



Show Notes
Episode #8 – Best Business Practices in Aphasia Care:
In conversation with Candace Vickers

Today, Dr. Janet Patterson (VA Northern California Health Care System) interviews Dr. Candace Vickers. Dr. Vickers is with the College of Allied Health at California Baptist University in Riverside, California. Formerly, she was part of the outpatient neuro rehabilitation team at the St. Jude Medical Center where she was the creator of the communication recovery groups program.

In today's episode, you will:

- Learn two benefits to providing a person with aphasia with the opportunity to share a conversation with a non-obligated communication partner.
- Learn about the value of supporting opportunities for both exercise and conversation with people with aphasia.
- Hear Dr. Vicker's describe how being part of an aphasia group can decrease the risk for social isolation.

Let me start by asking you about when you decided to begin a community-based aphasia group. How did you think about the infrastructure that had to be in place and then what questions did you need to ask to secure that infrastructure?

To start off answering that question, I have to tell a tiny story. In the 1990's, our hospital was preparing for managed care. I had been treating individual patients and referring them elsewhere to the only group that I knew of. At one point people had nowhere to go and I was seeing the impact of chronic aphasia on daily life in a great way. I had a conversation with my boss and she allowed me to start a one-hour group. It was a growing process, but it all started with the strong sense that something needed to be done and people with aphasia have to have a chance to connect with others. That was really the beginning. It coincided with the fact that managed care was limiting access to patients and my own reading of Dr. John Lyons and his discussion of communication partners as a form of treatment and the intrinsic value of the volunteer who is a non-obligated person to talk with the person with aphasia. To really answer this question, I say we really need to have something strong in your heart at the very beginning and then everything else kind of flows from that.

I think it's important to talk to listeners about the infrastructure of aphasia groups, so I'd love to have you speak up just a bit more about the infrastructure that you had to consider.

In terms of infrastructure, as an outpatient neuro rehab therapist, I was seeing people in an office. The beginning of my infrastructure coincided with the realization of the power of the person with aphasia talking with a non-obligated partner who was trained. I began, in a very small way by including discharged patients into the actual therapy sessions. From there, I grew to having a group initially using only my office and, ultimately, getting permission for two hours in a conference room. Then, I applied for some grant funds that St. Jude was spending on many community programs. At the same time that I began this program, I didn't realize St. Jude had started a huge initiative on exercise and having stroke survivors come in for a community exercise program two to three times a week. So, initially, when I began the program and got permission to use the conference room, everyone at the hospital just thought this program had always been there and they took ownership of it. Then, I applied for the grants.

The critical piece that really made the difference was simply knowing the values and the mission of the institution. Being a Catholic hospital, St. Jude Medical Center is very interested in something they called, "The Well Communities" - with values of dignity, service, justice, and excellence, especially for those in the community who might not have enough. I was able to include these concepts in the grant and highlight how important conversation is to these ideas. Once we got the grant, the group was automatically on my schedule. Then the group grew and we kept expanding into more hours and more spaces.

As this continued, another thing that helped with infrastructure was [CARF](#) - which is an organization that accredits rehabilitation facilities. They saw what we were doing and they reinforced to St. Jude how valuable our services were. By combining these ideas - alignment with institutional mission, use of existing resources, and support from CARF - we started to be seen as a valuable community resource for discharged patients and something that all of the doctors and therapists just knew about. That really helped us take hold. Eventually though we lost that spot and moved a couple of times, and now we're in a couple of churches.

That is wonderful, Candace. It tells the story of starting small, knowing what value you can contribute to the institution, and then building from there. How did you decide to build your groups? I know you started small, but how did you consider factors such as how many groups to have, how many people to have in each group, and what kind of communication support might be required during those groups?

In the beginning, I was building the groups according to needs. If there were appropriate patients of my own or other people's to be discharged into the group as a next step for them in their journey with chronic aphasia, then they joined us. As there was a need to split the groups, such as for lack of space or a group that was not homogenous enough, this would drive me to seek out another room or group people in particular ways.

I did not initially have the use of volunteers although I was interested in them, so I used family members. They were not allowed to talk to their own family member, but sat with other people with aphasia during group and I would do partner activities. This was the model for quite a few years until I began getting an influx of student volunteers. It was really learning a process from the ground up. I was writing my own stimuli, finding topics I thought would be enjoyable to talk about or activities that would be enjoyable to do and, of course. I was realizing that natural conversations are the best thing of all.

I was seeing what worked and what didn't work. So, for example, it didn't work too well to have persons with traumatic brain injury in the group every time since they might have poor pragmatics or dominate the group. It also didn't work to have certain persons with advanced forms of dementia come to a group as they might cause disruption. Most of the time, we have people all severities. I didn't try to group people according to the level of severity - so there could be a group with a person with very severe nonfluent aphasia along with people with a mild aphasia.

In terms of group size, when I left CRG in 2014, we had as many as twenty groups over two hours. These groups ranged in size from two or three people up to eight people. When you get over about eight group members it gets really tough. Also, we were using trained student volunteers and so these students would go through an interview process to become volunteers at St. Jude. It's a competitive process. Then, the challenge was to train these volunteers well and to oversee what they were doing and then to build groups that had different identities. For example, at one point we had a men's group, a women's group, an international group, and a variety of groups that created their own identities. One group was led by my husband - it was a self-help group and he would actually write trivia questions about having aphasia and he would use that as an activity. At one point, we had a Spanish-speaking group. We were fortunate that we partnered with the [Caregiver Resource Center](#). A former student of mine with a degree in human services worked there and she led a caregiver support group concurrently during the time that people were having their groups.

For infrastructure, it's important not to have a walk-in policy. We were the gatekeepers. There was a screening process to come into a group. We would meet individually with these folks with aphasia and their families in order to get a sense of what group would be the right one for this person. If there were red flags or problems, then we would see what those were at the time. We would use these screenings as part of a very intensive effort to help that person and their family understand what it is that we do. We can tell them how it works, what it's going to be like, and then you can ask them if that will work for them. We found that to be a really critical step in bringing new people in, getting them rooted into the group, and establishing a bond with them ahead of time.

As you began the group, and as you were growing, what kind of thoughts did you have about the business or stewardship requirements so that you could sustain this group, be valuable to the individuals in the groups, and also to the community as a whole?

At the very beginning, we didn't have any fees for the group. Around three years into it, my boss helped me to understand that the people in the exercise groups at St. Jude were paying a small fee and that we needed to come up with something as well. The reason for that is that the money would then go back into the fund that supported these programs. There were also documentation requirements that increased over the years that we had to provide back to St. Jude because it helped them to justify the program. Because this was all so new to me in terms of the financial aspects, I didn't approach this the way you might today because of resources like Aphasia Access. We kind of fell into it and we came up with a fee structure of \$5 a week. At the time I left St. Jude, and I believe this was still the case, it's about \$28 per month and then, if people pay for two months, they get something like a \$5 discount.

We found that group members are more than willing to give back in this way and that many people wish they could do more for us. For example, when we were at our second church, one of the members saw how much we needed partitions to block sound in this big fellowship hall with wood floors. He bought four giant partitions that we shared with the church and they stored them. It continues to be a grassroots, community-based program. It is essential that it remains on the radar of St. Jude Medical Center as being important, that it meshes with their goals, and that we provide the leadership with the documentation that they request. My hope is that this will continue because it's such a huge need in the community.

It sounds like you had a history of garnering support from the community - both the medical center community and the surrounding community - so that they could contribute time, money, and a belief in what you're doing in order to pay the bills of the group. What are some specific activities that you can recall or actions that you took to try to garner this amazing community support?

In terms of community support, I would have to say that the religious community really stepped up in a major way. We had outgrown the St. Jude Medical Center grounds, and we were about to lose another space, and there was a large megachurch in Orange County that let us use one of their big rooms for a Christmas party. They were also trying to reach out more into the community and so it worked out. We weren't reaching out and just asking people for money, we were seeking for people to meet us halfway and give us a reasonable low rent for this huge space. That lasted for a very long time until they needed to raise the rent beyond what we could afford. Fortunately for us, one of the group members was a member of another church who loved what we did and they invited us to that place.

In terms of seeking out community support, I honestly don't know how I would have done things differently. I think that it was more a matter of people seeing what we were doing, finding it kind of magical, and wanting to be involved because they saw the good that it did.

Did you have to do any formal reporting to the hospital, such as numbers of patients, for example?

Yes, absolutely.

One thing was a survey that had to be given to every person when they would start the program and then every quarter all members would have to take a survey. This was the same survey that was used for the exercise program as well.

Secondly, we were required to take attendance and, at a given point, it became more than just turning in how many people came in the month. It became a tally or how many people we encountered every single week - as well as keeping track of demographic data on individuals.

We also provided a quarterly report that focused on attendance, bookkeeping, volunteer hours, and information like that. My husband, Terry, is actually the one who came in and provided that service. He's a man with aphasia and the lead volunteer in that data collection program. This was a huge service that CRG didn't have to pay for because it was done by a volunteer. He's given over 3,000 volunteer hours to St. Jude and they put his name on a wall - it's a nice dovetailing with the Life Participation Approach.

Lastly, what piece of advice would you have for speech language pathologists who would like to either begin an aphasia group program or expand the program that they currently are running?

Again, I believe that everything begins in your heart. I believe that if you're going to start an aphasia group it comes from a passion to not let adults with aphasia live in social isolation. That is something that's very important to me and I just think it's critical. If that's the place where you're starting, then anybody can start a group - even if it's not large and fancy with a lot of bells and whistles. You can start with something small. Plan to start with who you are and where you are; make sure to include partners; and train people how to communicate. For those with aphasia, provide pleasurable communication opportunities. See if you can get on the radar of your institution.

It's my experience that when people are around you see what you're doing, they will want to join in. We were fortunate to have a large university with many students who want to become volunteers. So, I would say, even if you're outside an organization, you can try to bring in volunteers to extend your service. I highly recommend the use of trained volunteers.

I made myself aware of literature that would support my ability to work with these patients. I'm a big fan of Kathryn Garrett and David Beukelman and their Written Choice Communication (1992) and others such as Kathryn Yorkston, and techniques of Supported Communication. In our groups we were able to help people learn about aphasia and how we facilitate the ability of a person with aphasia to be part of a conversation. These approaches share commonalities about structured conversation and about the importance of communication partners. Our

program grew around these ideas and I would say that if you are not independently wealthy you can still start a program. Consider partnering with student groups and recruiting older adults to work with you. I would say that, as a caution when you're using volunteers, it definitely gave us a better feeling that we were under the entire umbrella of St. Jude Medical Center because those volunteers paid money to have their TB tests and background checks. So we were certain that we had good volunteers - it would be a bit more scary to start working with volunteers without an organizational partner to work with.

So, overall, what's your reason for wanting to start a group? Are you wanting to start small and then grow? Are you wanting to share this opportunity with others and let them join you in this venture? Then, trust that you're going to be able to get low cost space. My experience is different than others, but this is what worked for me.