PRIYA: Hello even and welcome to our 3‑part Webinar series, Tools2Use I improving healthcare outcomes through effective communication.

My name is Priya Penner and I'm with the partnership for inclusive disaster strategies.

INTERPRETER: (speaking in Spanish).

PRIYA: I use she/her pronouns and I'm a brown woman with long curly black hair. I'm going to get us started with accessibility remind and pass it off to Sarah to get us started.

INTERPRETER: (speaking in Spanish).

PRIYA: For this Webinar series we have available Spanish interpretation, American Sign Language interpretation, and CART captioning available in English and Spanish.

And for the first several minutes of this Webinar, you'll note I'll speak in English, and then I will pause for Spanish interpretation.

This method of interpretation allows us to access by provide instructions on how to access the Zoom interpretation feature. Once we provide the instructions the Webinar will then switch to simultaneous interpretation, which means that our interpreters will be interpreted at the same time as our speakers.

INTERPRETER: (speaking in Spanish).

PRIYA: And as I mentioned earlier, we will be using the Zoom interpretation feature, which has already been activated for folks. Accessing the interpretation feature looks different depends on device you're joining us from.

If you're using a computer, you want to click the globe icon on the bottom of your Zoom screen. And if you're joining us on a tablet or a phone, you can click the button tied titled more and a menu pops up and then you want to look for language interpretation.

INTERPRETER: (speaking in Spanish). Priya, I think people can't hear me.

PRIYA: This is Priya. For folks who are trying to access the Spanish interpretation E we're first starting with consecutive interpreting which means you are not hearing the interpretation in the Zoom interpreting channel yet.

INTERPRETER: I think people can't hear me in the main channel either. Is that true?

PRIYA: No because I can hear you.

INTERPRETER: You can hear me, right.

PRIYA: Yes. They might have original audio muted.

INTERPRETER: Okay. Cool.

So, dial that last part again

(speaking in Spanish).

PRIYA: Biento, are you in the English interpretation channel?

INTERPRETER: I think I am. Was I assigned as an interpreter already? I am speaking into the English channel but I don't have app option to speak into the main channel.

PRIYA: Let's keep moving and we will figure this out.

INTERPRETER: Okay.

PRIYA: To listen to the interpreting, and again depending on your device, you want to click the globe icon and then the language interpretation option. And then you want to choose your language channel and if you're using a phone or tablet, you're going to click done.

And if you can't hear the interpreter in your channel, please do let us know as we are in the troubleshooting phase already.

INTERPRETER: (speaking in Spanish).

PRIYA: Now we will start simultaneous interpreting to test interpreting function. Lease let us know if you can't hear the interpretation in the Spanish interpretation language. And please do choose your language channel depending on your preference.

INTERPRETER: (speaking in Spanish).

PRIYA: We have chosen to keep the chat open for folks. But there's do deemed we have a limited capacity to provide interpretation of the comments in chat.

And if you can't access chat, please do let us know via e‑mail at priya@disasterstrategies.org. We do also have CART captioning provided in English and Spanish. Our English CART captioning is provided by Visible Voices, and Spanish CART captioning is provided by ATmarios.

English CART is embedded in Zoom, and you can access those in the CC button at the bottom of your Zoom screen. You'll want to click once to show subtitles in Zoom. You can then edit the font size and text color within the CC button.

And you can access the both English and Spanish CART captions in the external links provided in chat.

Again if shot is not accessible to you, please do let us know via e‑mail.

If chat is not available.

We also have our ASL interpreter spotlighted for folks. If you cannot see our interpreters spotlighted, please do it us know as soon as possible.

You can also adjust the size of the interpreters and speakers from the slides. And you can do that by dragging the divider that separates the slides left or right.

And again let us know if you cannot access any of our language access pieces here today.

And then some general opening reminders for us all. The Webinar is being recorded and an archive of to Des' Webinar as all the Webinars in the series will be available in the following weeks after each Webinar.

You'll also receive the slides used today and a screen reader accessible format so please be on the look out for those archives in English and Spanish in the coming weeks.

Some additional opening reminders. We of course highly encourage questions. We have a couple of spots open for you all to share your questions and comments. Do use the Q&A box for the Q&A feature for any questions. If you can't access the Q&A feature, again, please do I mail those questions to us.

And with that, I'm going to pass it over the to you, Sarah.

SARAH: Thank you, Priya.

And welcome everyone. And welcome to the second Webinar of our series. Thank you so much for coming.

I am Sarah Blackstone. An 80 year‑old female using the pronouns she and her. With white hair.

I have a background in Speech‑Language Pathologist. I'm hard of hearing. And failing retirement obviously.

The logos that you are on the slide represent the 4 collaborating organizations. Ability Central funds our project. The Community Emergency Response Volunteers of the Monterey Peninsula is the project grantee.

The Patient‑Provider Communication website and network was established in 2009 and focuses on the topic we're all here for, Patient‑Provider Communication.

And the partnership for inclusive disaster strategies as you've met Priya already and many others who are helping to produce this Webinar for us. Together we share a strong commitment to improving healthcare outcomes through effective communication.

Next slide, please.

We want to give a big shout out to our funder, Ability Central. It's a nonprofit in Oakland California with a mission to expand communication access for people with disabilities.

Next slide, please.

>>: Call Travis on speaker.

SARAH: Here's a very brief preview of today's Webinar. Improving healthcare outcomes through effective communication, Tools2Use, with a focus on consumers.

The panelists ‑‑ as moderator I'm going to make some introductory comments to set the stage, and then you'll be meeting our panelists. I'm wondering if someone needs to mute.

Thank you.

Susan Coulter is going to share her unique permits as someone who is Deaf. She works at deaf and hard of hearing services in Fresno California.

Next up is Maryjan Fiala, she's the mother of a child with health and communication challenges.

She brings us perspectives as a mom, a professional, and an advocate.

Jessica Gormley returns to update us on this second Webinar about the communication access tools.

Jessica is codirector of the project.

Last up is June, our project director. June will discuss how disabilities impact outcomes and the importance of communication access across healthcare settings.

Ground rules, Priya mentioned, we have a tight schedule. Loss of content. Please put your questions in the Q&A as you have them.

We plan to leave time at the end to respond. Also all the panelists know time is tight and that I have a hook.

(chuckling)

Next slide please.

Next slide.

Thank you.

So I'm going to do a real brief recap of Webinar 1 in case some of you didn't make that, which was focused on providers.

We highlighted providers and stressed the importance of effective communication across settings and systems. We do that in all the Webinars.

We emphasize that all mandated by‑laws and policy, communication access is not always or easily provided or achieved.

In our first Webinar the panelists shared lived experience. Anita talked ant her changing and increasingly complex communication needs as a come who is blind, has difficulty hearing and moving.

She described a trip to the ER after her second stroke. Her tails tales from the trenches laid key ground work for all of us.

Jessica then introduced the project's communication access tool. It's a way to start a conversation about communication access with providers and consumers.

Tammy and Rachel both SLPs, Speech‑Language Pathologists, who work in major hospitals, shared real world descriptions as they strive to solve communication access problems for their patients.

All panelists emphasized that effective communication requires at least 2 people working together to create meaning.

During our discussion in Webinar 1, the participants expressed great frustration and emphasized the importance of getting information about communication access needs in medical records across health settings and keeping it updated over time.

Next slide, please.

So communication is so embedded in all of our lives that we rarely think about how complex it is. In this slide, it shows five circles that overlap.

Each of these circles indicates the kind of barriers that can interfere with communication access in healthcare settings.

The circle at the top is labeled communication disabilities, our focus. We're talking about difficulty hearing, seeing, speaking, learning, remembering, understanding, reading, writing, moving.

Estimates are that over 100 million people in the United States have communication disabilities.

The other 4 circles can easily overlap so that disabilities in many cases will not be the only issue interfering with effective communication.

People may have difficulties understanding or speaking English for, for example.

They may face issues related to cultural, religious, and gender differences.

They may have difficulty understanding, evaluating, and using health information known as limited health literacy. And of course there are many factors related to where services are sought and provide in an office to a hospital, nursing home, hospice and so on.

So the image ill straight that multiple issues can and do determine healthcare outcomes.

Illustrating that what we know and from research is that both providers and consumers face challenges across healthcare settings.

In fact, research suggests that 2/3 of people who live in the United States face some kind of barrier because of communication during a visit, a healthcare visit.

Next slide.

So what do we know? Research and practice confirms that communication access is essential across healthcare settings.

Why? Because it's connected directly to patient outcomes, patient safety, patient satisfaction, costs, and quality of care.

And it's not just patients who want quality of care, of course; it's providers as well.

Also effective communication prevents adverse events, all the bad things that can happen to consumers and to providers that significantly impact healthcare outcomes and costs.

Next slide.

So communication access is essential across healthcare settings. It's the law. And even so, there's many gaps in compliance. We are all here because we know about these gaps and we want to see them go away.

Next slide.

So law and policy does mandate the right to accommodate, to have accommodations that enable people to access services, to access buildings, physical spaces, treatment areas and programs, to access information, services and human and animal supports.

This is not the focus of this Webinar. It's important, however, that we all know about the laws and how to advocate.

In fact, knowing about and doing something about communication access can be life sustaining and life changing.

So next slide.

Our goal for all the Webinars is to increase effective communication across healthcare settings and systems. Today we're going to be introducing stories from the trenches, tools and strategies that consumers can use to provide information about what they need, what they use to communicate, and what they might need, the accommodations they might need during a healthcare visit or stay.

Next slide.

Also we will briefly discuss our plans to develop and organize easily accessible communication access resources on the Patient‑Provider Communication website.

Next slide.

Okay. I'm done. Now it's time to meet and welcome our Webinar panelists.

To access their bios in English and Spanish, you can use the QR code or click on the link you see here.

First up is Susan Coulter. Take it away, Susan.

>>: Next slide.

Hi, good morning.

I'm Susan Coulter. I'm the educational services director with deaf and hard of hearing service center in Fresno California.

Next slide.

I'm sorry. I'm a white woman with blond hair and glasses.

I want to show you how the Patient‑Provider Communication tool can be beneficial to deaf and hard of hearing individuals to ensure that they are provided with the communication mode that promotes effective communication for them.

Understanding that deaf and hard of hearing people and their various communication needs will help meet the goal for the patient to be fully comprehend information and fully participate in their own care.

There's a broad spectrum of people with hearing loss, from those who are hard of hearing, who use hearing aids or cochlear implants, to those who are deaf, deafblind, have deaf plus, and some also have other disabilities. Maybe a developmental disability or mental health issues.

So that means that each person is unique in their communication needs.

Next slide.

What are the communication options in the medical setting? The slides shows a list that I'm reviewing with you.

Lipreading is usually for hard of hearing people with hearing aids or people with cochlear implants.

Deaf people do not normally lipread.

A form of written communication would be an option for patients who have good English language understanding.

But for many deaf individuals, American Sign Language is their first language and English is their second language.

Once we had a client that was writing notes with her doctor and her doctor told her not to take a certain pain medication based on her medical condition. But she misunderstanding stood and she was actually taking that pain medication.

So if she had had a sign language interpreter, she would have been understood.

Next slide.

This slide shows video remote interpreting. Many professionals are now using video remote interpreting, which is ‑‑ can be called VRI for short.

In the photo, you have an ASL interpreter on the monitor screen, and the doctor looking at the monitor, speaking to the interpreter who interprets for the patient. The size of the screen is about 12 × 12.

Next slide.

The next slide you have an American Sign Language interpreter in the room. We call that an in‑person interpreter. The interpreter is standing behind the doctor so that the patient can see both the doctor and the sign language interpreter at the same time.

Normally medical facilities contract with an agency to provide interpreting.

Next slide.

This slide is showing how a patient may want to use a certified deaf interpreter. In the picture they're in the doctor's office, and there the patient's there and the doctor is there. There's an ASL interpreter and a certified deaf interpreter, which is also called a CD I.

They are deaf individuals who are used when the deaf person themselves may not be fluent in American Sign Language. For example, they're deaf but they may also have a developmental disability.

In those cases, the interpreter is able to use gestures, miles, using promise, using drawings, photos, whatever it takes to make sure that the patient understands hearing.

Next slide.

A person who is fully deaf and fully blind, may need someone in the room to provide which is called tactile interpreting. The slide shows hands of two people. One person signing while the oh person's hands are on top of their hands to be able to understand.

Whereas you may also someone addresses deaf with low vision so they will need an interpreter who's close up to them so they can see the signs.

Next slide.

The next few slides I'm going explain about the pros and cons of having video remote interpreting, or VRI.

VRI can be useful in some situations such as if the patient has good American Sign Language skills and can understand the interpreter on the screen.

The medical situation is something that's routine, they go to all the time, dialysis, for example. The patient is in the emergency room where communication is needed immediately. But there are also several challenges with VRI. One is the availability of the equipment. They have to bring the monitor into the room, and there was a situation a few months ago where a patient was in the cardiac Department of the hospital. And they did not have VRI equipment there. And they could not locate one to bring to the patient.

So the patient was not having communication access.

The size of the screen is an issue because it's small and it's difficult to see the interpreter. VRI equipment is used for many different languages, but all the other languages are auditory, so you just have to hear. But with sign language, you have to be able to see the signs.

Depending on the setting, the placement of the screen is not always effective. A few years ago I went with a patient for a physical therapy appointment and the therapist had her lay down on the bed. And the VRI monitor was next to her bed, but not in a position where she could look at it.

So I ended up going around on the other side of the bed and, and I repeated what the interpreter was saying. Because I was in her line of vision.

So if I had not been there, the communication would not have been effective for her.

Okay. Next slide.

Also VRI relies on high speed internet. However, the medical facilities often use a wifi, which is unreliable and the screen often freezes.

The patients are unable to understand the interpreter on the screen because maybe they have a secondary developmental disability. The interpreter themselves may have no medical background information on the client and don't know the client's communication style.

How can deaf person be sure that that interpreter is voicing things correctly based on what they said?

VRI is not appropriate when the patient is in pain or on medication or any other factors that limit their ability to concentrate.

There was a client recently in the ER for addiction withdrawal, and he was also in a lot of pain. He was angry, and he kept pulling the blanket over his head.

And he has supposed to have a psychiatric evaluation. We were waiting for that person to come. And as it turned out, the person was on the monitor with the interpreter. So the monitor is already small and now they're both half the normal size. The client couldn't see or concentrate on that. He was angry. And it was very difficult for him. He just couldn't do it.

So they ended up ‑‑ they decided because he couldn't concentrate that they just wouldn't do it there but if an interpreter had actually been there right next to him and been able to look at that person, that would have been provided more effective communication for him.

Okay.

Next slide.

Now having an ASL interpreter in the room. Okay. I think I have to move real quickly.

They can move around the room for the patient.

They can bring chart if they need to.

We can provide interpreters that are familiar with the client and their medical needs and their situation.

Next slide.

Patients are comfortable and confident when they have someone they're familiar with.

When they're in pain, they express that more than if they have someone on a monitor.

Oh, okay. The availability of an in‑person interpreter could be a problem because they can't be gotten immediately. So there are some pros and cons for both.

So in these various situations as a Patient‑Provider Communication tool, it's an opportunity for the patient and the provider to come to an understanding and agreement about what is needed for effective communication.

Patients will know exactly what they need, can clearly express what works for them through the communication tool.

Other patients do not always know their own needs or what to ask for. Communication tool will help them see the options they have and they can discuss it with their provider. And the providers also learn what all the options are. Many times they're not focused on those needs. They're focused on other things related to cost and time.

So this will allow an opportunity for them to sit with the patient and discuss what the needs are so that they can provide effective communication.

Thank you so much.

>>: This is the slide that didn't get put on, Susan. So you do want to just go back to that just for a second, so that people can see what Susan was referring to there in terms of the tool?

And I know that Maryjan will also be referring to the tool. So we're going to pass it now ‑‑ and thank you, Susan ‑‑ to Maryjan.

>>: My name is Maryjan Fiala, and I am mom to a now 6‑year‑old son who communicates using AAC.

I also wear several other hats which you can read about in my bio. But I want to use my time today to introduce you to my son and to share some of his experiences with you.

Next slide, please.

On the screen you will see my youngest son, Garren. In the first picture on the left you will see a young boy in an orange and white striped polo and blue jeans holding an iPad, standing in front of a three in an urban neighborhood.

And in this second image, you'll see a young boy wearing a blue, gray, and white Calvin Klein hoodie and an oxygen cannula, sitting in a hospital bed also holding an iPad.

Before I go on, I'll also tell you that I am a white woman with medium brown hair in a ponytail wearing glasses.

Back to my son, Garren. He was born 17 weeks early back in August of 2018.

Following his extremely premature birth, he spent more than 18 months inpatient between two hospital systems. He was discharged from the hospital on April Fools Day at the beginning of the COVID‑19 pandemic.

At that time, Garren relied on a ventilator for breathing support, which he received through a tracheostomy tube, also known as a stable airway in the front of his neck.

At about 2 and a half years old, Garren was able to tolerate a speaking valve for short periods of time. And a month before he turned 5, he had the tracheostomy tube permanently removed.

He has been using a speech generating device for more than 3 years. And he is a whiz.

For example, last weekend he shared with me, I want Pete the cat book, please, thank you, help.

With my time today, I want to share a tale of two types of healthcare experiences we've had recently.

The first is what a typical healthcare visit looks like with anyone other than our regular pediatrician.

The majority of specialists and residents during a rare, inpatient admission, fill in pediatricians in our clinic or Urgent Care, our outpatient specialists, almost explicitly talk to was about Garren and his healthcare needs.

They walk in and great Garren often with a hi, how are you today, what brings you in?

The enthusiasm to engage him is often short lived when he doesn't immediately respond to the multiple questions.

My husband and I can expect to have to model what making space for Garren to use his ACC device looks like when their attention is quickly turned to us.

Without this model, Garren's voice would go largely unheard in the majority of his healthcare visits.

Having witnessed firsthand the negative effects of paternalistic healthcare with Garren, my husband and I do everything we can to ensure that he is actively participating in his healthcare encounters.

Unfortunately, in our experience, few healthcare providers are prepared to allow extra time for a response, to repeat their question, to use objects or picture cards to help him understand, or to offer him choices.

All things that are written in his adaptive care plan.

That is except our regular pediatrician. We knew she was special the first time that we met her. Instead of attempting to send him to the ER because he relied on a ventilator, she was eager for the opportunity to care for our sweet boy.

She spends extra time asking him questions and patiently wait for him to respond, I feel sick.

She asks him about whatever book or toy he brought into the office with him, and she patiently explains everything she's going to do.

She shows him her tools, and she tells him what she's doing with those tools while she's doing it., explaining why it's okay for her to examine him in this space.

She involves my husband and I in the discussion in a naturalistic way that does not take care from my son's participation or from him being the center of the healthcare experience.

She'll turn the me and ask, what else can you tell me? Or is there anything you want to add?

Giving me space to fill in details without centering me in the visit.

I'm eager to tell her about all the exciting things Garren has opinion up to since our last Virgin Islands he listens enthusiastically while turning our attention to my son, celebrating each victory directly with him.

Her efforts are opened my son's up to aspects of his visits that he used to blatantly refuse.

For example, he used to refuse having his ears looked at. But because he is an active participant in his care, he is comfortable letting her use the tools to examine his ears.

We're lucky to have her on Team Garren, however, we truly believe that making time for engaging him in his healthcare experiences and celebrating his accomplishments to be a great bar for all providers to aspire to.

Sarah, I'm going to send it back to you.

SARAH: Well, okay. Thank you, Maryjan and Susan.

And now it's time for Jessica. Take it, Jessica.

>>: Hi everyone. As Sarah mentioned, my name is Jessica Gormley. And I use she/her pronouns, and I'm a white woman in her 30s.

Thank you, Susan and Maryjan, for sharing your experiences and shining a light on, not only what can be improved within healthcare interactions, but also on what you networks and families have tried that resulted in success.

First I want to say that I come to this conversation from the lens of a healthcare provider and specifically a Speech‑Language Pathologist and Researcher. So I'm here as an ally to people with communication disabilities.

Today I'm going share some tips and tools that I have seen be successful in the clinical and research environments I'm worked in and also show you some free materials to hopefully support you on your communication access journey.

And next slide.

So knowing that communication access barriers span across systems, sometimes it might feel overwhelming to know where to start. So today we're going to focus on what you can do today to start a conversation with your providers to get what you need, when you need it, and as soon as your next. And I we need each other. You can make a big difference by just starting with some small practical steps.

As a quick review, Susan and Maryjan and Garren experienced barriers that are unfortunately commonly reported in the disability community. One, providers sometimes use a one‑size‑fits‑all approach to care.

Two, Garren and Maryjan experienced a lack of respect and dignity.

And three, providers made little to no attempts to adjust when they did something that wasn't really working.

But what can we do use to support communication access?

Next slide.

First, you can tell the provider about your critical accommodation needs. Each person requires different strategies, and it's not a one‑size‑fits‑all approach, so when your appointment is scheduled you can share with the scheduler exactly what you need and also send a message to your doctor in the patient portal.

It's important to never assume that the provider will automatically know ahead of time what you need. Each provider sometimes comes to the table with different background experiences, and they might make wrong assumptions if it's not clear.

For instance, if the chart says be that you need an ASL interpreter, the provider might assume that the VRI or video relay interpreter, is appropriate and have that ready to go. But if you really need an in‑person interpreter, VRI will not meet your needs. So when you tell the provider what you need, make sure that you're really specific. And that you also encourage them to document those specific needs in the health record.

Sometimes organizations even let patients upload their information directly to the patient portal. But you might need to check with your personal organization.

But once it's in the health record, other people on your team can also know that information as well, which can be a huge time save to you and your team as you prepare for visits.

And next this suggestion takes a little colonel. Let your healthcare provider know if they are were not on the right track with accommodations you need.

Sometimes it might be the first time the provider is using a specific accommodation, and if no one tells them they're doing it wrong or it's not working, they might continue to do the wrong thing and create a bad habit.

So this could lead to frustration, not only to you, but for others.

And like Maryjan mentioned, if you catch someone doing something well, tell them. Healthcare can be a pretty unforgiving environment sometimes and many people I work with have more stories about when they've been given negative feedback vs. positive. Not because they're bad providers, but because sometimes it's less likely in our society to offer praise. And praise can be pretty powerful (chuckling) you might be creating a communication champion just by telling someone that they did something well.

SARAH: I'm getting in the chat the interpreters are wishing that we would slow down a bit.

>>: I will slow down. Sorry. I get too excited.

>>: I know, exactly. I had the same problem. Yeah, I know. Go for it.

>>: Yeah. Absolutely.

Yeah. So let me see here. Yeah, so basically just sometimes it can feel daunting to know where to start. And if you're like me, sometimes I get a little shy at appointments, so planning ahead can help build confidence as you start conversations.

And as a starting point, our team collaborated to create a tool to listen ahead and start a conversation about identifying accommodation needs.

You can go to the next slide.

We created the communication access tool which is now live on our website and freely available. And it might be a helpful tool for you to complete before your next appointment.

The tool asks if somebody has difficulty in 5 areas, seeing, hearing, expressing themselves, understanding, remembering, learning, or moving.

And since everybody has unique needs and sometimes those needs change over time, this tool is interactive so you can pick what you need support in and only those options will drop down to help you communicate those with others.

I'm going to show you part of an example that Maryjan actually filled out for Garren, and she told me it took less than 2 minutes to complete. So hopefully you can build that into a new routine.

First, the form provides some general questions about language needs in a preferred way to receive information. This is a screenshot of a communication access tool, and the text reads, I understand spoken information best when it is in English. I understand written information best when it is in English. And question one states when trying to reach me, use check all that apply. Says e‑mail, text message, TTY, video relay, speech to speech relay, mainline phone, USPS mail if not time sensitive, patient portal and other.

And for this case, Maryjan selected cell phone and other are selected, which says please call my mom or dad after the other.

Next slide.

Next are a few more general questions. Question ‑‑ this is another a screenshot of the tool. And question 2 text reads I understand best when I get information check all that apply, in pictures, in writing, including accessible formats. Explain to me, shown to me, including read aloud.

And in pictures, explain to me and shown to me are selected here.

Question 3 reads when viewing films and videos, I need descriptive narration, captioning or sign language and no options are selected.

And the last question reads, during the visit I need accommodations for hearing, seeing, speaking, understanding, remembering, and/or learning.

Also has moving, but that got cut off.

And for Garren, he needs help for speaking, understanding and/or learning.

So those areas with speaking, understanding, remembering or learning are selected for Maryjan to fill out.

I'm going to just show you a little part of this. For the speaking selection. And in this example, Garren uses communication accommodations regarding speaking and expressing himself so the a screenshot says I agree, I use gestures, speech it might be difficult to understand me, sign language, a familiar person to provide communication support, communication board, writing, speech generating device, phone or tablet with communication app, voice amplifier and other.

And Maryjan selected gestures a familiar person to provide communication support, communication board and speech general rating device.

And continuing on, there's more needs that are actual upon the whole tool, but for this little snippet, we have specific outpatient needs checked off.

So the text here reads I need outpatient extra time to communication, questions in advance, support person who understands my speech, providers that ask yes no questions, written instructions with relevant graphics and pictures to take home, graphic and picture displace realtime to setting. And of those Maryjan selected extra time to communicate, support person who understands my speech, graphic or picture displace relevant to the setting and later on there's another portion. She also wrote in encourage me to use my words or ACC device which is fun you can add some specific information.

And since the tool is interactive, each time it's completed a unique print out will be available in PDF which can be saved or e‑mailed.

>>: Jessica, timing.

>>: Yep. Yep. Another option will be to e‑mail or you can use the patient portal. I just encourage you to if you try it out, save it somewhere and share it with others.

You can go to the next slide which is just a little more about what you can do to learn more about communication access possibilities, which is visit our website. And there will be additional resources that our team have found related to all of the different areas that I just talked about, seeing, hearing, expressing, understanding, remembering, learning and moving.

And the last slide here you can move on to is how can you become more involved. We would love to hear from you. You can rate the tool. Use the tool. Give us some contact information or feedback about ways that we can improve it.

And if you have other tools or resources, you can share that with us and we can highlight that on our website.

Turning it other to June so she can also share some additional examples and suggestions.

Take it away, June

>>: Okay. Thanks, Jessica.

So next slide.

And I'm June Kailes. My pronouns are she and her.

And as a person with a lifelong lived disability experience, my view and approach to healthcare has been shaped by working in healthcare and working in emergency services, independent living, and other disability organizations, plus growing up in a family of healthcare providers and being a constant and incessant question asker.

I saw firsthand repeatedly the positive impact of those using assertive advocacy and savvy survival skills in healthcare.

I saw people insisting on being a partner their healthcare, being part of the process, being ‑‑ so our big goal in all of this is where accommodations are provided seamlessly to those needing them, is where we want to get to.

In the meantime, we as consumers play a critical role in advocating and getting what we need for more successful appointment.

It's about what we must do and providers must provide.

My first exposure to a communication access like tool was in 2000. As a new physical therapy patient, I had to complete a form that asked me how I learn best and how I want to receive information. Now, that really impressed me and drove me to create many drafts, earlier drafts of what you see today in our communication access tool that Jessica covered.

I'll call it cat for short.

Next slide.

Now, CAT is not a one‑and‑done process. It's an important part of the beginning of the process, but it's not an endpoint. It's not all there is. It really takes work on the provider's side to plan for and provide for our documented needs. And takes work on our part, the consumer, in terms of what we must have.

Now none of us like surprises when it comes to healthcare. Providers need notice to avoid surprises. So planning can help you get the support and services you need in planning and help the provider better prepare to deliver the support we need.

You've seen healthcare provider before reminding them about your specific needs is really important. Next slide.

It takes work to identify your needs, document your needs, and then send it, explain it, confirm it, get it, that is get your needs met, and repeat it.

We've got to identify and document our essential needs. And when you're a new patient, send it with other required forms, e‑mail it, mail it, fax it, reinforce it and confirm it. And bring a copy to the appointment. And again, explain what you need and confirm that it will be available.

So I have to do all of that. And I assume nothing.

Next slide.

Being prepared and having faith and confidence in our disability, in our lived experience, in our common sense helps decrease our feelings of anxiety and intimidation. These feelings are often caused by a false thinking that we don't have the status, the training, the degrees to question healthcare providers.

So a few quick examples. In the C A T, referring to the moving area, I checked, I use a mobility scooter and I need an accessible building, bathroom, scale, and an accessible exam table or a height adjustable table. Why, okay, well, here is my circus act.

Next slide.

I'm using a long grab bar and a small step to perform an unsafe aerobic move to get on to a very high exam table. Next picture.

Next slide that is.

So I get on this exam table. I'm anxious, I feel unsafe. I feel unsteady. I'm sitting on a table with my feet dangling about 2 feet off the ground.

Vs. the oh picture in the slide where I'm sitting in a adjustable exam table with my feet firmly and safely planted on the floor.

Every time I would ask for a room with a height adjustable table, they would tell me repeatedly, Oh, we don't have those. And I would say, Yes, you have them, and they're in room 3, 12, and 15. I just got so tired of doing this every time.

Next slide.

So I started asking why can't this be highlighted in my record? Why can't it be an accommodation alert that says use high‑low table in rooms 3, 12, and 15.

So another example. In the C A T. For a mammogram,

Next slide.

document under moving that I need two technicians to assist withholding still, positioning. So in the slide there's a woman assisting the woman to hold still, to get positioned. And the other is taking a picture, look at the computer monitor.

So I wasn't maintaining the position I needed to, and as a result the images have often been unclear and not very usable.

So one story, I've been going to the same place for a mammogram for years and years and years. So one day I go and there's a new technician. And I say, Oh, remember, we need two people to get a clear picture.

And she says, Oh, honey, I've been doing this for years. Let's do it my way. And I say, Oh, honey, I've been doing it for years too, and we need to do it my way.

Well that ‑‑ in the end, she said, You know, you were right. I just looked at her with a cross‑eyed expression.

Next slide.

Again on the record, there could be an alert that says need two technicians to help with positioning.

So another area of the CAT, understanding, remembering, and learning. I will check under I need, I need providers to check that I'm understanding what they're saying, and I need visual supports to help me understand.

Also I don't ask anymore. I just record the visit. And if I get challenged, I say I need an accommodation to record this visit because I don't take notes quickly, and I want to fully focus on what you say. And I know my recordings are a whole lot more accurate than my faulty memory.

Next slide.

So what I use in this slide, I just use the recording app on my phone. And before that, I used to use a very inexpensive recorder rather than struggling and being distracted with taking notes that I often couldn't even read after words given the clarity of my writing. Much more effective for me.

So when I do not understand what a provider says or the information is vague or unclear, I do ask them to explain it again, draw me a picture, show me a model, give me something to read. And I take a picture and I copy what they draw or take a picture on my phone.

And at the end of the visit I try to check my understanding, by quickly repeating what I think I heard.

My last example regarding understanding and remembering involves physical therapy because it's all about CRS, can't remember stuff. I can never remember stuff, even half of the details. They so quickly share. So I document under other, it helps me to understand and remember and follow through on the information and instructions when you show me how to do the exercise, give me videos, along with plain language that describes the key parts of the exercise, where I should feel the impact, and not tell me I should feel it in my glutes, where they are.

I need plain language.

What is each exercise for, why is it important, how many should I do, and however. And what do I do if it hurts?

So in this slide, you'll see two videos that appear as an app on my smart phone where the exercises are shown and narrated and there's also a specific place for instructions that are put in there by the physical therapist. And it's really helpful.

As opposed to on the right, just the line drawing, of how to do a stretch. That's okay, but I often not good enough for me because I just don't remember accurately exactly what to do.

So to sum it up, so we have time for questions ‑‑

Next slide

 ‑‑ this is my, I call this my cartoon nightmare. It's a terrified looking woman lying on a table clutching its sides. She's under a huge piece of medical equipment aiming at her belly and wheelchair is parked next the table.

So the message is, we all want to keep our bodies out of the shop. But sometimes we need a means checked or a tune up and sometimes more and sometimes a whole lot more. So whatever is the case, we must use all the tools in our tool box to get which we need to prevent failed appointments.

So that's it. Back to you, Sarah.

SARAH: Okay. (chuckling) this is ‑‑ we are never going to have enough for this.

And this is a documentation right now where we don't have a lot of time for Q&A. However, we do have a couple of unanswered questions. I do want to make sure that everybody knows that the tool that we've all been referring to is actually available online at the Patient‑Provider Communication website. And the tool is in the chat. P

And we want you to share it, use it, and we would love to have your feedback at the survey in the end and just a description how you used it.

So we do have a question for Susan. I don't know if you've silent, Susan. Do you find that providers speak to interpreters rather than patient and would it be better for providers to look at patients, but have patients look at the interpreters to get the information?

I think you gave an example of that, actually. In your presentation.

Can you show us yourself and answer?

And I'm just not sure that

>>: Could you repeat the question again.

SARAH: Sure. It's in the Q&A. The question is really should providers speak to interpreters rather than patients?

And then should the patient be looking at the interpreter to get the information?

So what is your suggestion there?

>>: That's an excellent question. Actually the provider should be looking at the deaf person. I know in the one picture on the slide the interpreter was looking at the VRI. And that really was not appropriate, but it was a good photo show what VRI looks like.

But the provider should be look at the deaf person and the deaf person looks at the interpreter.

SARAH: Great. Thank you, Susan.

Let's see. There's a question about we referred to resources available on the website, and I think that it's been clear thanks to Jessica and everybody, that the communication access tool is there. And we've made reference to the fact that we are ‑‑ there are also resources there. We are in the process of collecting more resources. We've applied for funding to spend next year organizing those resources and making them available for both providers and for consumers that will be in a readily accessible way on the website that would link ‑‑ that could link from here are my needs and if you don't know about a certain tool that might support you, you can go and link to an explanation, a video, maybe a story about the use of that particular tool that might be helpful to you as a consumer, but also as a provider who may not know as has been mentioned many times, about all the tools that people might use on a daily basis or need in a healthcare situation.

So Jessica, you want to say anything more about that?

>>: Um, I think that, yeah, just what Sarah mentioned. Our plans, we have a lot of tools right now on the website are geared towards helping people who might have difficulty speak or use other ways to communicate other than speech. But we have a list, I think at the 156 or more tools that our team has found that will be updating and uploading in the near future.

So be on the look out right around the area of the on the website where it has communication access tools. It would be also an option that says like communication accommodation guides. And I'll show you where to look. I'll drop that link. Right now it says coming soon, and we've hoping it will be easy to or the, according to those different areas of communication access needs. And also how expensive if tools are free or a at a cost, yeah, just different ways that you can learn more about those things.

SARAH: And our team is generated some other questions that are very interesting too, and maybe we'll get to them next time.

But asking the team and yourselves, how do you see your family using the communication access tool, for example. Or I've heard about a support person, and that a support person might be use informal a healthcare setting. And what does this mean, what's that about?

Or I worry that my healthcare will be negatively affected if I question, challenge or disagree with a provider. And we've heard about, and we've had some comments about that. And it often works out well. And I guess as a ‑‑ one of the two woman with white hair in this gathering that we can see, anyway, or have heard about, that the older you get, the less concerned you get about you can still be very nice and kind and respectful, but also make it clear what your needs are and when it doesn't happen, ask for some modification to the situation. Even if it's just please turn off the music, I can't understand what you're saying.

So we are running ‑‑ out of time. The next slide shows us your invitation to Webinar number 3, which is coming up before Thanksgiving on the 18th.

And we'll be talking more about integrating tools to improve healthcare outcomes.

And you're all invited.

Next slide.

So we are asking you to respond to the poll that will give us some feedback about what worked, what didn't work during this Webinar.

So you can access the poll on screen or click the link in the chat, which I'm ‑‑ there it is.

Here comes the poll. I'm knot going to read it to you for the sake of time. There's just a few questions.

... and

And while you are completing the poll, we can, I think, wrap this up.

Sorry we can't have more time for discussion. We will leave more time for discussion at the third Webinar. There's so much information to share, so much that needs to be done, so many avenues that we can all go down. And the more we can do that together, obviously, the stronger we can be and maybe we can make a bigger impact.

And the panelists should take a look at the chat because we want you the satisfy on to do some debriefing. On how to do that. What else, Priya, do you have anything else or Megan?

>>: Thank you, Sarah. I think if we go to the next slide, it also shows some.

SARAH: Oh, good.

PRIYA: Appreciation to our partners.

SARAH: Yes. Now is time to give everybody a big, big, big round of applause, the presenters, the panelists, all of you who attended and participated, all the partners who have helped us plan in, our language access team, amazing, and of course our funder Ability Central.

And if you have any other comments, put them in the chat, and we hope to see you next time.

PRIYA: Also on the full time slide, there should be a way for you to follow up.

SARAH: Oh good. Here we go.

PRIYA: So you can contact me, at juring@gmail.com, Megan Juring and I'll make sure your queries get to the appropriate panelists.

And here again is the website link and Jessica's dropped so many of the direct links in the chat.

So hopefully you will all dig in and give us feedback as well.

SARAH: And I just want to say, thank you, Megan, so much for everything. And that there was a question in the Q&A about will there be some resource available to assist on the website?

And I think we've answered ‑‑ there are resources there.

And you also asked about a help line. So I would refer you to Megan (laughter) if you want to talk about that some more. It's not something on our to‑do list. I'm not sure it's possible. But we are always happy to try to help.

Anything else?

Okay. Thank you all for coming.