



Show Notes - Episode #24 Aphasia Choirs With Melinda Corwin

Ellen Bernstein-Ellis (California State University, East Bay) speaks with Melinda Corwin about aphasia choirs.

Melinda Corwin is a professor and clinical supervisor at the Texas Tech University Health Sciences Center Department of Speech, Language, and Hearing Sciences. Her research and clinical interests include adult neurogenic communication disorders. She directs the Stroke And Aphasia Recovery Program (STAR) and is an affiliate of Aphasia Access.

In today's episode you will:

- Compare and contrast two models for aphasia choirs--one embedded within a summer arts program and one embedded within an academic year day program.
- Learn about the value in providing IwA the opportunity to transition from music listeners to active music makers.
- Gain insight into the challenges and some potential options for capturing outcomes for choir participation
- Discover some tips for selecting music and the challenges of integrating new members into an ongoing choir

Note: These show notes have been edited and condensed.

I just want to start today's show and ask you to share one experience or role that has been meaningful to you as an aphasia ambassador.

I remember a woman named Cathy who had pretty severe Wernicke's aphasia. She asked me to accompany her to an orthopedic appointment one time after she had broken her arm and I had the opportunity to gently educate the physician that she was working with about the communication supports that were needed to help Cathy understand what was going on with her aphasia. It was exciting and, since then, I've gotten to work with many more medical students and physicians about the best form of communication for persons with aphasia. And I enjoy being an ambassador in that regard.



That's a wonderful story and I sure wish that we had more opportunities to provide that type of support to our clients when they are out in the community whether it be a bank, a community book club, their church or their doctor.

I want to be transparent because we have both been involved in aphasia choirs for some time. You asked that we make this more of a joint conversation than a typical podcast interview.

Aphasia choirs are a growing activity. I know that there are over 30 official choirs worldwide. So, can I ask you to start by sharing a little bit about your setting and your STAR program?

Our STAR program is a university-based, community outreach program. Right now, we just have funding for nine months of the school year and we have programming for just one hour per week. But it's a large program that involves 10 different small groups, a total of about 40 persons with aphasia, 20 graduate speech language pathology students, and five clinical supervisors. One of our 10 groups is a caregiver's network. From that Star program, we're currently funded through grants and an endowment fund. We've also been able to fund a two-week summer program and it's a day camp of sorts and it's called the Aphasia Arts Program. This program is really where our aphasia choir was born. It's an arts camp and so we start at 10:00 in the morning and we have a brief current events discussion followed by choir practice for about an hour and 15 minutes. Then we all have lunch together and then we have art classes taught by an art therapist. In total, it's three hours every day - Monday through Thursday - for two weeks. At the end of that two-week summer program, our program culminates with a choir concert for the entire community and an art exhibit. Typically, we have about 150 people in attendance for that including not just friends and family, but also members of the community who hear about us through public service announcements on the radio.

Ellen, I'm very excited to make this more of a dialogue and exchange of ideas between the two of us because you've helped me so much in learning things about implementing an aphasia choir. Could you share a little bit about your aphasia choir in East Bay?

The Aphasia Treatment Program (ATP) is also a university-based community outreach program but we kind of flip it. You run your choir during the summer and we run our choir for nine months during the school year. ATP offerers aphasia treatment groups from 10:30 to 3:30 two times per week. We are currently funded through donations and university support. ATP was started by Dr. Jan Avent in 1996 and the Aphasia Tones Choir was added to the program in the fall of 2009 when I came on. So, that's a quick snapshot of how the Aphasia Tones fit into our clinical program.



So let's start back with the origin of your aphasia choir. How did you get started?

I had a graduate's speech language pathology student who came to my office hours and she shared that she had her Bachelors in Music Education. We had been reading some of the research and, at that time there wasn't a lot out there, but we had been talking about the benefits of aphasia choirs and she said that she would like to start one. She served as a director and we tried it for the first time in the summer of 2012.

Similarly, we had a graduate student help us launch the Aphasia Tones. There was just this increased energy and engagement of our ATP members doing music-themed group activities. I was very influenced by the work of Carol Pound and her colleagues. They commented that there's reduced access to the creative arts when you have aphasia. I was fortunate that first quarter as director of ATP because I had a graduate student named Michelle Lussier who had a background as a singer. She was just courageous enough to say "yes!" when I asked if she'd help lead a choir so we could transition the members from being just listeners of music to participants. That was our goal.

I was wondering if you had to convince your members to give it a try.

We did. I remember that first year we created some aphasia-friendly flyers and we talked about the benefits of using melody and rhythm to promote speech. Like you, we also talked about the opportunity to participate in and appreciate the arts. I believe that we had about 10 persons with aphasia that first year. We've since doubled that number and have closer to 20 - 25 each summer. How about you?

We had to do a little sales pitch as well. We used part of a wonderful resource created by the Aphasia Institute. They had a music therapist named Linda Dessau who had created material for their website promoting the benefits of singing in an aphasia-friendly way. So, we used the elements of that and created a Powerpoint slideshow to show our members. We started out with about 10-12 people out of the 25 in the program. But, after everybody heard the laughter and engagement that came out of the room during rehearsals, people's interest piqued and we quickly grew. Now we're somewhere in the neighborhood of about 25 members.



When you started out, did you view your choir as a LPAA Model or an Impairment-based model?

I think when we began we probably were thinking a little more under an impairment-based model. That is seen through how we suggested that it might improve participants' speech. But, now our entire STAR program is more under the Life Participation Approach to Aphasia model. Our arts program falls under that model because the participation is what's so enjoyed. The humour, the laughter, the involvement - the group dynamic is just such a wonderful part of it.

We felt the same way from the very beginning, actually. Our choir is embedded within a larger program and most of the members who are in the choir are part of the ATP full day program. So it was really hard to tease out changes in impairment-based measures that we could ascribe just to the choir because maybe the changes could come from their book club participation or their news group or their cooperative therapy, Because of that, we really just felt it was strongly a life participation choir - getting individuals to be members of a choir.

Do you keep any outcomes of choir participation? Have you learned what best captures your outcomes?

Yes, we do keep data. It's been challenging, but over the years we've actually tried several things. My colleague **James Dombroski**, who is a motor speech expert and who also helps to supervise the aphasia choir, does record a brief language sample pre and post choir. He measures breath support in terms of sustained phonation both pre and post participation. We've also tried some different measures such as the SAQOL-39 and we've used the Assessment for a Living with Aphasia (ALA) to try to get at some of these outcomes that may be a result of the choir.

We have modified something called the Program Evaluation Inventory and we've turned it into a more aphasia-friendly inventory where we just ask them: What did you think of the choir? Would you recommend this to someone else who has aphasia? Did you find it beneficial? Then we give them a rating scale - very similar to what's on the Assessment for Living with Aphasia scale in terms of being a visual analogue scale with the anchors of a sad face and then a happy face at the other end. They can place a mark anywhere along that 100 millimeter continuum and then we can go back and measure that to get more of an idea of ecological validity and what the members take take from the choir experience.

What outcome measures have you guys tried?



Again, because our members are part of a larger program, when we started out we didn't have access to being able to take measurements of breath support. We were really interested in things like that because our clients were telling us that they think their breath was getting stronger. We use something similar to your program inventory, but we just called it a Social Validation Survey and we also generated a set of questions specific to the choir and their participation and asking questions about their enjoyment, their ability to participate, and if they felt it was impacting their communication. It was also on a visual scale and we were able to get feedback. The strength and positivity of that initial feedback really helped us to propel and keep going with the choir.

I have had the really good fortune to work with a talented graduate student, Madison Cano Fox, who decided that we could capture more outcomes in by doing qualitative interviews with our members and looking at the impact of long-term participation in the choirs. At this point, we have members who've been part of the choir for up to nine years and it really has been a very insightful and rewarding process to do these individual member interviews. We have some preliminary data (15 member interviews) and we're in the midst of analyzing it. I think the qualitative aspect is really able to get at their opinions and we adapted the interviews to really support the clients with aphasia so they can share their opinions and experiences. I think the qualitative approach is maybe one of the best ways to capture the outcomes.

I think one of the challenges in some of the research coming out is the different ways people are trying to capture outcomes in a real life activity like this.

I completely agree with the qualitative analysis. I'm excited to see what your student finds. Two years ago, we started having a focus group at the end of our two week arts camp and trying to get information from our members - again, using as many aphasia-friendly supports as possible. We haven't analyzed that data yet, but maybe I can find a really good graduate student who is interested in that!

I'm really excited to see that there has been emerging evidence and research coming out in the literature. I've really appreciated some of the work that's been produced by Laura Fogg Rogers and her colleagues including Ali Talmage and one of the early studies done by Tamplin, Baker, Jones, Way and Lee in 2013 from the Stroke-a-Chord choir in Australia. So we are seeing more and more research and hopefully we'll learn more about what measures do help capture change and I think we'll see that across a variety of areas - both impairment-based measures as well as the impact on confidence and identity. Some of the strongest findings in our initial analysis is the impact on creating a positive identity-based membership in something positive like a choir.



Could you talk about the organization of your choir? What are the roles and responsibilities of the director and the students? Does your choir only include people with aphasia?

We are so fortunate to have had the same director - the woman who was initially a graduate student has graduated and now works in a different state as a speech language pathologist. However, she volunteers her time for two weeks during summer. Her name is **Bryna Price** - she's both a music educator and a speech language pathologist. Interestingly, her husband Kyle Pryce serves as our accompanist. Brenna and Kyle are both fabulous musicians and so they actually not only direct and accompany our choir, but they help to arrange some of the music that we sing. They've arranged patriotic medleys as well as pieces they call "Evolution of Music" medleys - where we do different snippets of music from the 1950s, 1960s, 1970s and so on. These are fabulous medleys that the groups really enjoy singing. Bryna also serves as a supervisor because she's a licensed speech language pathologist and so she helps our graduate students in learning how to use facilitated communication techniques and aphasia-friendly strategies.

You have the best of both worlds in that situation!

I have to give a shout out to a continuous flow of very talented and committed graduate students in our program who volunteer their time on top of their clinical and academic assignments to lead the Aphasia Tones choir. We usually have one or two new choir directors each year and they can serve for up to two years during the academic year. I wish I could list them all here because each and every one of them has contributed so much to our evolution as a choir and we're so fortunate that so many students come in with singing backgrounds into our field.

We are fortunate in that regard. I'll also have some students who have never sung in a formal group and they will be a little hesitant. I encourage them to give it a try and show all of the members that it's a fun new skill to learn for everyone.

We meet once a week during the school year. You meet eight days across two weeks, correct?

Right. Monday through Thursday. During our very first summer, we did do once a week across eight weeks, but the feedback that some of our members gave us was that they would rather that time be compressed so that they could take vacations. So, the next year is when the day



camp idea was born and we've been doing eight days over two weeks for the last several years and it's worked quite well. This means that we only have eight rehearsals before our concerts.

We only have eight rehearsals in the quarter so I think it all evens out. Does your choir just include individuals with aphasia or do you include others?

It's mostly just individuals with aphasia, however, we have added a few people who have primary progressive aphasia because they voiced an interest and it has gone very well. What about your groups?

It is primarily the individuals with aphasia since that's what our program focuses on. There are lots of choirs that include caregiver's quite successfully and feel that's very positive. There are also mixed neuro-communication disorder choirs like the one Fogg-Rodgers and Talmage have studied that involves clients with both aphasia and Parkinson's Disease and they've developed a very successful model. I know choir composition can be done a lot of different ways. When we asked our members if they'd like us to open it up to include caregivers, they told us "no". We're sticking with aphasia only, but truth be told, our student clinicians and volunteers sing along sometimes. It's just too hard to resist.

We do as well!

Could you share what a typical rehearsal might look like for your group?

Our choir director starts us off with warm-ups. She has a large white dry erase board at the front of the room and she's very adept at using it to support what she's saying and she visually shows people what she wants them to do with breath support or sustained phonation or singing different notes using a high or low dots on the board. It works very well. We go through warm-ups for the first few minutes. Then we begin rehearsing our songs. We work on anywhere from five to eight songs in preparation for our concert. And so she works different songs on different days and different parts of those songs. Because Bryna is a musician it's very important to her that our members have actual music in front of them. I know some choirs use just text which works great too but are our members actually see the music and we have enlarged the lyrics or the words on the page for easier reading. But the words are underneath the actual notes that are to be sung and then they're looking at an actual music staff. During our rehearsals, she requires that all members have a pencil and she will have them mark their music - things like dynamics, tempo, emphasis on certain sounds, when to hold a note, or when to watch her if she's going to slow down - just like some other choirs that I've been in. She's very passionate about this and it works. Our members are eager to make these marking. For some, it



may be a copy task while others may be able to do it on their own. She accommodates all levels and needs and this has been a really interesting part for us. We also take water breaks. Everyone has their own water bottles. We rehearse for about an hour and 15 minutes every day during those two weeks.

So good vocal hygiene!

I'd like to give a nod to Kagan and Gailey's reference to communication ramps and how you've tried to put those in place throughout your rehearsal. We'd like to use the model participation at every level so when we structure our rehearsal we're looking all the time at how we support participation at every level regardless of the severity of the aphasia. We've never used the musical notes so I think that's fascinating. We do text only and sometimes we will create powerpoints that will illustrate the meaning of the song. Each line of text will have a picture. We'll do that when we are first rehearsing the songs so the clients have the opportunity to understand the lyrics of popular music. After that we just go to large font and we number each stanza and we hold up big numbers so choir members know which stanza to go to. They also mark dynamics in but just write them onto the lyrics. So, it's a little different but it's very fun to hear different ways to approach it.

I know that music selection is always a hot topic. Should you do only familiar music versus new songs? Are there any favorite songs that have become anthems for your group?

Every summer we've had a whole completely different set of songs. But I have been so amazed at the ones that are well liked and our choir director will often have folks take a vote on which ones they want to do. We've done every genre. We've done some traditional hymns, patriotic songs, and things like "Peace in the Valley" and "The Lion Sleeps Tonight". One of the favorites was "The Banana Boat Song". So a lot of variety and it's been a fun experience. How about you?

We started off making the assumption that we needed to use highly familiar songs in order to promote success because they'd be more accessible to the clients. The first couple of years we used a lot of Beatles songs, but then we slowly started to expand because what we found is that our members really want to have some challenge. So that's when we started to introduce new music and I give my graduate students credit for their awareness of popular music and being able to expand the repertoire. They've brought in songs by artists like Coldplay and Katy Perry - just a wide variety of songs



that clients have had to learn. They love it. We think we can put it within the Environmental Press framework that Hoepner, Sather and colleagues have discussed where people do well when you set the challenge at an appropriate level.

We do the same. It's a mixture and some people seem to like that extra challenge and push while others really like the more classic and familiar tunes. We've tried a mix and it works well.

What has been a little more challenging is that new members come in and can feel a little more overwhelmed because we've taken on such new music and the new members are not getting the same opportunity to start up and get used to all these nice familiar music things that they can get comfortable with. So, we're having to balance the challenge of new music and keeping new members comfortable in a comfortable zone with familiar music.

You've already mentioned that you perform and we also do performances throughout the year. We're just delighted to get to sing at our state convention, for CSHA, and we do an end of the year Aphasia Awareness concert. You've done a wonderful job promoting advocacy and awareness through your performance. Do you do one performance or do you do others as well?

Just the one performance right now, but we do pass out aphasia-friendly invitations for our members to give to all of their friends, family, and neighbors. On our program, we try to always explain what Aphasia is and encourage people to learn more about aphasia if they're interested.

So it really serves a dual role, both aphasia advocacy and client engagement. That's one of the magic pieces of being part of the aphasia choir. I just love that our members have this opportunity to see themselves in a new light--we say in the limelight. Instead of being seen as an individual with aphasia, they are seen as someone who is a member of a choir. That seems to have a positive impact.

What do you think the benefits have been for your members? Have you noted any changes over time?

Oh yes. I think this psycho-social component is huge. I watch them transform on the night of the concert. We don't really have costumes. We wear black shirts and we provide red bandanas. Family members are amazed that their family member is up on the stage with the choir performing and our members seem to take such pride in finding a post-aphasia identity and having it reinforced in a very positive way. I just don't think there are many things that can compete with aphasia choir for accomplishing this because it has worked so well.



Do you have any stories you want to share?

I remember one man here. He came from a long term care facility and they transported him every day. His daughter and two of the employees of the long term care facility reported that before he began coming he tended to stay in bed and they felt he was probably clinically depressed. Within our two week program, they saw a change in his demeanor. He got himself out of bed and dressed every day. He interacted with more people at the long term care facility and they really felt that all these changes were due to his participation in our arts program. That was heartwarming.

Do you have any advice for someone who wants to start a choir?

It can be done. It's an awesome experience and there are people such as yourself, Ellen, who can provide some wonderful resources. It's not difficult to do and the benefits are many.

We'll take a little shift from just the choir focus and quickly ask you: What are some reasons that you continue to support Aphasia Access through your continued membership?

I am grateful for the podcast, the webinars, and the educational videos that are available to members. For me, it's an honor because many of my heroes - the pioneers in the world aphasia - they are involved in this organization and I'm honored to be a part of it.

I couldn't agree more. I want to thank you, Melinda, for your time and for sharing your expertise.

For more information on Aphasia Access and to access our growing library of materials, go to www.aphasiaaccess.org. If you have an idea for a future podcast series or topic, email us at info@aphasiaaccess.org.



Links: This is a very small sample of the many videos or resources available on the internet when searching for aphasia choirs. It is not a comprehensive list by any means (my apologies if I didn't include your choir), but rather it showcases a variety of worldwide aphasia choirs.

Facebook Group: Aphasia Choirs Go Global (closed group; request membership)

Adler Aphasia Center Tip of My Tongue

<https://www.youtube.com/watch?v=AWQIxPnGvcs>

Aphasia Choir Full Film featuring Bath Aphasia Choir

https://www.youtube.com/watch?v=UMV6ZaUF0-s&fbclid=IwAR0PvAs7PvdVrllEVUJOLV6phCwh_fx3ryhFHUVcrg_FRQ-t0_RNmc02ek

Bay Area Proud: Aphasia Tones Choir from California State University East Bay

<https://www.nbcbayarea.com/news/local/Finding-Their-Voice-Aphasia-Patients-At-CSU-East-Bay-Form-Singing-Group-366949861.html>

Brainwaves Choir Original Song - 'Aphasia'

<https://www.youtube.com/watch?v=dPtS12ntQv8>

The CeleBRation Choir (mixed neurogenic communication disorders choir)

<https://www.youtube.com/watch?v=DqtMTi37GJk>

La Coral Canta Sant Pau, et felicita el Nadal 2017

<https://www.youtube.com/watch?v=AOGq9YIxTOs&fbclid=IwAR0AmzBDY7yJ5dtuuU923jaAy2dnwtAKd4wxAbPIBDSS4X7k0eHGyUq6vTk>

The Loud and Proud Singers from the Aphasia Friendship Center

<https://aphasiacentermi.org/chorus.html>

Loyola Clinical Centers Aphasia Chorus

https://www.youtube.com/watch?v=O-_eKvYHHBU&feature=youtu.be

The Mumbles Aphasia Choir

<https://www.youtube.com/watch?v=iQQUOeKIUuE&t=56s>

Sing It Out: Unique Choir Helps Aphasia Survivors featuring Texas Tech choir

<https://www.youtube.com/watch?v=NQtPwrAulbA>

Stroke_a_Chord Choir



https://drive.google.com/open?id=1TNDAYfZds0PkI17_SWEe5-Jgg3Ylu_Wf&fbclid=IwAR2rcVxQQoemMpH-ZdlyLhuqmmfYP0xq7GeASbrV1sKFmpID-Omja7a3kgl

And

<https://www.youtube.com/watch?v=xrcInZDqJRc&feature=youtu.be>

University of New Mexico NeuroChoir Virtual Choir Experience

https://www.youtube.com/watch?v=guU_uRaFbHI

Voices Moving Forward Aphasia Choir Minnesota Connect Aphasia Now

<https://mncan.org/aphasia-choir-2/>

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