day program. Denise has over 30 years of experience as a clinician and a researcher. She has served persons with aphasia across the continuum of care and has contributed to international research and grant programs to improve aphasia care. Denise is a certified speech language pathologist and is one of the founders of Aphasia Access - currently serving as an active member on its Development Committee. She also serves as a state representative of the National Aphasia Association. Denise received a B.S. in Communication Disorders and in Psychology from Towson University and earned a master's degree from George Washington University. Her research experience is primarily focused on investigating the effectiveness of software-based language treatment for people with aphasia and she has collaborated with interdisciplinary researchers in the fields of neuropsychology, neurology, linguistics, and computer science.

In today’s episode, you will:

- Learn about SCALE’s history and the unique manner in which it combines an LPAA model and a medical model for serving people with aphasia;
- Understand how SCALE was transformed through their search for new funding opportunities;
- Hear about SCALE “Accounts Meetings” and “SCALE Tenets”.

Note: These show notes have been edited and condensed.

SCALE has been in business for about ten years - four of them in association with the League for People with Disabilities. Could you tell us about the unique operation and funding model that SCALE has followed?

Absolutely. We were a freestanding aphasia center from 2008 to the end of 2014. At that time, we realized that our self-pay and scholarship model was really not sustainable due to the huge need for financial scholarships for tuition - people just couldn't pay for this year after year. And so we began to seek out a partnership that would allow us to develop a more sustainable model.

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We reached out and hired a consulting firm for nonprofits who guided us in finding a nonprofit organization that matched well with our mission and vision and we were able to find the League for People with Disabilities - they're a nonprofit that serves over 4000 people with disabilities a year. These are mostly folks with developmental disabilities but they have several programs that include a night club for people with disabilities. They have a youth autism program. They have day habilitation and a workforce development program. SCALE is a natural fit with their medical day program because the folks that attend that program come all day and participate in a number of classes very similar to the kind of things we offer - except we offer only programs for people with aphasia. We're still in the same building that we have always been in and we're separate because we still have self-pay members, but we also have folks that come in through the medical day program as well.

It's a little different than a freestanding nonprofit aphasia center in that we have this umbrella organization that has a lot of services that are paid for by the state and/or by the Veterans Administration. That has it's benefits, but it also has some constraints. For example, since we merged with a medical day program, it's required that our services are medically necessary - that is a tension with the Life Participation Approach, which is a social model rather than a medical model. However, we're able to make the argument that our services are medically necessary in terms of communication access. Our members require assistance in communication about medications and health issues, understanding medical information, reading prescription bottles, having conversations with their physicians, and adhering to medical recommendations. This model has been received well by funders that are looking at us as being medically necessary and that's allowed us to come in under the umbrella of this medical day program.

SCALE has three full-time dedicated speech-language pathologists who provide over 60 weekly group treatment classes to over 60 individuals with aphasia. You also mentor graduate interns from local speech-language pathology programs in addition to pre-med students from Johns Hopkins University. And, if that's not enough, you provide community partner training programs for students and community volunteers. That's a full schedule for both you and the clinicians who work at SCALE. How do your day-to day-activities as director differ now from when SCALE began in 2008?

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Before we merged, I was working over 60 hours and was not getting everything done. Our initial model utilized two directors - myself and Lisa Thornburg **-** who is a very strong speech-language pathologist with experience in hospital administration. We were both managing all aspects of running and directing this nonprofit: grant writing, development, billing, programming, fundraising...we were literally a two-woman show. We had a very active board, but we didn't have any support personnel, so we utilized consultants for all of our services. We were also co-supervising new staff, training students, and running the classes.

When we merged, I became the program director - that's what I do now. I direct the program. I get the privilege of leading all of these new and innovative classes (bible study, book club, storytelling class) and I get to come up with new initiatives that can be funded. I collaborate with the development and marketing teams at the League, but that's not my responsibility. We have the leadership of a strong CEO who has experience operating a nonprofit for more than 10 years - and that's what he was *trained* to do as opposed to a research speech-language pathologist turned into an Executive Director and finding out that the learning curve is going to be huge. We have a billing department, nursing support, and access to professionals. That means that I have time to nurture these new partnerships that we're developing in the community, lead classes, and supervise students.

It sounds exciting to be able to think up a new class, see it develop, and offer it to people with aphasia, and also to develop a new class that the members with aphasia request. That must be fulfilling to you as a director.

Absolutely! That was one of the beautiful things about starting SCALE with 17 individuals I had know from my work in research. It really has been member-driven. We have had people with all levels of aphasia. We had Sean Mackey, the architect who designed the building. We also had Judy Crane who was initially a participant in one of my research studies and helped me design the program, and served on our board. She was a member of our program and received community treatment, then she returned to work and left. She returned later to work for us and is the first person with aphasia to be an employee of a community aphasia group. She runs classes such as a peer advocacy group, and a mindfulness movement group. Judy is a huge addition to keeping SCALE member-driven. The group members meet regularly to review programs and decide which are getting stale and what new program might be interesting - the members drive the ship!

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How has SCALE membership changed since you've implemented this model with the League for People with Disabilities?

There have been some changes that have come with the merger and some changes that have just come with time - it's been open 10 years this fall. After 10 years, most of our founding members have moved on. There were 17 of them. Another change that has been wonderful is to be able to offer the program to veterans who can attend two days a week now - so, that's 10 hours of community treatment that they're receiving that they weren't able to get prior to the merger. Some of our members who were on scholarship were veterans and so once we merged with the League we were able to bring them in as medical day members which had a significant impact on their tuition bill.

The demographics have changed because individuals with limited financial resources have been able to come in if they have medical assistance, which is a funding source for the League. This has really made our program much more diverse and we can serve more minorities. We have many African-Americans in Baltimore and we also have Asian members so that's really been a beautiful integration where we see all of these people who might not know one another prior to a stroke, being in community together and developing these lovely friendships.

We are also able to accept people with more complex medical needs because we now have nursing support and we have aides for individuals that need help. We are able to provide counseling through the League for members who need medical assistance and that's huge. As you know, it's hard to find counselors who are equipped to counsel someone who knows more than they can say, and the League has folks that have been doing that for quite some time with their clientele. That's been a real nice addition to the number of people we can accept.

These are exciting changes in SCALE since association with The League. It has opened the world for people with aphasia especially veterans who have aphasia. Cheers to you for having the foresight and drive to create this program and welcome many more people than you were able to before.

I imagine that there's a paperwork side to your program's expansion. What sort of reporting requirements do you have to The League for People with Disabilities or to other governing bodies that you might encounter?

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There is a lot more reporting that is done when you have a program that is a medical day program than other types of programs. Fortunately, all of those systems and paper trails were in place prior to us merging. They were doing it for many years so the nursing department continues to do that work and I simply have to report some of the statistics to them to allow them to include our members in that.

I have to report on our daily attendance, statistics, staff utilization, demographics of our members, and their funding status. The League is largely responsible for marketing, but we are responsible for marketing to our medical professionals. We are the ones who go out and meet with other speech-language pathologists, neurologists and nurses to let them know about our services.

I do a monthly report regarding our membership and our marketing efforts. I talk about new members and discontinued members - this is mostly for the CEO to share with the board. I have a bimonthly meeting with my CEO and regular meetings with Development. We have to submit a budget and, of course, get it approved. We're a little bit involved in the billing for the self-pay members that aren't part of the medical day program.

These are primary differences, and it is really a big reduction. It was such an incredible merger in that we found David Greenberg and a board who were able to understand the vision and mission of SCALE. It just meshed so well with The League’s mission and vision and we've been really fortunate. From the outset, David Greenberg and the board were able to help us develop a program that was integrated with their medical day program but still gave us the autonomy to be what we had always been: A Life Participation Approach to Aphasia program. The first day that I was employed as a League employee, David Greenberg came to SCALE and my visitor for the day was Todd Von Deak (Executive Director of Aphasia Access). Todd immediately started talking about the national work that Aphasia Access is undertaking and David was able to envision it and embrace it and he's been a great support ever since.

Do you keep any program data for quality improvement purposes? If so, how do you use those data?

We do keep a variety of program data. As I mentioned, SCALE members always drive the class offerings that we have. We have a lengthy process for supporting our members in selecting their classes. We provide sample classes to allow them to try out a class before choosing to attend regularly and we provide slideshows describing our classes. The members complete a survey stating whether they are interested in a class or not.

We receive daily feedback about our specific groups. We've used an Effort Scale that Janet Whiteside's Aphasia House designed which allows our members to provide feedback about the class. They answer questions such as: Were you bored? Did you feel challenged? Did you feel like going? Did you enjoy the class? Shall we continue this class again or should we do something different next time?

We also receive feedback in our quarterly meetings where our members attend what we call "Accounts Meetings". We use that time to review the roles and responsibilities for our members; we get feedback from them about the center, about our outings, about our parties; and we have discussions about future plans. We use a feedback form for volunteers that is designed by members, with students and community volunteers so that they can learn how better to communicate with the members.

This year we're starting an annual meeting with members and families on their anniversary of joining the program. We used to complete this full test battery for a study that we were conducting with Audrey Holland, the Adler Aphasia Center and the Aphasia Bank, but we found that it was really labor intensive, so we stopped using that. It was one thing to use a full test battery when we had 17 members but a whole different problem when we started having 60 members a week. Our new annual meetings include something a little less labor intensive. We use the Communication Confidence Rating Scale as well as portion of the Assessment of Living with Aphasia, and we get feedback from them about their satisfaction with participation at SCALE, their participation at home, and their participation in the wider community.

We also are conducting an annual review of the SCALE tenets. This is a list that we recently created and includes statement such as: "I'm the director of my own life"; "I know and use my strengths"; and "I learn from other people who have aphasia". Our members rate each statement on a *strongly disagree* to *strongly agree* scale. Lastly I keep program data for the League CEO, David Greenberg, which include statistics, demographics of our members, attendance, the number of calls, the number of tours, the number of new members, any attrition, and our marketing efforts.

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What are some of the lessons you have learned from your work at SCALE that you think would be helpful to other speech-language pathologists who might hope to begin a program like SCALE?

One of the lessons I learned is the importance of a well-articulated vision. When I was talking with some of my mentors from LPAA programs, learning about what's being done in the United States, and going out and talking to prospective supporters in Baltimore, I was disappointed that folks weren't as enthusiastic and passionate as I was. Then I realized that it was an opportunity for me to perfect my presentation and really articulate what I was envisioning. And I didn't give up.

I also really agree with Lynn Maher in her recommendation that you hire a consulting firm for nonprofit organizations. We found that incredibly helpful to us and because neither Lisa nor I had a background in administrative nonprofits, we really used that guidance and mentoring.

Being honest about your strengths and areas that are outside of your expertise is really important. I have always been very transparent with my board and with my CEO about what I'm capable of and what really needs to be supported by others.

The most important thing is to always focus on being member-driven and understanding that the people with aphasia know what they want - they're the experts. Sometimes they can't articulate it and they can't envision it because they don't know the possibilities.

So, in the early stages of SCALE we spent a lot of time looking at the other LPAA programs that are so well done and saying to our members, "Do you want to try what they're doing? Do you want to try something similar? What what should we change?”