



Show Notes - Episode #12

Best Business Practices in Aphasia Care with Francie Schwarz

Today, Janet Patterson will be speaking with Francie Schwarz about a unique partnership between library science and speech-language pathology. That partnership led to the first book group for persons with aphasia that is hosted at a public library.

In today's episode, you will:

- Hear how creating a partnership with your local public library is a novel and unique way to embody the principles of LPAA by bringing a book group for people with aphasia to the community;
- Learn tips on developing a relationship with the adult programming librarian in order to navigate library regulations, locate resources to obtain books, and manage lending practices;
- Learn strategies to work with libraries to help them demonstrate their unique contribution to their communities and serve their mission of inviting residents into the library through hosting a book group for people with aphasia.

Note: These show notes has been edited and condensed.

Janet Patterson

It's unusual for me to be interviewing a librarian and not a speech language pathologist for the Aphasia Access podcast, so could you tell us a little bit about yourself?

Francie Schwarz

I am a public librarian with the city of Los Angeles. My official title is Public Service Librarian and I've been at the Echo Park branch for about five years.

My husband, Mike Biel, is a speech pathologist - so, that's my connection to the world of speech language pathology. He is an Associate Professor of Communication Disorders at Cal State - Northridge. He had this idea that we could do a book club together for adults with aphasia - it would be a chance to combine our skill sets and help a population that he's always been interested in. I believe that Mike got the idea from the Aphasia Center of California in Oakland which, to my knowledge, had the first aphasia book club. Our book club with the L.A. Public Library is, as far as I know, the first public library to have such a group - and I'm very proud of that fact.

Mike got one of his former patients involved and they had a number of friends at the Aphasia Support Center from Cedars Sinai. We got a core group of people with aphasia to come and plan out what this book club should look like because it was very important to us that we involved people with aphasia in the planning. After that, it was decided that we'd meet once a week and that the meetings would be two hours long. We also



decided that we would start by using materials from the Aphasia Center of California. So, our initial books were ones that had already been at the Aphasia Center and already had produced reader's guides. We used and bought those, but eventually we decided to generate our own content because our members really wanted to

choose their own books. Since I worked for a very large public library, that's a possibility because we have 70-odd branches and a big central library. It's relatively easy for me to get multiple copies of popular books and get them in an audio format which is important. Sometimes we had to get the books in large print, as well.

Right now, I'm largely responsible for producing chapter highlights. We do about two chapters a week, but we don't just do books. We've also had poetry days and we've actually done a couple of plays. We read all of *Who's Afraid Of Virginia Woolf*. We also did a discussion of the characters of *Awake and Sing* because we do have some theater people in our group.

It's been going really well and it's constantly changing as it goes along. I've been figuring out some things that work and some things that don't. I've been doing most of the moderating because Mike is not always available, so it's usually me. Sometimes we're both there and we can both ask questions and moderate. We also get a lot of student volunteers from Cal State - Northridge and that's been very good for them. A lot of these young people don't have access to adults with aphasia and this is a way that they can learn about that aspect of speech pathology.

I think the partnership between speech language pathology and library science is a great idea. I think you're leading the way for this. At the beginning, how did you navigate the various permissions or regulations that the library or any other organization might have required?

That's an important topic. One thing that anybody who wants to work with a public library needs to know upfront is that library programs have to be free. Libraries are public institutions. So, any program that they offer has to be free to the public. When we were purchasing materials from the Aphasia Center of California, we could not ask the book club members to chip in. I had to get a grant. Another benefit of working with a big institution is that you might have a big foundation that can give you grants. We have a program called the *Ideas Grant Program* where you can map out what it is you want to do, state your ideas, answer their questions, and then get up to \$5000 of seed money for your program. That is what I did to get started. Remember that a lot can be done for free without a big grant, but as a starter especially, if you're not sure about how to use the materials or how to create the materials it was a good way to get us going. Now I largely create those materials myself and that cuts the expense down considerably.

The other thing that's beneficial is that I work for a large public library, so I can get multiple copies of books. I can get ten copies of *The Color Purple* and I can get it in audio and other formats. That's important for this group because it *has* to be available in audio. So, the other thing you may need money for, if you're trying to work with a small library that doesn't have multiple copies, is that you may need to get some donations, then go to Amazon where you can get these things cheaply. But, it's important that the money cannot come from the group itself.

Also, it's important to remember that all libraries have rules. For instance, they have check-out limits and, sometimes, limits on how many things you can get on the same topic. Most libraries will let you check



something out for two or three weeks at a time. You can renew it assuming that nobody else is waiting for it. Where I work now, most people can check things out for nine weeks total. However, for someone with aphasia who is reading two chapters a week, nine weeks isn't really going to cut it. So, you have to make sure that you get a librarian on your side. Find out who it is that does the adult programming for that branch, talk to that person, and find out if there's any kind of special dispensation you can get for keeping the materials for longer.

It can take a couple of weeks to get all of the materials to one branch, so if you're using library materials then you have to get a librarian who can work with you who and help you accumulate those materials. You'll need to give them plenty of advance notice.

Another thing to consider when you're working with a public institution is that whatever you're doing has to be legal. That might sound odd because what kind of rogue, renegade thing are you doing in your branch with all these adults with aphasia?! But, when it comes to things like creating a study guide, you have to be sure you don't just cut and paste from other sources. So, you can use things like SparkNotes as a point of reference, but you can't just cut and paste. It's important that whatever you do generate that you make it so that it's largely your own.

There's also the issue of how do you get multiple copies of something that maybe is not available on CD. A lot of things now are you know available digitally and not in a physical format - with digital copies there are digital rights management to consider. For instance, my library has downloadable digital audio books. However, only one person can check them out at a time - it seems like you could make multiple copies, but legally you can't. You can only give it to one person at a time, So, that's a limitation. Through Audible, you can purchase gift copies that costs money, so you'd have to think about where you're going to get that funding. There are other digital resources that are free. There's Open Culture, for instance, that has a lot of classic books that are now part of the public domain that are available online in audio format.

If you're partnering with a library, be sure you know what their rules are and that you're following them to the best of your ability. They'll appreciate that.

I'm interested in the composition of your program. How long has it been in existence and who are your members and how does your group work? Do you have a set amount of days or weeks that you read a particular book or do you read the book until it's finished? How do you select a book?

Well, we've been doing this for about four years. We have a core group of people - about seven or eight - that have been regulars and that have been coming pretty steadily that whole time. We meet weekly for two hours and that's different from most book clubs. Most book clubs meet once a month and they discuss the whole book all at once. We meet every week and we break it down to two or three chapters at a time (or maybe 30 to 45 pages depending on how easy that book is). So, we have a group of regulars and then we have about six others that come occasionally. We don't require anybody to come every week. We don't make them commit to finishing the book. To a large extent, I like them to choose what we're going to read. Sometimes they don't want

to, but most of the time they do and most of what we have read has been based on their suggestions. Of course, it has to be something that we can get in many copies - and that's often the deciding factor. One



member gave me a list of three or four choices that she had come up with and I chose the one that I could get for free, in large print, in audio, and in multiple copies.

There are things that make books easier or more difficult for people with aphasia. Books that have a narrative that jumps around, for instance, are not the best option for us. I was looking at *One Hundred Years of Solitude* and some of the sentences are an entire paragraph. It's also a narrative that takes a long time to tell you what's going on. So, I realized that probably wouldn't be a good choice. But, for the most part, I let them decide and

they're very motivated. I have never seen anything like it. Lots of people will tell you that most book clubs might have a few core members that are super diehard, but it's hard to get most people to come back because they take reading for granted. They can take reading a book and talking about it for granted and it's never going to be their top priority. But, for people with aphasia who have limited choices for what they can do (very few services out there for them, limitations in their social life...) these are some people that really want to be there. They come pretty religiously and want to participate. It's lovely.

What funding sources are required to sustain your book group now that you've been running for a few years?

We've been fortunate in that we've actually had people just offer us money after we used up the initial grant. We've had enough people who have actually given us some donations, so we've been able to experiment a little bit. We bought some Kindle Fire devices which are newer Kindles that actually have an audio component; so, if a book is available in print and audio, then the book will be read aloud. While the audio is going, the book text will be highlighted. We are about to use some of our funding for a poetry workshop that we're going to be having. We found a local L.A. poet who's really interested in doing this and we want to compensate him for that. We've been very lucky to have the donations.

We're a very big library, but a lot of libraries have smaller groups called "Friends Groups" and they can generate a fair amount of income. My mother volunteers for one here in South Pasadena and they make a ton of money. They collect donated books and they have a little bookstore at the branch where they sell them. That money is used to provide special programs for their branch for the library. A lot of libraries will have that. There are different stroke associations that might provide some assistance. There's the National Endowment for the Arts. I think there are other ways to go about that and maybe your local librarian can actually help you research that. The whole endeavor can be done *largely* for free, but not entirely because if you're in a small branch that doesn't have access to a large institution, then you're only going to get a couple of copies of something. You could also work with a local university that has a speech pathology department and do some fundraisers. We haven't done that, but it's definitely doable.

Do you have any kernels of wisdom that might be valuable for a speech language pathologist who might like to implement a book group in his or her library whether it's a large library or a small library?

One thing to keep in mind is that most libraries want to have programs at their branch. In fact, a lot of libraries are required to have programs and regular meetings look good on their monthly reports. They love that. But, most librarians are also working very hard already. So, I think one thing to consider would be ways to approach that institution and that librarian that you're going to be working with and have those things in mind. You'll have



a higher chance of success if they have the least amount of work possible. I've done it as a labor of love, but I know that approaching another librarian would be a lot. So, I think if you're approaching a librarian. try to have all your ducks in a row.

Also, be sure that you know what that institution's rules are. That's really important. Talk to your librarian. If you want to operate as a partnership, there are certain things you're going to need from them. You're going to need somebody to be a liaison for you to collect all the materials (print, audio). You're also going to need to inquire about extended check-out periods. Basically, just help them understand what aphasia is and how their assistance would go a long way in helping to serve an underserved population.

That's something that's at the heart of what public libraries are about: bringing information to the people. But, if you have a group of people who have language impairment, it doesn't matter that your services are free or that they're there for anybody who wants to walk in if you're not creating a welcoming space for them. They're probably unlikely to just voluntarily walk in your institution. So, starting a book club is a way to bring in an underserved population. It's something that will benefit a library and make it look good.

If you want to get a librarian more personally involved, a good way to do that might be to invite them to one of your meetings and they can see how it goes. You could even ask them if they would be willing to moderate - most libraries have book clubs and librarians have to moderate those from time to time. So, asking them to moderate your book club from time to time might help give them a better understanding of what it entails and how beneficial it is.

That might be a really great way to get the staff more personally involved. We've had family members and friends attend and they have found it really enjoyable and very moving. There was a woman from our library foundation who was interested, but couldn't quite wrap her head around it. We had her come in and she liked it so much that she kept coming back and then she finally [wrote an essay about it for the Los Angeles Review of Books](#). I think bringing people in is a great way to get your institution involved and invested.

Resources and Links:

Article in Los Angeles Review of Books: *The Aphasia Book Club*

<https://lareviewofbooks.org/article/the-aphasia-book-club#!>

Aphasia Center of California Book Connection

<http://aphasiacenter.net/the-book-connection/>