



Show Notes - Episode #11

Great ideas in aphasia care programming: In conversation with Dr. Jerry Hoepner

Today, Ellen Bernstein-Ellis (California State University, East Bay) speaks with Dr. Jerry Hoepner about programming for the Chippewa Valley Aphasia Camp.

Dr. Hoepner is an associate professor at the University of Wisconsin-Eau Claire. He teaches numerous courses including neurogenic disorders, neuroanatomy, and counseling. Jerry's teaching research focuses on non-course-based learning, pedagogy, and training CSD students as educators. His clinical research includes outcomes of the [Chippewa Valley Aphasia Camp](#), social networking applications, videos self-modeling, interventions, and communication partner training.

In today's episode, you will:

- Learn about how the [Chippewa Valley Aphasia Camp](#) got its start 14 years ago and how its mission to increase social interaction and communicative success guides its programming;
- Hear more about how the concepts of therapeutic landscapes and environmental press dovetail with the Life Participation Approach to Aphasia (LPAA);
- Learn how the student volunteer experience is guided at camp from the initial training to the daily de-briefing.
- Learn how Snapchat - a photo-based social media app - can increase social interactions among campers.

Warning: Listening to the following episode may make your craving for a s'more and a campfire dangerously high.

Note: These show notes have been edited and condensed.

Ellen Bernstein-Ellis

This is your 14th year of running camp. Would you mind sharing how it got started?

Dr. Jerry Hoepner

Sure. I should say that I think it was brewing in Mary Beth Clark's mind for years and years. The spark was really ignited when my colleagues Tom Hintgen and Mary Beth went to the Aphasia Institute in Canada to work with Aura Kagan and people like Ruth Patterson and so forth. We had been facilitating the community-based aphasia groups for a number of years at that point.



Tom and Mary Beth came back with this resolve to initiate this camp. Mary Beth had grown up going to a YMCA camp - the very same camp where we host camp, actually. She also worked for a number of years as a camp counselor there, so she really knew the storyline of the YMCA camp and she valued those interactions and the participation that those experiences fostered. Once the idea was out there, there was really never a question of should we do it, we knew that we were going to do it and we just moved forward from there.

I think for some people it may really be hard to envision what camp could look like. I think the concept of an aphasia camp is unique, so could you describe your setting?

I really think it's idyllic. We have camp the first weekend in September which is often very nice - temperatures in the 60's and 70's. It's this rustic, close-knit setting. The log cabins are rustic but comfortable. The camp looks over this beautiful northern Wisconsin lake where you have beautiful sunsets and beautiful mornings. A lot of activities take place along the edge of the lake. There's just really something about that wilderness setting that puts people at ease. Sitting by the campfire is a great place to just connect with people in a low pressure context. It just feels like the ideal setting for a camp.

How many times is a camper allowed to attend your camp? Do you have criteria in terms of age, severity, or mobility limitations?

Good question. There's really no set limit. We try to make things fit an individual's needs. Certainly, there are situations where someone has a lot of physical needs and they don't have a care provider who can help them at the level that they need. We might restrict them, but otherwise we try to keep our camp open and we try to make it fit their needs. We've been really close to capacity many times but we've never exceeded it, so I kind of hope to do that someday. But it's nice to have that close knit interaction. Our total capacity is probably around 100 and that includes staff and students (we bring up about 24 students each year). There's also about four or five staff members who make meals and deal with maintenance and other camp needs.

I'd like to talk about the broader context of the aphasia camp movement. You've shared with me that we have a North America Aphasia Camp Association. Can you tell our listeners a little more about that?

This really started as a kind of a thought at the inaugural Aphasia Access conference in Boston. There were discussions about other aphasia groups meeting together and a few of us thought that it would be beneficial for us to connect with other camps so that we could share resources. Shortly after that we began meeting through webinars, web conferencing, and phone calls. From that point, Tom Sather and Esther Kim have kind of emerged as those that are really



leading it and moving it forward. But there's been some really good contributions from all of the the camps that are filling this rustic residential camp role.

I was wondering what you feel is the value in having a nature-based experience.

Throughout my career and through what I've read about aphasia and related disorders, I've grown to really value the physical environment and the role that everyday partners play in that context. And we really strongly believe that there's something therapeutic about a wilderness type of environment. We have recently started to investigate this idea of *therapeutic landscapes*. That concept is pretty prevalent in other disciplines but really hasn't taken a foothold in our discipline. Actually, Martha Taylor Sarno did a therapeutic alliance study years and years ago with this idea of gardening and aphasia. However, to our knowledge, that's the only article to this point that's investigated that.

In an upcoming article, we're thinking about this idea of how the physical environment, the people within that environment, and the kinds of demands that we shape or construct for them offer opportunities for these successful interactions. We think about these planned interactions and then these somewhat serendipitous but planned interactions, as well. So, opportunities for people to connect where there is an environment that is supportive and lends itself to opportunities that are low pressure and that are going to be more successful, hopefully. Part of that is the physical environment, but part of it is the people within that environment that understand what aphasia is - they understand how to interact with aphasia - and I think that just lowers the pressure and increases the likelihood of success.

What have your campers actually said to you about entering this more physically challenging environment? What type of feedback have you gotten?

So one of the things that they say - and I think this is due to the partners and the people within that environment - but, they just value not standing out. They value not feeling like they have aphasia for a few days. Our hope is that if they're successful in that context then that will be a springboard for them to try some of those more challenging things when they return to their community. That's at the heart of a life participation-based approach. It's just very holistic. Camp puts them in a position to do things that they personally value and that they enjoy with the people that they enjoy interacting with.



Your beautiful 2017 camp brochure says the camp mission is “to offer people with aphasia, and their significant others, activities and resources to increase social interaction and facilitate communication success.” So, how has this mission influenced your program development?

We're always thinking about camp as a springboard. Every year, we meet with an aphasia camp board and that board is staffed by speech language pathologists like myself, but it's also staffed by individuals with aphasia and their partners. One of the things that we've developed are these themes for each year. For example, one year our mantra was “Because of camp...” which really signified what the person might do after they leave camp. Those things aren't always based on a communicative goal. They might be based on returning to an earlier activity. Another year we followed a wilderness camp principle called “Challenge by Choice”. The idea is that everyone chooses the level of challenge that they want: Some may choose a really high level of challenge and others may choose something else. We try to say, “If it's something that you want to do, then we're going to try to figure out how to make it happen.”

You have chosen themes and you also have special guests that come to camp or become featured guests related to your theme, right?

Absolutely. This year, we're really privileged to have Barbara Shaddon coming as our guest for the weekend - her research and clinical knowledge about identity is really valuable. We'll be focusing on renegotiating identity both for people with aphasia and also their everyday partners. We follow some principles of Aura Kagen's that I think are a little bit hard to pick up. Early on in my career, she produced some writing about the idea of the “Little C” - your aphasia-friendly community - and the “Big C” - which is the rest of the world. We like this idea of taking those skills that are nurtured within the “Little C” and then transferring them into the “Big C”. We try to be somewhat metalinguistic about this and intentional about that transfer of activity and engagement from the camp setting, where they have some success, to their home.

You and your colleagues have an upcoming paper coming out that's an expansion of your 2013 ASHA presentation. You mentioned that your camp followed the Environmental Press Model. How does that model relate to the life participation model of care?

I really think it's a natural complementary fit to the life participation approach. I started reading about the environmental press model based on some work of Jennifer Brush with individuals with dementia. It just seemed like a perfect fit for the kinds of things that we do at camp and in a lot of my everyday interventions. It's kind of nestled within this wilderness camp principle of “challenge by choice” - that idea that people participate or engage optimally when they have that right.



We always talk about this Goldilocks balance between challenge and support. If there's too much support and not enough challenge, we all know that becomes very patronizing or boring and that decreases participation. Of course, if there's not enough support or there's just too much challenge, then that leads to failure and hopelessness. So we're always trying to balance those challenges and support on an individual level. It's really important for us to think about what an individual needs and how to help them to get there.

Early on, we were really focused on the idea of communicative and physical ramps. Sometimes we try to make better access to everything at camp. And that's important because we want it to be accessible, but we don't want to take away all of the challenge because that's what camp is. It's a real life context where there are those those physical and communicative barriers and it's okay to have some of them. If you completely strip it down so that it's just easy to get around, in context and you lose some of the value of the challenge. So, we have to retain some of that.

What would be the role of the communication partners within that context?

We're always looking to train our students and staff so that they can provide whatever support is necessary from a physical, cognitive, and communication standpoint. Again, we want people to be able to stretch themselves, so when physical demands are high maybe we can give more support in terms of communication or when communication demands are high maybe we give more support in terms of the physical ramps. By being tuned in to that, we can help assure that that person can participate as much as possible.

I was just impressed how your 2017 Clinical Archives of Communication Disorders article considers the value and impact of both formal and informal programming. Do you want to describe a typical day at camp? I hope it involves s'mores.

It definitely involves s'mores, although sometimes we're all worn out by the time we get there. You can always rely on the students to make some s'mores and campfire popcorn for us.

There's a lot of activity and we have the kind of things you'd expect at a camp. We have camp standards like boating and fishing - both big fish and little fish. We have kayaking, canoeing, sailing, hiking, adaptive archery, and adaptive golf. We also do things like woodworking, crafts, field games, theater, and music. We've had storytelling sessions. It's always great to have real storytellers come up. We also have some learning-based opportunities like technology - especially how to use a device, using social networks, and connecting with other people. We know that campers really want to stay in touch with each other and, often with some of our students or with the staff, so this gives them the tools to make those connections from a distance.



Because the Aphasia Tones Choir back at Cal State-East Bay has a harmonica group, I have a special interest in harmonica. I was just wondering if you would share a little bit about your harmonica playing. Making harmonica aphasia-friendly requires some adaptation, so I'd love to hear a bit more about that.

One of the things we started capitalizing on is the talents of our staff and students. We used to assign students to certain kinds of roles and now we just seek out their talents and it's amazing the talents they bring. I think last year we had a band with banjos, mandolins, ukuleles, and percussion. Tom Sather plays a mean guitar if anyone's wondering. All that's been fun. A lot of times, campers feel comfortable to bring their own instruments. A couple of them play the harmonica - in particular, a younger gentleman that comes. This year we're really fortunate to have a singer and harmonica player - actually of American Idol fame - and he's going to be joining us, leading sessions on learning the harmonica, and hopefully he'll join us for campfire activities so it should be a great time between the s'mores, the music, the parties, and everything else.

You've got over 12 activities that all need specialized equipment. How did you manage to get the resources you need?

A lot of generosity from people in the places around us. We've been fortunate to have grant funding to cover some of that and that support has allowed us to buy some of the specific adaptive equipment that you know we couldn't develop on our own.

We had a company who makes special adaptive fishing equipment donate around 25 fishing poles. A couple of years later, they ended up going out of business and they gave us the rest of their inventory. So, now we're stocked for a camp of about 100 people to fish.

We also have all of these talented and amazing staff members. We have physical therapists that come from a hospital setting that's about 45 minutes away from us - and they've been there for years and years. A couple of them have a lot of ingenuity, so they've made their own adaptations for keeping your feet on bike pedals. They've also helped people with unilateral weakness hold the paddle for the kayak. You know, occupational therapists can make something about out of anything so they can adapt. In recent years, we've had campers that have come up with their own adaptive equipment so they've brought that to camp and we've used some of those kinds of things as well.



There is a number of stroke survivor camps as well that focus on both campers with and without aphasia. There is The Refresh and Retreat Stroke Camp Association with camps in over 14 states. But I'm guessing that the aphasia camp movement puts a very careful focus on the supports for communication. How does your aphasia camp approach skilled communication partner training for student volunteers?

We're really focused on giving opportunities to really young students. The National Survey of Student Engagement survey looks at high impact practices and they found that the earlier that someone has an experience, the more impact it will have on their learning in the future. So, their experiences at camp puts them in a position to be more intentional learners when they actually have a class. When we have a student that's been at camp, who years later is in our Aphasia and Related Disorders class, they already know aphasia classification. So, when we're talking about what a nonfluent aphasia is they know because they can say, "Oh, that's Bob," or, "That's Judy."

We really recruit across undergraduate and graduate students, but we do value having that heavy emphasis on younger students - whether or not they end up working with people with aphasia or not. We believe we're seeding the world with people with life participation approach to whatever it is that they want to do. I think the life participation approach is a pretty universal principle in whatever context they're in.

What tools do you use to get the students ready for camp?

They complete an online training module first, so that they become familiar with the principles and techniques for supportive conversation, the life participation approach, and the camp mission. We have a number of videos, demonstrations, and screencasts that the students use. They also participate in face-to-face training for two to three hours and then they practice those techniques again through role-playing possible scenarios at camp - sometimes they're playing the role of the person with aphasia. By the end of that training, we send them home with some homework and things to do before their next meeting. Lastly, we do a little bit of a refresher at the final meeting - that's also when we talk about camp logistics and their specific roles. It's just fun at that point to see how much our students' thought processes have developed over the course of a few days.



Can you talk about how you craft the family experience at camp? How do you assess the experience of the family members and caregivers?

We're actually thinking about doing a little bit more work in that area. We've done a number of things specifically directed at partners. We always have activities at camp that are available to both people with aphasia and their partners, but we also have a spouses or partners retreat. That's become a mix of a spa-like getaway with some activities that they can engage in - just to start spending time not being a caregiver as they renegotiate their new identity. It also includes time for peer mentoring and peer support. All of these experiences create a really low pressure situation and gives the caregivers the opportunity and the environment to share and to be able to mentor one another.

In a recent paper, you describe a pilot exploration of Snapchat at aphasia camp. Could you briefly explain that project?

It actually was born out of a couple of different things. One was some work that **Heather Buhr**, some computer science colleagues, and I did on a program called Aphasia Web. That is an aphasia-friendly social networking tool. People with aphasia really valued that aphasia-specific application for connecting with other people with aphasia, but they still wanted some ability for universal access to their family and friends. So, they wanted us to explore a more universally-accessible tool and Snapchat kind of fit.

One of the things that people with aphasia identified was the idea that initiating an exchange through a photo is much easier than initiating through words. There's a bit of previous research on this idea of participant generated photography. It's been used in mental health context, but it's also been used in aphasia. Taking a photo is a good way to share things that are complex or hard to explain through words. From that standpoint, it's just a natural modality for people with aphasia to help convey some of those complex thoughts. If you can support that with a little bit of words and a little bit of drawing, then that person has the ability to use a multimodal tool right in their hands.

My daughters have been using Snapchat and one of the things that really struck me was just how they communicated - it's kind of a teenage thing. They would take a picture of themselves in whatever context we were in - eating at a restaurant, for example - and that really struck me as a way to share participation.

The nice part about Snapchat is that whatever moment that the person with aphasia is engaging in, they can share that with other people right away. It's a way to say, "Here's what I'm doing." One of the ways we've see that play out is that those Snapchat messages act as a call-to-action. When someone shares a photo of themselves snowshoeing, for example, then



somebody else can say, "I want to do that. Tell me about that. Can we meet some time?" The great thing was to see a couple of days later the two of them snowshoeing together. Sometimes the other person doesn't want to snowshoe, but they can share some greeting cards that they made from scratch. So, it's just really neat to see that reciprocal exchange happen through Snapchat.

What are some drawbacks to Snapchat?

Images and video only stick around for 24 hours and that got in the way sometimes, because people didn't always check the app. So, other people suggested something like Instagram. That's a little bit more reviewable since it leaves photos and videos up - that can be very useful. You do lose some of the value of Snapchat since you can't draw on the photos with your photos and add other fun things.

What have you learned from this Snapchat study?

We noticed that they shared different kinds of things when they were in their community or home setting than they did at camp. At camp, they shared images of the people around them and at home they shared images of the things that they value and the kinds of things that they do. That just tells us something about how influential environment is and it might say something about how many opportunities they have for those communication exchanges with people around them.

You comment that "successful social engagement is the product of many factors"--if that's the case, you certainly need a variety of measures to get at outcomes. What are your best lessons in regards to capturing meaningful outcomes?

Yes, it is complex and I think we're still refining ways to capture that. I think there are potential strengths and shortcomings to each measure we've employed. We've used self-reports and surveys, which are useful in program development but not very controlled or consistent across people. We have used video cameras to capture social interactions, but it is difficult to get good fidelity as people are moving around and engaged in real activities. The accelerometers we used to capture physical engagement were great most of the time but we had data voids when people went out of range for connectivity - same goes for Snapchat and similar wireless technologies. We're trying techniques like qualitative interviews and follow-up interviews or surveys as a way to glean specific information. Certainly, components of the ALA lend themselves to this type of measure. That being said, we want to avoid disrupting the context to get data, which may be less ecologically valid as a result of that intrusion. That's something that we're always weighing.



What story comes to mind when you think about all of the years at camp?

Wow, so many. The core Chippewa Valley Aphasia Camp staff and Chippewa Valley Aphasia Group staff has been together for a long time. This marks our 20th year of group as colleagues and friends. The staff that has been added along the way has grown close to us in the same way. We have OTs and PTs from other institutions who've been coming for over 12 years - often, that's the only time we see them - they just keep coming back. There is a ripple effect for community volunteers and staff as well. Along with my dad, we have session leaders who have been coming for many years - and for them, this is their only connection to aphasia. Our tech guy is a former student who came for 4 years as a student and now takes several days of work each year, just to do this. The best moments are the real, enduring relationships formed with campers, students, and fellow staff. The core staff have strong friendships, mutual goals and values in terms of LPAA, and are really funny when you're sleep deprived staff at camp.

Resources mentioned in this episode:

<https://www.facebook.com/aphasiacamp/>

<http://mayoclinichealthsystem.org/locations/eau-claire/services-and-treatments/neurology/aphasia-camp>

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