



Show Notes - Episode #17

Insights and "Aha!" Moments About Aphasia Care with Dr. Janet Whiteside

Dr. Katie Strong (Central Michigan University) interviews Dr. Janet Whiteside. Dr. Whiteside shares her aha moment and her 40 years of experience working with individuals with aphasia and her time spent running the remarkable Aphasia House at the University of Central Florida.

Janet D. Whiteside is the Founder and past Director of Aphasia House at the [University of Central Florida's Communication Disorders Clinic](#). She has been an advocate for innovative programming and clinical services for persons with acquired neurogenic communication disorders, including the exploration of augmented reality in therapy. She received her bachelor's degree from Augustana College, her master's from Vanderbilt and her Ph.D. from Indiana University. As an Associate Lecturer at UCF, she realized her dream of creating the Aphasia House which encompasses an Intensive Comprehensive Aphasia Program (ICAP), traditional delivery of services and psychosocial groups for persons with Aphasia. She was among the founding aphasiologists who formed the Aphasia Access, which she credits with broadening her horizons and networking capabilities with like-minded colleagues throughout North America.

In today's episode, you will:

- Learn the power environment has on changing communication;
- Take away a few tips on how you might 'remodel' your own clinical program;
- Learn about three models of clinical training programs within three Aphasia House;
- Be inspired to be a dreamer and go after your dreams to further the LPAA mission.

Note: These show notes has been edited and condensed.

Can you share your "Aha!" moment that led to create what is now known as Aphasia House?

My "aha!" moment occurred about 40 years ago - in the spring of 1975. I was a graduate student at Vanderbilt University and one semester I was assigned to the Mama Lere Home (a literal home there on campus). It was a place where parents brought in their young children that were deaf and hard of hearing and we as graduate students got to interact with and introduce sound to the infants and toddlers. It was a very enjoyable and happy place to work. Then, the next semester, they assigned me to be the VA in Nashville and that is truly where I fell in love with aphasia. Every night when I left, all of our veterans that were on the rehab floor were lined up in the hallway - wheelchair to wheelchair - waiting for their next meal. And it truly disturbed me to see this every night as I walked out. So, one night when I was walking out, I turned around and I simply extended my hand and I said, "Hey! See you tomorrow!" And their faces would light up. Then, I had this epiphany: Why are we treating our adults as if the most



important part of their day was their next meal? And we were treating our children with hope and happiness. So, I told myself that someday I would have an Aphasia House and it was going to be a place where we treat people with aphasia with the same hope and happiness that we use with our young children.

What a terrific story and what a legacy you now have with your work with Aphasia House! I'd love to hear more about the setting and programming there.

Fast forward about 35 years. At different places where I worked, I would share my dream for an Aphasia House, but that nothing ever took off. So, in 2008, I was a clinic director at the [University of Central Florida Communication Disorders Clinic](#) and we had a new dean. He had three tiers of funding and he called one of those tiers, "Tell me your dreams". When he said that I thought, "Maybe this is my opportunity." So, I share my dream with him and he said, "Okay. Let's see what we can do about that."

It was two years of jumping through hoops. He needed pilot data. He needed some evidence in our literature that intensive programs would work. We also became Medicare providers. I also raised some money. And I had to create a business plan. It took about two years and we opened in June of 2010. When we opened our doors, one of the most important things to me was to have a context enriched environment that truly spoke of a home - because I believe the home is where we build our first relationships and those relationships are truly built on communication. So, the mission of the Aphasia House is to provide the best therapy possible, but in a context-enriched environment. It's also there to give hope and a means of communicating to our people who have aphasia and to their family members and significant others.

Fantastic! I've had the pleasure to visit and it's such a beautiful setting. Could you talk to us just a little bit about how the program works? How many clients do you work with at a given time?

Since we opened our doors, the Aphasia House has already expanded and grown. We've moved from our first suite of rooms in a building adjacent to campus to a much larger suite of rooms that I got to design. We never call them treatment rooms. Each room is named after a room in a house. So, as people walk in, they walk into our Living Room - it's fairly large and it's a place where families can feel comfortable getting to know each other. Then, the next room is our kitchen and it's as one of the largest rooms in the house because I feel like the kitchen is where people gather in a home. It has a very large island that has two heights: One height is to accommodate those that are in wheelchairs and the other height is for those who stand. We also have a restaurant-seating style where we can seat up to 20 people. I also believe that kitchens should be full of wonderful scents. I love cooking and baking, so just about every day you can find something in the Aphasia House that's healthy (or maybe not so healthy) to eat.



And then, in the back, we have eight rooms in total for individual treatment. But, again, we don't call them treatment rooms. We have an entertainment room, a music room, a sports room, a UCF room, a coastal garden room, a parlor room, a hobby room, a garage, and an attic.

You've mentioned the importance of context and environment and you've previously used the phrase "communicatively handicapped environments" when discussing treatment for aphasia. I was wondering if you could describe what you mean by that and how this influenced your vision of Aphasia House.

I believe it was Dr. Barbara Shadden that used the term back in the 1990s. It resonated with me because of what I observed in the 1970s. Many of our skilled nursing facilities and institutions are not designed to really encourage personal communication. For about a year and a half, I actually worked in a secured unit for persons with memory loss and I realized how important environment was to them in order for them to feel more comfortable. So, looking at lighting, seating arrangements, ambient noise and all of those things all made a difference for our persons that were memory impaired.

I took that opportunity and used the same careful scrutiny when we were designing a home for a person challenged by aphasia. So, it's very important to me that the rooms lend themselves to a conversation. We all have unique stories to tell. One of the things we encourage is that our people that come bring pictures that they can put in their their rooms while they're here for six weeks. I believe that environment has the power to change behavior and I believe all of communication is behavior. That's one of the reasons I am so excited to have an environment that is communicatively-enhanced rather than communicatively handicapped.

And that's so apparent from the moment you walk into Aphasia House. It's a special place and you feel like you're comfortable. You do want to stay and and hang out and communicate. I think you've achieved your goal there for sure.

It's fun to see and hear the differences in six weeks. In our six week intensive program, the students and people don't know each other that well and so the conversations are a little stilted and I'm facilitating more. But, by the second and third week, they are all over the place! They are engaging in conversations, laughing, and playing games together. I just love it. It feels like a home. Everyone becomes comfortable, so not only the clients but the UCF students become very comfortable here as well.

You've previously stated that communication is relational and that we learn about relationships in the home. What are some advantages of delivering services in a home-like setting? How important is environment on communication?



We truly do infuse the Life Participation Approach for Aphasia. Our clients are the ones that are driving the therapy. The therapy is designed by the client, for the client. We like to look at that totality of communication. What's the handicap that they may have? How can we treat that comprehensively? How can we get them back engaged in the activity that they want to be engaged in? It all goes back to our home environment. What are the things that we do at home? What are the things that we like to talk about and be engaged with (whether it's cooking, tinkering in the garage, being outside, or tinkering in the garden)? So I think having that homelike environment that allows the client to feel like the client is the one that's making the choices as to how their therapy is going to progress and it all comes together as a package.

If someone couldn't build a full Aphasia House, but wanted to do a little remodeling in their own clinical environment, how could they bring some aspects of the Aphasia House model into their clinical home right away?

That's a great question. I think part of it goes back to the philosophy of care. One thing that I appreciate about the foundation that's been laid here is that we believe in and infuse the Life Participation Approach for Aphasia - we want our clients to engage in activities that they want to engage in again. But also the Aphasia House is a place where individuals can work on what they feel is still handicapping to them. So, we truly infuse both impairment-based therapy with client-driven goals and aspirations.

Whatever setting that you may find yourself in - whether it's outpatient or even inpatient - I believe that we can marry both of these philosophies in a way that's truly going to benefit our client the best and is going to maximize their improvement in their journey of rehabilitation. Hopefully, along the way, we can have some latitude in what our space looks like. As we look at hospitals trying to become more inviting, more 'hotel-like', hopefully some of our rehab spaces can truly become a little bit more welcoming and a little less like a medical environment. Simple things like different lighting arrangements, different chair arrangements, and the addition of soft music can create an ambience that is more like a home.

I think a major aspect of the LPAA model is that we are not just treating the person who has the aphasia but we are treating the entire family. So if you look at your environment as being family-friendly. Whether that's bringing in their children and helping them in how to talk with someone with aphasia or different friends. The environment is going to allow the children and friends to enter in and engage with the person with aphasia in a much more substantive way.



There are a number of listeners on this podcast who are clinical educators and Aphasia House has a unique model for engaging students in the programming. Could you talk with us about your approach to clinical education within Aphasia House?

The Aphasia House has actually expanded now and we have three different programs. The one I probably talk the most about is the Intensive Comprehensive Aphasia Program (ICAP). We accept 16 graduate students to that program. They are in their fourth semester of graduate school and they are vetted by previous clinical educators as well as their own interest in wanting to pursue a career working with persons with aphasia. Those students then meet with me a week prior to our candidates and our clients coming in. Hopefully, that's a time where we can broaden their knowledge base, so we do an extensive literature review on the areas that our clients want to work on. It's highly individualized.

Secondly, I believe the Aphasia House truly fosters a team approach. Every single one of our clients for the intensive program has four students (one an hour between 9 am and 1 pm). So, each day in the intensive program they receive four hours of individual treatment and the client gets to decide on four areas that they want to work on (e.g., reading, writing, conversation, speech intelligibility). Then, each student is assigned a particular area and they have to find the best evidence-based practice for it and then we meet as a team every week to go over how things going for each hour.

Finally, in the Aphasia House, students truly learn through modeling. I like to say that I am a co-clinician with them. I'm in every single session for at least 10 to 15 minutes. I'm up at the table. I'm modeling. I'm helping that graduate student to hear and to see what I'm hearing and seeing after doing this 40 years. For me, the clinical education piece is at the core of what we do. The Aphasia House is part of the Communication Disorders Clinic at the University of Central Florida.

Besides ICAP, we also see students in their third semester of graduate school. They see our local clients that come once or twice a week for one to two hours and they participate in both individual and group therapy. Then, thirdly, we have our psychosocial groups which meet on Friday and these are wonderful clients that have been with us for a number of years and they've really built a community. We have groups of about 10 individuals that meet either in the morning or in the afternoon. These groups decide on group activities that they want to do each semester. It may be something like a book club, gardening club, travel club, or a computer club. We always have an advocacy club and they're the ones that are going out into our community and telling other people about aphasia. They also create a newsletter every single week to share with others. So, we're very fortunate in the Aphasia House when it comes to clinical education. To provide our students with programs that are primarily based on the LPAA model, as well as programs that are a nice hybrid, as well as programs that are more impairment-based.



What a fantastic opportunity for students. I'm sure they enjoy this very much. Do you oversee all of this yourself? Or do you have support with this?

I am an overseer of all of the programs for adults. We have some additional programs for persons with memory impairment, traumatic brain injury, right hemisphere disorders, and primary progressive aphasia. But I am part of a team and I have a full-time clinical educator that works with me as well as five adjunct clinical educators.

What is one thing that we need to urgently achieve as a community of professionals and providers for aphasia advocacy?

I believe we need to foster an environment of dreamers and visionaries. People that embrace the idea of creativity and imagination. People that see how we can maybe do things differently to maximize the rehabilitative journey of our people that we work with. So, that's the one thing I try to infuse with my students. I am blessed. I was able to have a vision 40-some years ago and to see that come to fruition... But this isn't the end of the story. I just laid the foundation. And, as you may know, I'm getting ready to retire and I'm passing the Aphasia House forward and I'm truly happy to because I believe that the next generation can build on it and run in directions that that I can't see yet. So, the one thing I would love to leave with other people is to be a visionary - to to dream and then to go after those dreams.