INside the OUTcomes: A Rehabilitation Research Podcast

Episode 25: Improving Customer Service for People with Communication Disabilities
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On this episode of [INside, the OUTcomes](https://www.sralab.org/research/labs/cror/projects/inside-outcomes-rehabilitation-research-podcast), I'll be speaking with [Elissa Larkin](https://www.sralab.org/researchers/elissa-larkin-ms-ccc-slp-hec-c), a bioethicist and research speech language pathologist in the [Center for Aphasia Research & Treatment](https://www.sralab.org/research/labs/center-aphasia-research-treatment) at Shirley Ryan AbilityLab. Elissa works on a study that aims to improve the customer experience for people with communication disabilities by offering a unique online training for workers in the retail and service industries. Welcome to the podcast, Elissa.

ELISSA LARKIN:

Thank you so much, Sharon. It's wonderful to be here.

SHARON:

Okay, so let's first talk about communication disabilities. What are some of the features of a communication disability and what are some types of specific communication diagnoses or presentations that you see?

ELISSA:

What a great question to start on. So communication disabilities come in many different forms. People can be born with a diagnosis that impacts their communication, or they might develop them later in life. And it can impact things like someone's speech, how clear it is, their voice, as well as their thinking process and their language. And so you can imagine there could be many different permutations and combinations when people have changes in any of those areas.

In this project that we're going to talk about today, we partnered with people with four different kinds of communication disabilities to learn more about their experiences. And we worked with people who were stroke survivors who have aphasia. So a stroke is an interruption of blood flow to parts of the brain and people who have aphasia. The blood flow is interrupted to the language networks and areas in the brain, typically in the left side or left hemisphere. And so these are people who know what they want to say but might have trouble getting it out in their talking or writing, or they might have trouble getting information in understanding it, auditory or reading, but they know what they're thinking. And so that's one group that worked with us.

We also talked with people who have had brain injuries that impacted their speech and voice and also some of them their thinking skills, how they kind of put their thoughts together. We spoke with people who have cerebral palsy, which is a condition they were born with. So they've lived with their communication disability all their lives. And then people with Parkinson's disease, which is a neurodegenerative diagnosis, so people experience changes in their brain and mobility over time that progresses. All of these people, I should say, are adults we talked to for this research study, and they really shared a variety of types of experiences and thoughts about what could make things better.

SHARON:

And we're talking here about when people are out and about running errands, going to the store, that kind of thing. So the research project is focused on providing training to people who work in the retail industry and service industry on how to best serve people with language disabilities.

ELISSA:

This project is trying to address that group in particular because there has been other work done on this kind of education to raise awareness about what a communication disability is. I tried to give you a bit of an elevator pitch, but you probably got a sense even just from that, that it can be really variable. And so in addition to that, a lot of people don't necessarily get education about what a communication disability is. So they might have a customer come in who has a communication difference and they might make incorrect assumptions, you know, because someone isn't able to get their thoughts out with their words. If they have never heard of something like aphasia, then they might think that person doesn't know what they want to say, not understanding that they absolutely do, but they're just having trouble getting it across. And as you can imagine, if somebody is making an incorrect assumption about their customer that impacts how they're going to interact with them, how they're going to serve them. And it absolutely impacts the experience of the customer feeling misunderstood or underestimated or ultimately not getting what they need or want from that business.

We in the Aphasia Center have known and worked with people in the community who have aphasia, typically after a stroke, as well as people with other kinds of communication disabilities, as I mentioned. And, you know, that's been a real privilege. And also people have generously shared their perspectives and experiences.

Unfortunately, lack of awareness is pretty widespread. And so the Aphasia Center has a number of different projects trying to raise awareness and then also do something about it. The really nice thing, helpful thing in our Center is that we also have a number of people who are trained in evidence-based methods to provide this kind of education about what communication disabilities are and how to accommodate the communication needs of someone who has a communication disability. And it's kind of a special type of education that, again, not as many people are trained in and not many people receive this kind of education.

We talk a lot about the fact that many of us, I think, thanks to the Americans with Disabilities Act and a lot of the advocacy of people with disabilities who are living with disability, we've grown in our awareness of physical disabilities and the societal collective responsibility to provide physical accommodations for people who need them. But I think often because a communication disability might not be obvious, we might not be able to just see it. There's just not that same kind of awareness. And I think there's a lot more work to be done to raise awareness and teach people how to provide, how to accommodate communication needs.

SHARON:

So you've described the idea that with the Americans with Disabilities Act, we see the implementation mostly in the physical environment. But there is a whole communication environment that may not be so obvious, like you said. So can you provide an example of what an obstacle might be that someone with a communication disability might face when they're just out in the community, running errands, shopping, doing their thing?

ELISSA:

Yeah. Actually, that brings to mind a particular example that one of our community members shared, where she had a number of errands to run in her day. So she needed to go to a bookstore, a pharmacy, a gift shop and all of that before meeting her best friend for dinner that evening. And this person has cerebral palsy and a communication disability where it really impacts how her voice and speech sound and can make it difficult for people to understand. Maybe the first time she might have to repeat or a phrase. And she also uses an augmentative communication device. So like a speech generating a computer where she can type things in and it can say messages for her if people don't understand her speech.

And so, a really striking part of how she told us this story and she gave us permission to share this is that, you know, she doesn't always know how people are going to respond to her. If they have difficulty understanding. She might have to repeat herself multiple times, multiple ways to be understood. And she doesn't always know what kind of attitude she'll encounter or, you know, how willing a person will be to sort of work with her.

So she said in the past when she went to that bookstore, the employee there kind of ignored her. And she said that when she goes to that pharmacy, she often has to take a lot of time to communicate just one idea in multiple ways, because the pharmacist is often really pressed for time and often doesn't understand the first time, or they may not be like looking and really concentrating on her as they're listening. And often in the book store or the gift store, she said, there's a clerk there who often kind of talks down to her even though she has a master's degree. But these are the places in her neighborhood that are most convenient for her to go. So these are the places she's going to go to despite those experiences. But would she like it to be better? Absolutely.

The other piece of her story that I think was so striking is that she budgets a lot of time for these errands because she doesn't know who she's going to encounter or how the interaction will go. So for myself, I think about if I'm doing multiple things, like if I'm trying to pack in three different errands like that before heading to a restaurant, for example, I might give myself, I don't know, maybe a couple of hours, right. She told us that she budgeted five hours to do these simple errands, in part because she just didn't know how the interaction would go. So I think that says so much about not only how it can feel in these interactions when they're not going well, but also the real cost in terms of someone's time.

SHARON:

So you mentioned that there is a significant time cost that might be associated with running typical errands for someone who has a communication disability. But there's also a cost to companies that fail to provide service to people with communication disabilities. Can you talk a little bit about that?

ELISSA:

There are an estimated 33 million people living with communication disabilities in the US currently. So that's a lot of potential customers from a business standpoint. And according to Nielsen research, consumers with disabilities in general represent a $1 billion market segment. And when you include their families, friends and associates, that total expands to more than $1 trillion. So you're right, from a customer base standpoint, certainly it seems like it would be of interest to businesses to learn how to accommodate the needs of those customers and those many customers and keep them happily coming back to their establishment.

SHARON:

Well, that leads me right back to this project that you are a part of. I know that it's funded by the National Institute on Disability, Independent Living and Rehabilitation Research. So can you tell us a little bit more about the research project itself?

ELISSA:

Yes. This is a multi-phase study and we're in a second phase currently. So the first phase was we held focus groups with community members with those four different types of disabilities, stroke related aphasia, cerebral palsy, brain injury and Parkinson's disease to understand their experiences. And we also talked with members of the business community to understand their side of things. And we took that input in addition to our experience as educators in this area and put it all together into an online training that has these microlearning modules.

The businesses made it clear that it needed to be sort of quick, very accessible and engaging. And so we took the lived experience, expertise and put that into these kind of quick, hopefully easy to understand learning modules. And most of them also include videos that people with communication disabilities from the community actually acted in.

So we developed scenarios like many of those that they shared with us that they had experienced and then acted them out with them in kind of a, you know, what not to do and what to do, how much better it can go when you accommodate someone's communication needs. And that process was so meaningful and we got ongoing input from them just creating those videos. And I think watching them back to it's just it's really powerful. You feel it right away. The difference that accommodations, communication accommodations make and the phase that we're in now.

The second phase is actually the recruitment and launch phase. So this is a really exciting time to be doing this interview because this is when we're starting to reach out to businesses and community members to get folks enrolled. And so one other part I think that's really unique about this study design is that we are asking community members with just communication disabilities to identify businesses they think would benefit from a training like this where they go and they've had maybe less than optimal experiences and they're going to help us reach out to these businesses. I talked to some of the other day and I was just starting to describe the study and before I could even get halfway through, he said, please come with me to my any named grocery store pharmacy and this local pizza place that he really likes.

And so, you know, we're really hoping that it will feel empowering to the community members to be identifying these places and offering this training and that the businesses will feel also, you know, interested and hopefully enthusiastic about getting this training for their employees. We're offering it for free because it is a research study.

We have two different sort of tracks of training and so people will be randomly assigned to one or the other. And then we will sort of look at outcomes. So the training itself is meant to take each employee about 20 to 30 minutes total. They'll complete a short questionnaire beforehand so that we know where they're starting out in terms of their knowledge. And then immediately after the training and one month later and our hope is that we'll be able to see changes both from the training and hopefully after a month of maybe implementing some of what they've learned in their customer interactions.

You know, as I said, we're offering it for free. It is online. Any business that wants to enroll in addition to businesses that community members identify. We're sort of casting a broad net and just sharing this as an opportunity with other business partners. Through Shirley Ryan AbilityLab, we have an amazing business team, a group of businesses who have partnered with our organization for a long time, and especially our vocational rehab team, to advocate and to promote, you know, education, employment opportunities. And so we've also had some interest from some business members of that group, and we're hoping to be able to offer directly to some of their employees as well.

SHARON:

If there's a business that's interested in participating in this kind of training, is there somewhere they can go to learn more about it?

ELISSA:

Absolutely. We have online information on the [Center for Aphasia Research & Treatment website](https://www.sralab.org/research/labs/center-aphasia-research-treatment) on the [Shirley Ryan AbilityLab web page](https://www.sralab.org/clinical-trials/community-outreach-model-education-and-training-communication-comet-c). And we also have a direct email there that you can contact us with. So multiple ways to reach out to us, and I'll happily share that information for you to link in the notes.

SHARON:

To wrap up, what are some suggestions or tips you would give someone who finds themself in communication with someone who has a communication disability?

ELISSA:

Yes. So the first thing I'll say is something I learned from community members through the course of the focus groups, which is, number one, treat them like any other customer. And if they are attempting to communicate with you, sorry, whether you're an employee like in our trainings or just someone in general, if you're unsure of what to do, ask.

You know, I think we can feel uncomfortable when we think we are supposed to know what to do and we don't. And then it can lead to awkward. Just try whatever you can think of and it can be really respectful to just acknowledge that you're not sure. And I often this comes from the teaching methodology that we use to acknowledge a person's competence even by simply saying, I know you know what you want to say. I'm sorry, I'm not understanding. Can you help me so that we can figure it out together? And hopefully then that person will be able to provide some guidance. Maybe they need you to write something down instead of just saying it. Or you can point to things together. Maybe they can write or use a device, or they might have other strategies too. But I think starting from that place of humility and we talk about communication is a partnership. So just thinking of yourself as a partner and, you know, if you're going to tackle anything with a partner, you're going to try to do that in a collaborative way. So just trust yourself to be sort of doing that team approach and trust the person with the communication disability to guide you.

SHARON:

Well, this has been a super interesting episode. Thank you so much for being on and I will link in the show notes to more information if organizations want to get involved in the study and participate in the training or have their employees participate in the training. So thank you so much. This has been just great.

ELISSA:

Thank you, Sharon. It's been a pleasure and such a wonderful opportunity to get to talk about this project that we're so excited about, and especially at this point where we're launching this next phase. So thank you again for your time today and for this opportunity.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is produced by the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. It's supported by grants from the National Institute on Disability, Independent Living, and Rehabilitation Research. This is Sharon Parmet, your host, signing off.