



Show Notes
Episode #2 – An Interview with Dr. Jackie Hinckley
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In this episode, Dr. Nidhi Mahendra, San Jose State University, speaks with Dr. Jackie Hinckley. Dr. Hinckley is a professor emeritus at the University of South Florida and the Executive Director of [Voices of Hope for Aphasia](#).

Today's interview includes:

- Best practices for raising awareness of any condition
- Top marketing tools for promoting referrals in support of your aphasia community
- Important trends to understand in order to generate a response to your aphasia services

How do you think we're doing regarding raising awareness about aphasia?

Maybe I can answer on two levels. First, a global overview. I'm not sure how much progress we have made regarding people knowing the actual word "aphasia". On the other hand, there are so many people who have various communication needs, not just aphasia, who have created other organizations. More and more, these organizations are being empowered to speak out and become active in their communities. We are also using additional methods of communication and have become tolerant of so many different communication modalities. I don't think I can count how many I've used today. Between different types of technology and running an aphasia group, it would be too hard for me to count. So we're all becoming more and more tolerant of various ways to communicate and I think that is something that works in our favor from the point of view of advocating for people with communication disabilities. This helps those suffering from aphasia be accepted and less stigmatized in the community and it also allows for the community to more readily understand the different ways of communicating with them. So there *are* some trends and forces in our favor. But, on the other hand, we have a long way to go in terms of people truly understanding aphasia.

What do you think are some of the most important considerations today for raising awareness about aphasia?

Well, I've been thinking about this a lot because here in the Tampa Bay area we are trying to go out at least once a year and use a survey regarding awareness of aphasia. The surveys results show that, on average, ten percent of people in the general population recognize or have some basic understanding of the word "aphasia". We do find that if you're attending something like a health fair, for example, you can get at least twice - maybe three times - as many people who know the term.

We need to ask ourselves what we really mean by "aphasia awareness". What are we really trying to accomplish? I know that it is important, especially to many people with aphasia, that other people know the word for their condition. But I think that the real thing is not that they know the word, but that they understand that speech and language can be separated from



mental competence or from thought and memory. People suffering from aphasia want others to know the term because they want people to know that, even if they have trouble speaking, it doesn't mean that they are stupid or that something is wrong with their thinking. Our main challenge is understanding what we want the general public to know about aphasia and what we want them to do with that understanding.

I've been very compelled by this view of yours - that merely raising awareness about aphasia doesn't move the needle much and that we, as advocates, have to demand more than simply having people know the term. Can you share more about that idea with our listeners?

Absolutely. I did a little looking around in the health information literature and if we're going to talk about evidence-based practices, it turns out that the best practice for raising awareness of any health condition involves linking an *action* to it. So, I think the twist in any kind of aphasia awareness activity or a campaign is that we have to ask ourselves: "What do we actually want these people to do with this knowledge of aphasia?". We need to link any activities or campaigns with either a specific communication behavior or some other action. Maybe you are telling people about the issue because you want them to help you raise money for your cause. We had a great example earlier this year with the National Aphasia Association. Their Aphasia Awareness Month poster featured very specific actions that people could take and I think that is something we need to really focus on as we continue developing activities and campaigns.

In our conversation you touched on the concept of aphasia-friendly communication and strategies. If you look down the road a bit, how do you think we can expand this important conversation about being more aphasia friendly?

If we want people to take action, then we need to talk about making our communities aphasia friendly. Here in St. Petersburg Florida, we have sensory-friendly movies and dementia-friendly museum outings. On one hand, that is fantastic! On the other hand, we may be losing a little power that we would gain if we weren't in these particular silos. I think that some of the ways that you might make a museum accessible to someone with *dementia* might be similar to how you might make it accessible to someone with *aphasia*. Now, we don't want to blur the lines because that reinforces the idea that people with aphasia may have difficulty with memory or thinking. We definitely don't want to do that. But, on the other hand, when you think about it from the point of view of the museum's Director of Community Affairs, there's probably not as big of a difference as it seems like there is to those of us who are speech pathologists. We don't have a solution here *yet* and I'm not exactly sure how to do this, but I think it's worth exploring and bringing together some sort of communication-friendly community which which would also help those with language differences.



Within your larger community, what have been some challenges that you have experienced in trying to promote services for your aphasia program?

I think the first challenge for us was really figuring out *who* we are trying to target and what actions we want them to take. Our community-based programs are usually designed to reach people beyond the point of typical therapy. Therefore, we might be able to connect with these individuals through the medical system. So, while we can target these individuals' speech pathologists and social service workers, we also need to reach out to those individuals out in the community who are not currently connected to these recourses. Primary care physicians are a great place to start. Methods like TV and print, while good, are often less helpful because it now takes between 10 and 20 exposures to an advertisement for someone to take action. A couple of decades ago, it only took three exposures. That number has increased dramatically because we are inundated with information from so many sources.

One program that we've started here that has been very successful is a two-day workshop called "*I have Aphasia, Now What?*" We ask hospitals, rehabilitation facilities, and retirement communities to host these wonderful events. This has provided an opportunity for social workers and therapists to come down and discover how we can help their clients reintegrate back into the community. It's really a great service to hospitals that provide both community-based connections and family-based education. The hospitals let us come in and help them extend services to their patients - we really serve as a bridge between the two. So that's something that was not designed as a marketing activity originally, but is probably one of the best marketing efforts that we're doing right now.

You've given us so much to think about. Is there anything else we haven't covered yet?

[Voices of Hope for Aphasia](#) is an organization that is bootstrapping its way along. However, there are *many* creative ways to get by without grants. Holding our meetings in the senior center has been a great marketing tool for us. Suddenly, we knew all the other organizations that were in there and all the other folks in the senior center. Then, the City of St. Petersburg started to know us and started to refer to us. So, it's good to keep an eye out for simple things that you can do that expand your programs.