



Show Notes - Episode #28

Aphasia Celebrations: Engaging Group Members in the Planning A Conversation With Melinda Corwin

Ellen Bernstein-Ellis , director of the Aphasia Treatment Program (ATP) at California State University, East Bay, speaks with Melinda Corwin about ways to engage aphasia group members in planning a special event.

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:

1. Learn about five different areas for involving group members as partners in event planning
2. Hear about three kinds of awards that may enrich your event program
3. Consider the dual benefits of member-guided celebrations: Building ownership in a fun event for PwA and their guests and promoting aphasia awareness to the broader community

Show Highlights and Key Points:

- Dr. Corwin was motivated to start groups 20 years ago because she noticed that many stroke survivors needed more services after their insurance was exhausted. She benefited from the generous guidance of Dr. Pelagie Beeson from the University of Arizona who provided advice about starting a group program. In 1998 they launched their first group of 3 individuals with aphasia.
- Today, her program meets once weekly and has grown to include five supervisors, 20 graduate students, 25 caregivers, and 40 stroke survivors. They recently started groups for individuals with primary progressive aphasia and right hemisphere stroke.
- One year, while sitting at their annual end of year banquet, it occurred to Dr. Corwin that, while the students typically took lead in organizing the event, they were probably doing the group members “ a disservice”. She thought that we could do a better job of involving group members in the entire process.
- The next year they gave each of the 10 groups an assignment to contribute to the planning of the lunch banquet and their integral participation has become a tradition ever since. As they celebrated STAR's 20th anniversary event in 2018, members were fully involved. This celebration also served as a way to raise aphasia awareness and promote advocacy as they sent out press releases to help generate media coverage.



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- While my ATP members seemed to be more interested on giving input on the menu than other areas like entertainment and decorations, her group isn't as involved in the menu. They carefully select food items for the yearly luncheon that can be easily managed with one hand, like chicken strips. Her members are enthusiastic about the other planning activities and she's careful to make sure student clinicians incorporate Supported Conversation strategies to increase involvement.
- Each group is given a specific duty early in the year to start planning, including: door prizes, decorations, entertainment, opening and closing remarks, giving out member awards. They begin to take ownership of the planning and implementing of the event. These assignments are based on an annual rotation list, so groups get a different duty each year.
- Entertainment has been a particularly interesting category. Two different groups are assigned to develop a different form of brief entertainment. There has been a wide array of choices: from member performed skits to visual humor found on the internet such as a video of a baby eating a lemon. Another favorite example is showing a Mr. Bean video or creating a Mr. Bean-inspired skit. Magic acts have worked well, as did the classic camp skit where one person is another person's hands and they work at eating pudding although the "hands" can't see what they are doing. Groups are very eager to share their choices of what evoked humorous reactions. There is a strong sense of community that comes out of sharing humor.
- Having a reason to celebrate and holding meaningful roles in the implementation of the event seems to be motivating and engaging for the members. This supports the research showing that having something meaningful to do is an important factor to living well with aphasia. Our ATP members speak of their desire to have a reason to dress up and have a party. Dr. Corwin emphasized the value of having a purpose and looking forward to something. For many of her group members, their STAR group is often the only activity outside their home or living residence that they attend each week.
- Although it started as an evening event, transportation was a barrier for many members and it evolved to a luncheon activity instead. It has become such an important event, that many caregivers plan to take off work to attend this celebration. They are given ample notice.
- Dr. Corwin explains the five-part framework they have developed to guide their event planning: 1) Programming 2) Entertainment 3) Community Awards 4) Member Awards 5) Door prizes.
- Dr. Corwin credited the idea of selecting Community Awards to Kathryn Shelley at the Aphasia Center of West Texas. It began as a way to attract media to the event and to acknowledge and promote individuals in the community who were advocates for communicative access. This can



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be given to an individual, organization, or group that is identified as being communication friendly. The members nominate and then vote, using an aphasia-friendly ballot with photos. Over the years, the awardees have included a specific Starbucks, Chick-fil-A, and even a specific waiter at a local restaurant who had an outstanding reputation for communicating well when waiting on members with aphasia. This recognition is another way to promote community aphasia advocacy and education with the event.

- The second award is called the Life Participation Award. It's awarded to a community member who has helped a member with aphasia participate actively in the community. It has gone to employers who made it possible for IwA to return to a meaningful job or activity. Dr. Corwin provides two examples of employers hiring IwA.
- Member awards are generated in partnership with the clinicians who help generate an award category for each member. The members and clinicians consider their choices carefully and select award names that often reflect insider humor among the group members. Some examples include the "Burrito Queen", "The Puzzle Master", "The Problem Solver Award", "Most Diligent", and the "Kindest Heart Award".
- Instead of using a paper program, they do an aphasia-friendly, visual program using a PowerPoint file. They show each person's photo along with their award.
- The luncheon is 2 hours long. The awards for 40 members take 10-15 minutes. They use "runners" who deliver the awards to each member in the audience in order to be efficient and keep the program on schedule. Dr. Corwin has seen these awards displayed in the homes and living facilities of members she has visited, indicating the importance and enjoyment members get out of this recognition.
- Another category that involves members is door prizes. The prizes are donated or collected by generous group and caregiver members. Members of the Door Prize group are diligent about practicing drawing and reading the names aloud. They also enjoy selecting the appropriate gift for the person and then delivering the gift to the winner at their seat. This part of the program typically occurs following lunch.
- There is no direct fundraising component to this event. Instead, the focus is on community building and advocacy. However, Dr. Corwin has been surprised that some community members are so touched by the program that they come up afterwards and inquire about making a donation.



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- Dr. Corwin noted that the benefits to involving members as integral to the process of event planning are mostly anecdotal and she'd like to incorporate more ways of quantifying the outcomes. However, she would say "a good time is had by all." It ends the school year on a wonderful, high note and feels like an invaluable part of their program.
- When asked to offer any final wisdom to someone who is doing this for the first time, Dr. Corwin emphatically states that one of the benefits of Aphasia Access membership is the willingness of members to share with each other. She reiterated her offer to share her materials with Aphasia Access members trying to plan their event. She appreciates what she has received from the Aphasia Access community and is happy to pay it forward, remembering how Dr. Beeson helped her many years ago.
- Dr. Corwin offered another pearl of wisdom: "Trust in the members". Don't over-focus on the product, but rather emphasize the process with the event. Dr. Corwin concludes by saying it's been wonderful to see the process of member participation evolve over time. The effort is well worth it when you see the sparkle in the eyes of the members and their enjoyment of the event.