



### Show Notes

#### Episode #5 – Insights and "Aha!" Moments About Aphasia Care with Professor Emeriti Barbara Shadden

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Today, Dr. Katie Strong (Central Michigan University) speaks with Dr. Barbara Shadden. She is a Professor Emerita in Communication Disorders and Co-Director of the Office for Studies on Aging at the University of Arkansas.

In today's episode, you will learn:

- How to define identity and understand the impact it has on aphasia
- 4 Tips that support the emotional and physical health of client caregivers
- 3 ways to help make your aphasia therapy more identity friendly

#### Dr. Katie Strong

***Aphasia Access is committed to making the Life Participation Approach to Aphasia move from theory to practice. I'm going to take a quote from a 2004 article you published with Joseph Agan as I think it's a great kick off for this discussion. Specifically, you said that "when people with aphasia are moved out of the therapy room and into engagement with life, identity takes on an overriding significance." What do you mean by identity?***

#### Dr. Barbara Shadden

The concept of identity is deceptively simple. It's made up of many different elements which come together to explain me – Barbara Shadden, or you, Katie Strong. We may not be able to define precisely what we mean when we talk about our identity, but we seem to know what it is and how it feels. One of the advantages of the word "identity" is that it's a kind of shorthand for a very complex set of ideas and it's a term, along with the word "self", that we all use daily. For example, we say things like: "That wasn't like me at all" or "I'm just not myself today". We even talk about identity crises, something most of us have experienced. While there is a lot of powerful theory about identity and self, today – I'm going to be practical and say that "identity" refers to that same deep sense we each feel about who we are, where we've been, and where we are going in our lives. So, identity is tied to the life story. Our identities evolve as we move

through life stages and having a grounded and coherent sense of self is crucial to anyone's quality of life - or, as we are fond of saying in our clinical work, psychosocial well-being.

***That makes sense and certainly is something we can all relate to.***

Right. When our identity is challenged or threatened, the impact is profound. Sometimes we can describe our identity in words – the facts of our lives (our biography), the roles we play, who we are in relationships and interactions, and where we fit in the broader community and culture. So I'm an SLP, a woman, have several deep friendships, am part of a stroke support group community. Talking about roles often seems easiest –that's usually what we turn to when someone says..."tell me about you." And, in fact, we often talk about how roles may be diminished or lost because of stroke and aphasia – the teacher who can no longer teach, the public relations firm exec who can no longer pitch his case. But for someone with aphasia, identity challenges come from many more directions – some aspects of biography may remain stable (except the body itself may change), but relationships and interactions are at considerable risk, as of course is a person's role in society and how others view them. Certainly the social reintegration emphasized by the life participation approach speaks to these social challenges. I actually believe that every client with an acquired communication disorder is an individual who may be facing identity challenges.

***Could you talk a little more about that?***

I've already said that identity isn't static - it's constantly evolving. It's altered by circumstance, through relationships, by life events (such as stroke) and the passage of time. We all want a stable, secure sense of who we are but we're all vulnerable to life change.

What's most important is to understand is that identity is socially constructed - it doesn't just "happen" to us and we can't do it alone. In every interaction we engage in a process of negotiating, building, sustaining, and modifying who we believe we are. We make choices (conscious or unconscious) about how we present ourselves, and we show selected aspects of who we believe we are to other people. They in turn respond with acceptance, or rejection, or even confusion. Our sense of who we are changes as others respond. We need people and groups and society to recognize and validate us and our evolving life story.

But here's the 'kicker' -- communication is at the heart of this 'identity work' – it's the tool we all use. We make choices of wording, topic, or through organization of our discourse. We tell pieces of our life story that define us. These stories are the building blocks not only for communicating what we want or need, but more fundamentally, these narratives help convey who we are, or believe ourselves to be to others. And of course it is language – this communication tool – that is damaged by aphasia.

***What do you see happening to someone with aphasia?***

Well, if we start with the big picture, in many cases it begins with a stroke – a medical crisis that challenges our sense of who we are almost immediately. One minute the person is competent and active and the next minute, he can't do everyday things and has been given the new identity "patient" or "sick person." The perceptions that go along with that "sick" identity are things like being weak, passive, or damaged. Within this medical model, the power is in the hands of others and we have little or no voice. Becoming a patient - e.g., the L CVA in 424 Bed A - is extremely hard on identity. I'm sure many people have had a taste of that experience.

***That is so true. Especially in the context of medical settings, we depersonalize our work and often think of cases and diagnoses versus people and who they were before this crisis occurred.***

So what happens next? Well, there's a rich literature about the need to reclaim our lives through the telling of our stories – our illness narratives – as a way of coping with major health challenges. These stories clarify what has happened and how the health crisis may have created a bit of a narrative wreckage in our life story. A successful illness narrative makes sense of this disruption in the flow of our lives and lets us move forward after having integrated illness into our lives. Some call this idea "biographical accommodation". The shared story can also bring us a new community of people that can uniquely validate who we are becoming - you see that in the community of breast cancer survivors. But here's the additional challenge facing those with aphasia: Yes, as I keep saying, the communication tool we need to renegotiate who we are and our stories is damaged. And partly because of that impaired communication, others treat us differently, see us differently, so what is reflected back at us is not the identity we believe is who we are. And I wonder if we as SLPs reflect deeply enough on this reality.

***You sound rather passionate about this.***

I am. This has become a part of my story and my identity since my husband had a stroke and developed aphasia back in 1997. I saw firsthand the impact of aphasia on the core of a person. Harry's initial visceral reaction to being ill and impaired was to fight against it and then, when that failed, to sort of disappear in delirium. When he came home after 3 long months, he was able to get around and care for his basic needs. Lucky him, right? At this stage, relationships are crucial to the well-being of the PWA (Person With Aphasia). Harry wasn't supposed to drive, and his aphasia was a major barrier to communication – both receptively and expressively. For a person who spent many hours of his life regaling others with stories and anecdotes, and who was typically the center of attention, these restrictions were devastating. Harry was eager to tell his story – his version of his illness narrative – but others struggled to understand him and were uncomfortable and distressed by the changes they could see. This is a common experience underscoring how difficult, if not impossible, it can be to pick up old patterns of interacting – those patterns that were originally so validating. The more trouble Harry had making people understand his life, the more angry he became.

Harry once said the most insightful thing, *“When I’m alone, I don’t have aphasia.”* In other words, he could sort of frame a sense of who he was – his identity – as long as he didn’t have to talk with others, or to deal with other people who didn’t understand him and/or saw him as impaired or different. When he was alone, Harry didn’t have to deal with people who didn’t accept or validate his life changes. Yet he was determined to be recognized for who he was before stroke, making it difficult to integrate his past, present and future into the life story.

So, returning to your original question about the significance of identity outside of the therapy room, what I was trying to say is that it’s in those moments of interaction with others that identity work is done. Improved skills are great, and getting people involved in life activities is crucial, but it is not just about the *doing* but rather the quality of the participation and the engagement that matters. As we know, the world outside of the therapy room doesn’t understand identity issues or support the telling of stories of those with aphasia. Instead, it is all too easy to judge a person based on outward appearance or impairment. I hope that we never delude ourselves into thinking that TX goals that target needs and wants are enough for true quality of life and life participation.

***Yes, we really need to find ways to support wants and needs that are obvious in a therapy setting to bigger picture goals. We also need to balance that with focusing on how we can support people with aphasia to engage in their lives in meaningful ways.***

Exactly. We have to remember that aphasia has many costs, apart from the primary loss of language. Bottom line: It threatens our sense of who we are and how others see us, while simultaneously damaging the tool we need to move forward with a revised self/identity.

***Barbara, it seems like whenever I’m reading about identity as it relates to aphasia, one of the primary sources cited is your 2005 Aphasiology article entitled ‘Aphasia as identity theft: Theory and practice.’ What was the inspiration for this article and how did you get interested in thinking about identity as it relates to aphasia?***

It is related, in part, to our mutual personal experiences with aphasia – the talk that led to the article you mention was also titled “Lessons Learned the Hard Way”. Having said that, the path to ideas of identity wasn’t that simple. I’ve always been fascinated by how some adults with aphasia seem to move forward with their lives, while others struggle greatly, in ways not explained solely by severity of language impairment.

Thirty-four years ago I had a client who was deeply depressed about her life with aphasia despite a very mild language impairment and a supportive family. One day I mentioned something about another client with aphasia and she stopped me and said, “Do you mean there are other people out there who have what I have? I’ve been feeling like I was so alone!” She was truly angry! And I was honestly stunned. You have to remember this was before the information explosion on the internet. This was my first “Aha!” moment. My client felt aphasia had destroyed her life and no one really understood. After listening to her and visiting with other

clients, we founded the Northwest Arkansas Stroke Support Group which is still in existence today. Because of this client, our group has always focused on the sharing of stories with each other and on supporting social community. The “Aha!” moment had to do with the deep need to be understood, accepted and validated by others.

After my husband’s stroke I didn’t just live the experience and suddenly understand it! We both felt pretty empowered by our knowledge of aphasia when it first happened. Harry had actually helped me facilitate the support group on occasion, so I knew we could handle this. Then time passed and the aphasia was still there and all the education and information didn’t seem to make life better enough. And I kept asking myself, “Why can’t you practice what you preach? Why do you feel your life is so profoundly disrupted?” And I even asked “Why can’t Harry just move on?”

And, of course, I didn’t have an answer. As we struggled through this personally, I was also trying, rather unsuccessfully, to write professionally about this experience of living with aphasia. I just couldn’t find the vocabulary that captured what I wanted to share. I read about psychosocial changes and loss. I *did* feel like I lost something but it was more like something was abruptly taken away from me. So it was more than loss - it was about rediscovering a center of gravity, for each of us, and moving forward. Then, Roberta Elman introduced an element of time pressure when she invited me to provide a keynote address at the 2004 Clinical Aphasiology Conference. I read even more widely and began to see how this idea of our socially co-constructed identity really captured the bigger picture of what I had learned and experienced with aphasia. It shed light on the unique experiences of my clients and it also explained what my husband and I were going through. Life was 24/7 about Harry’s stroke and aphasia. It was about his need to be recognized as who he used to be, to try and get back what he had lost. And, it was also about my attempts to support him which meant giving up my own identity in many social interactions. Finally, at that point, the “Aha!” about identity became clear.

I confess that using the term “identity theft” initially was the product of an internet search for some clipart on identity, self, and loss. I typed that in and, magically, a cluster of clever images for “identity theft” popped up and my “Aha!” moment became locked in stone — all thanks to Google Image! What really worked is that the idea of “theft” captured the sense of being violated, of an active assault on one’s identity – better than the term loss. The human imperative is to move on, to not remain a victim. We have an obligation, as SLPs, to do a better job of seeing what each client feels has been taken from her.

***When reading or talking about identity, the term “renegotiation” seems to come up frequently. Could you help us understand what that means?***

Such a great question. I love that term because it expresses how I now see identity - as being constructed and revised in collaboration with others. In essence, it’s a work in progress. Dictionary definitions suggest that the word *negotiation* involves conferring with others in order to come to terms or reach an agreement. They also suggest that *renegotiation* speaks to the

process of revising that agreement or contract. Translated for our purposes, renegotiation of identity implies there is a kind of social contract involved in the ongoing work of sustaining our sense of who we are. We don't do it alone. As we share, as we communicate these bits and pieces of our changing life story with others, we look for them to accept and validate what we have shared.

The reason we don't focus solely on "negotiation" of identities is that people with aphasia have already created rich identities and a place within society. It is those preexisting elements of identity that have to be revisited and revised; hence the term *renegotiation*. For persons with aphasia, as Harry found, some people are no longer responding to them in the ways that they did in the past. Sadly, society doesn't always accept the narrative experiences of the PWA.

I should note that renegotiation also applies to caregivers and to loved ones. I became a caregiver at age 49 and my life and sense of who I was changed in so many ways. Unlike Harry, I could communicate, I had tools for sharing a new shared understanding of who I was but it wasn't that simple. When others learned that I was a caregiver, they understood caregiving in ways unique to their own experiences, not mine. So, I too was still renegotiating a shared understanding of who I was in the context of life with aphasia.

Going back to those with aphasia, sometimes they have to rely on others to facilitate renegotiation. My former client Mike is an example of this. He had global aphasia and almost no verbal communication for at least 1½ to 2 years after his stroke. He was very passive and mostly non-communicative socially. His wife, however, refused to give up on the person inside. With everyone, she shared his history which included his experiences as a dive instructor and as a Vietnam veteran. Diving was the single most important element in his identity. So, in treatment we used that information and supportive tools (photo albums, actual diving gear) to help Mike share his experiences. I watched my two students go from focusing on his severe aphasia, to beginning to engage with Mike the person. Of course, Mike himself then became more engaged – excited about communicating, attempting to clarify, showing humor. Yes, there were measurable language outcomes, but mostly, that communication interaction provided ways for him to reclaim his identity so that the fact of his global aphasia became less important than his experiences. Mike has become increasingly more active in sharing his identity with others over the years. In a recent support group meeting, he needed no prompting to share something that had happened recently, using a range of communication tools. Others picked up on his story, on his taking control, and began asking questions, interacting with him (not his wife) as though the aphasia wasn't a problem. When his wife attempted to add some incorrect information, he stopped and challenged her.

For me, those are amazing moments because they mean the person with aphasia has regained some mastery of his own socially-constructed identity.

***Thank you for sharing that example about Mike and his expertise and identity as a scuba diver. That story allows us to see how, as clinicians, we might be able to really embrace both client interest and their identities – who they see themselves as.***

***I'd like to ask you about one vivid statement from that 2005 article. You wrote that "Aphasia creeps in like a thief in the night, stealing the carefully constructed identities of all of those affected." This implies that changes in identity aren't just for the person with aphasia but also happen to significant others. Could you talk more about that?***

Clearly, one of the advantages of talking about identity is that it also helps us talk about significant others, like myself. That's why the phrase "living with aphasia" is so important - the challenges of the person with aphasia are interconnected with those close to him or her. As one wife told me, her husband's identity changes changed her identity.

***Yes, it really is bigger than only the person who has aphasia isn't it?***

Absolutely. We don't have time to do it justice right now, but as SLPs, when we look at a significant other, we often think of that person's role in treatment. We rely on those closest to the person with aphasia to provide us with information, support communication, and take therapy out of the clinic, particularly communication strategies. But when it comes to the impact of aphasia on the same loved ones, we tend to think a bit simplistically about their experiences. We may talk about depression or fatigue or caregiver strain, but we don't often delve deeper into the impact on the significant other's sense of self.

As you've gathered, my sense of who I was changed after my husband's stroke and aphasia. There were times I felt I was losing my way after years of trying to facilitate his efforts to reclaim his identity. His unique aphasia and his way of coping with it crept into almost every corner of my life because I hadn't yet understood what was happening to either of us and why. There is a kind of helplessness as you find that your behaviors and feelings are totally inconsistent with the person you thought you were.

What we have to remember is that each caregiver is unique and no set of psychosocial terms captures that uniqueness. Even the term caregiver is tricky. We need to listen to their words. Some people might be interested in reading an interview I did with Elizabeth McIntyre about her experiences as the wife of Carl McIntyre, star and subject of [Aphasia the Movie](#). The interview is on the [Aphasia Corner blog](#). I asked her what the movie would look like if it were about her. She immediately brought up a number of identity issues - changes in roles, relationships, social engagement. She also wrote about the loneliness of living with aphasia and went on to talk about how all the chit chat, the small talk was gone from their lives – the "how was your day" questions and funny anecdotes had disappeared. Later, she said:

*I remember driving one day and I saw a couple walking down the sidewalk talking, and I thought WOW, I wonder if they know how lucky they are that they can share their*

*thoughts and feelings with each other. Carl and I talked all the time [before the stroke].  
Then out of nowhere it is all quiet, no more conversations.*

I am so struck by the importance of these little validating moments that occur throughout the day and how their absence leaves a wrenching hole. It's not that people go around having profound conversations about their identities. But it is sometimes in the small exchanges that we feel most accepted and known by a loved one.

***Barbara, you have challenged clinicians to be better custodians of the emotional and physical health of their client's caregivers. That seems like a really tall order. Could you give us some tips on how we might do this?***

Well, that is a tall order, but there are simple places to begin.

I think we need to recognize that we are, by training and instinct, advocates for our clients. We often support, and even defend, our clients' needs for recognition as well as opportunities for communication and participation over and above the needs of others. There's nothing wrong with that; that's part of the needed identity work. But we could be a bit more sensitive to the perspectives and the challenges that significant others face as well.

In the best of all possible worlds, we could reserve time at each session for taking the pulse of the SO. We need to build relationships of trust with them, as well as with the person with aphasia. It may be helpful to acknowledge more than once that living with aphasia can be difficult for everybody - that is not the same as taking sides!

We might think about the questions we ask. The most obvious questions are about the significant other's well-being. Many family members have almost no one they can talk to about how they are feeling. They may have concerns about how others might judge some of what they're feeling. We may be the one who can offer validation and recognition that some emotions are understandable and common and to validate or affirm their changing sense of who they are.

Questions about daily life and how it's changed can be important from the perspective of the significant other's world. Just ask them what a typical day is like? Also, asking what the person misses the most, particularly in the context of chronic aphasia, is another way to tap into life change. You may learn more with this one simple question than with a whole interview. Obviously, this is a sensitive area and it can only be probed if you have a solid relationship with the significant other.

One spouse told me she missed reading the paper together over a cup of coffee in the morning. This was the time she had felt most content in her life and most grounded. Her husband's aphasia made it almost impossible to continue this shared time and left her feeling like their relationship was radically altered, even though it sounds like such a small thing. Another spouse told me that she never realized before how dependent she was on her husband's positive

encouragement and compliments, since she was a very insecure person. Her husband had given her self-confidence and a sense of self-worth. Now, with his aphasia, his daily validation was gone and she felt lost.

Another thing to remember is that, in a therapy session, we can focus all of our effort and attention on communicating with our client, but it's not as easy for the significant other if we ask them to follow through at home. Before we get frustrated with what may not have been done, it's important to understand why. Reasons might include: 1) not enough hours in the day; 2) client resistance to the family member becoming the therapist; and 3) the difficulty of overcoming a history of good and bad communication patterns and personal issues when asked to implement supportive communication strategies.

As a final thought, we need to remember that significant others often become quite isolated, even in social activities. Spouses may feel responsible for helping the people with aphasia to communicate with others, and this can be exhausting. Some don't believe they can or should talk about themselves or their issues because the person with aphasia needs the social validation and the focus. Helping find a community of peers can be as important for significant others as it is for people with aphasia. In the best of all worlds, there would be aphasia centers accessible to everybody.

***Really great tips! You mentioned earlier about wanting to talk about support groups. Could you tell us more about the role and importance of a community of peers, for both persons with aphasia and for significant others?***

For some people, support groups, and perhaps more basically groups, are among the most important pieces of the puzzle that we call living successfully with chronic aphasia. They provide opportunities for identity work, particularly for those living with aphasia long after the initial medical crisis. This is the time when most other services fall by the wayside and we have the greatest needs in managing the chronicity of aphasia. In fact, it is usually over time that the sense of loss and diminished sense of self emerge. Support groups are low cost, relatively low maintenance, and that makes them feasible for SLPs. One spouse, Marie, wrote in a local newspaper that:

*It was our first visit to a stroke support group that gave the hope and help we needed. Here were people who understood, not only his physical limitations, but his emotional needs. They allowed him to talk, to tell his story. They listened and verified everything he was feeling. The group gave us literature and information. But when we would go into our separate groups (spouse vs stroke survivor), my small group of women encouraged me to talk. How do you feel? What are you going through? I was no longer alone or had to feel isolated and keep my thoughts and feelings to myself. Talk. Talk. Get it out. They understood because they'd gone through it before me.*

Her last comments underscore a guiding principle and practice in our group. We provide time for the whole group to meet and share, then there's breakout time for the stroke survivors and for the family members. I think some of the most important moments of validation of identity comes from these breakout times.

Marie's comments highlight a few ways in which support groups can provide a foundation for the journey forward living with aphasia.

**People in support groups find acceptance, validation and recognition for who they are.** I keep repeating this because it is so important. Each person's story and identity are valued and respected, plus the community also lets people reframe their private stories within the large community narrative (e.g., all people living with aphasia) in order to explore what the new life story feels like.

**Just being a part of a social community with the shared story and shared identity of stroke and aphasia has a powerful impact.** In essence, you automatically belong to this group because of your life experience. Rather than feeling alone, you are instantly, if you wish, a "member" in a situation where your unique story fits in.

**Support groups reject the narrative that disability means marginalization.** In most cultures, there is a narrative of disability which marginalizes those who are different. Support groups reject this narrative, in part, and substitute narratives of growth, improvement, and participation. This supports a transition from helplessness to feelings of empowerment.

***There are so many challenges that clinicians are faced with as the direction of healthcare is changing. SLPs are struggling to provide high-quality outcomes and evidence-based therapy. Could you share a few tips on how clinicians can make therapy more identity-friendly?***

In a practical sense, therapy becomes more identity-friendly when it elicits and uses aspects of the client's life - their biography, roles and relationships, or social activities - essentially, any kind of personalized content. We all know this! Support for treatment may involve what I call life artifacts (photographs, memorabilia, etc.). One of my favorites was when someone brought in an antique lawn mower, and of course, when Mike brought in his scuba gear. Communication becomes "real". Having the facts and the artifacts made it possible to learn what matters to a client about his or her life. I think part of our early assessment should involve probes of the person's most significant parts of life history, likes/dislikes, hot-button topics, etc. This is information that goes beyond names just the names of children, previous jobs, and stuff like that.

Any kind of personal narrative supports identity - whether it's a brief story about what happened yesterday or, more broadly, important chapters in our life story. As mentioned, it can be challenging for some people with aphasia to share the little things that are part of who they are,

so they often give up. Yet these little things, and our reactions to them, truly capture our uniqueness as people.

We also need to see more interventions working purposefully with the actual life story, because this is fundamentally about identity and that involves communication at every step. I'm thrilled that there are now clinicians and researchers who are exploring what works and what the impact is. Certainly your work, Katie, with the My Story Project is a perfect example of what's needed. I've run what I call "Life Stories" groups – where clinicians and clients share aspects of their lives after having time to prepare and bring specific life artifacts to help them communicate. Many things can emerge in the fun of talking about "life's firsts" or "favorites". Suddenly, we really feel like we know the person and they get to know us as individuals. This process creates a more natural social interaction.

Also, conversation groups provide a rich opportunity for identity work, as Simmons-Mackie and Elman (2011) have discussed. Their study is really a brilliant example of how one can target goals for both communication and positive identity. The group facilitator used group interactions to address both a personal and a group sense of identity by targeting identity-enhancing discourse. Their article highlights some of the points I've raised today: the importance of group membership, group support, markers of group identity, treating members as competent, and of providing respect. Their work establishes that outcomes are possible in the more traditional domain of communication as well as in the domain of positive identity support and renegotiation. In essence, any intervention that taps into the power of social communities (like groups) and/or the importance of sharing parts of one's life story supports identity work. While some of these interventions may not be reimbursable, these groups provide quite a "big bang for the buck".

***Any final thoughts you'd like to share with us?***

Perhaps I can simply urge SLPs to reflect on the concept of aphasia as challenging identity, at its very core. If we really believe this, we can better support our clients *and* their loved ones. After all, we talk about person-centered interventions all the time. So what do we mean when we say "person"? Presumably, that is a unique human being distinguished from others by the complex elements that make up his or her identity. We can do a better job of "seeing" and "knowing" the person, not just his or her wants and needs.

Beyond that, of course, we all need to set our sights on the target of life participation — which I believe requires us to consider identity. The LPAA framework opens the door. It's up to us to take it forward through organizations such as Aphasia Access and through our own direct clinical work.

Barbara, this has been fantastic. Thank you so much for sharing your "Aha!" moments and expertise on identity and aphasia. You've certainly given us a lot to consider as we continue our work supporting living successfully with aphasia.