>> Priya: Hello everybody, and welcome. We are going to get started in just a moment.

Hello, everybody, and welcome to in the first of the Webinar series: Tools2Use: Improving Healthcare Outcomes through Effective Communication.

On the screen you have a title screen with that text. And the below is the logos for Ability Central, CERV of the Monterey Peninsula, Patient Provider Network Communication.

As well as the Partnership for Inclusive Disaster Strategies

My name is Priya Penner and I'm with the Partnership for Inclusive Disaster Strategies. I use she/her pronouns and I'm a Brown woman with long curly black hair.

I want to start off to a huge thank you to you all for joining us, to our speaker, facilitators and access team that are coming together and helping us prioritize equity within these conversations. Thank you.

I'm going to go ahead and get us started with a few accessibility and technical support reminders and then I will pass it off to Sarah Blackstone. I will first speak in English to access the various accommodations today such as language interpretation.

And then the Spanish interpretation will immediately follow, as is already happening.

We will then switch to simultaneous interpretation, which you will only hear in language in English or Spanish, depending on your preferred language.

And that will be only once folks know how to access the interpretation.

And first and foremost this Webinar is being recorded and an archive of today's Webinar as well as all the Webinars in the series will be available in the coming weeks following each Webinar.

We will also receive all the slides used today and in future Webinars in a screen reader accessible format. The archive and slide decks will be available in English and Spanish.

Today we have Spanish interpretation, as you can maybe hear hopefully if you access it auditorily, American Sign Language or ASL and CART captioning provided in English and Spanish.

Those links to access the CART captions are in chat for folks. Today we will be using the Zoom interpretation function that has already been activated for folks.

Just reminders on how to use the interpreting function. If you have a computer you will see a globe icon on the bottom of your screen. If you're on tablet or a phone you will click "more" and you will see an option for language interpretation with the globe icon.

To listen to the interpreting in your preferred language, click the globe icon or the language interpretation, and then choose the language channel. English or Spanish. If you're using a phone or tablet, you can click "done" afterwards. If you can't hear the interpreter on the language channel, please let us know in chat. Or you can e‑mail us at Priya@Disasterstrategies.org.

Disasterstrategies.org

Now we will start simultaneous interpreting to test the interpreting function.

Again, please choose your language channel if you want to hear the interpreting in English or Spanish.

If you have any difficulties accessing the translation or interpreting, please do let us know in chat or e‑mail.

We have chosen to leave the chat open, but please do keep in mind that we have limited capacity to provide interpretation of comments in chat.

And once again, if you cannot access the chat and need technical support you can let us know via e‑mail at Priya@disasterstrategies.org

As I mentioned earlier, English CART captioning is provided here today as well as Spanish CART captioning.

The English CART captioning is embedded in Zoom and you can access those captions via the "show captions" button, CC button ot the navigation bar on the bottom of your screen.

Click once to show subtitles on Zoom and you can edit to change the text and font size and color within the CC button.

You can access the English captions as well as Spanish captions via the link in chat.

Again, if chat is not accessible to you, we are happy to send both links to you or your preferred link via e‑mail.

Our ASL interpreters today are Travis and Jasmine. You can drag the divider that separates the speakers from the slides to the left and right.

If you can't see interpreters, please do let us know via chat or in e‑mail.

When you have questions about the content of today's Webinar, please feel free ‑‑ and we welcome actively the use of the Q&A feature or the Q&A box.

If you cannot access the Q&A feature you can e‑mail questions to us. And please do ask questions as they come to you.

We do have folks monitoring the Q&A and we will ask your questions during the discussion.

Please raise your hand or type in chat for any technical assistance or alert us to an issue.

For example, to slow down.

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

>> Sarah: Thank you Priya. Welcome everyone to our first of three Webinar series focused today on tools providers can use. We want to thank you for coming.

My name is Sarah Blackstone. I'm an 80‑year‑old woman with short white hair. I use pronouns she and her. I am failing retirement.

I'm also today's moderator. The four logos that Priya mentions I will say more about them.

Ability Central funds our project. The community emergency response volunteers of the Monterey Peninsula is the project grantee.

Patient‑Provider Communication area is a network as well as a website established in 2009 focused on patient‑provider communication.

As you know the Partnership for Inclusive Disaster Strategies is producing this Webinar for us.

Together we share a strong commitment to improving healthcare outcomes through effective communication.

Next slide, please.

Soon you'll be meeting our Webinar panelists to access their bios in English or Spanish, you can go to the link provided and I'll put that in the chat as well. Or use the QR code.

Next slide.

We want to give a big shout‑out to our funder Ability Central from Oakland California that expands communication access for people with disabilities.

Next slide.

I got it okay, thank you.

Onto the brief ‑‑ onto our Webinar. And I'm going it give you a very brief overview.

You'll be meeting some of our subject matter experts for the project. We will begin with Anita Aaron Executive Director for Agencies of Blind and Visually Impaired. She will provide unique perspectives and lived experience.

Next up is Jessica Gormley from the University of Nebraska Medical Center. Then you will meet Rachel Santiago, a clinical specialist at Boston Children's Hospital.

And then Tami Altshuler, the patient‑provider communication coordinator at NYU's Medical Center.

By the way, Jessica and Rachel and Tami are the co‑leaders of the Patient‑Provider Communication Network.

Our panelists will help remind us of the complexities providers and consumers of healthcare face whether it's in an office visit, a hospital, etc.

There's a few ground rules. It's my job to introduce some of the panelists, as well as to make some introductory comments, monitor your questions in the Q&A, and keep us on time as much as possible. Because we really want to facilitate the discussion we can have.

Panelists know this and know they may even get a one‑minute warning. Next slide, please.

Communication is so embedded in our lives that we rarely think about how complex it is. We also may not recognize that successful and effective communication requires two‑way processes. Messages are negotiated until information is correctly understood by both parties.

By patients and by healthcare providers. On this slide is an image. It's an image of a Venn diagram.

There are five circles that intersect, illustrating peoples' needs in accessing healthcare.

These include, No. 1, communication disabilities, difficulty hearing, seeing, speaking, learning, remembering, understanding, reading, writing, moving.

Those are the focus of our project. In the United States today there's an estimated 100 million people who have communication disabilities.

The diagram also shows intersection among other factors that relate to communication access.

Another circle intersecting is difficulties understanding and speaking English.

Another circle, a third one, is issues related to cultural, religious, and gender differences.

A fourth circle is being unfamiliar with how our health system works, our health literacy.

And finally, the many situational factors that influence the lives and the events when there's a health issue in a visit, an emergency room, hospital, rehab, etc.

Results of survey ‑‑ research results suggest that as many as two‑thirds of the U.S. population face communication barriers during healthcare visits.

Next slide. Thank you. This Webinar focuses on providers. We include licensed professionals as well as par‑professionals, assistants, administrators, even community health workers.

We will be initiating discussions related to increasing effective communication between healthcare providers and persons with disabilities across healthcare settings and systems.

We will also be talking about using tools to gather information from people with communication access needs, identifying ways that can increase effective communication between providers and consumers of healthcare.

And the next slide, we will be talking about resources and implementation strategies that enable providers to obtain, add, and update relevant communication access information in a patient's healthcare record.

There's an AI‑generated graphic of a man in a hospital room speaking or signing from a hospital wheelchair to a medical provider.

Next slide. Thank you.

So what we know through lots of experience as well as research is that communication access to healthcare is essential across healthcare settings.

We also know that addressing communication barriers positively impacts patient outcomes, safety, satisfaction, costs and quality of care. And that effective communication is critical to preventing adverse or bad things that happen to consumers and providers and also significantly impact healthcare costs.

And next slide, communication access is in the law and policy of the U.S. And we know also that there are multiple gaps in compliance today. So although this is not a focus of this Webinar, it's surely a good idea to know the law and how to advocate.

Next slide. For example, law and policy do mandate that communication access to healthcare is necessary for people with disabilities. They have the right ‑‑ we have the right to accommodations, rights to provision of some mandated accommodations ‑‑ not all, and right to access information, services, as well as human and nonhuman supports.

So knowing laws and policies and how to advocate is important. Next slide.

I'm going to pass this to Anita now. She's one of our subject matter experts. And a contributor to this project. Anita will introduce herself and share a story from one of her many patient‑provider communication experiences. Take it away, Anita.

>> ANITA AARON: Thank you Sarah. It's still hard to hear, but I have many ‑‑ ( ) with people but it's the truth.

In my 20s I had vision loss. I couldn't read or drive but I could walk for miles and hours, so if I needed to get somewhere I just got there.

In my 30s I added Type I diabetes to my collection of disabilities. And what complicated self‑management of Type I diabetes was vision loss.

But in my 60s, I added hearing loss to my collection and in my 70s, I have had two strokes, each leaving the effect of a little less mobility ability and more vision loss.

The story I want to tell is that when I began to experience the symptoms of my second stroke, I knew what was happening.

I knew because of what I hasn't known the first time.

So we went to the emergency department quite early on in the process. And the emergency room was very attentive. Was basically in a monitoring mode, but was really making sure my blood pressure was not elevated and doing all those things.

As I'm sitting quietly in this very darkroom, because it was nighttime and my husband is there by me. I say to me, you know, I've lost all my vision.

Well, what the ER team didn't know, because of the way electronic medical records are kept, they didn't know I was already nearly functionally blind.

So they immediately jumped into action dealing with my vision loss.

And I tried to say to them that I obviously didn't ‑‑ but I obviously didn't try very well. I tried to explain that this wasn't a crisis for me. It was almost a point of interest.

Anyway, they kept me overnight. I was put in an hospital that was understaffed. I was given a cot in an expanded hallway with no way to get to the bathroom on my own.

Somewhere in the process my mobility cane got lost and it was one of those situations where I felt that ‑‑

>> Priya: Sorry, I'm hearing the Spanish interpretation in the English channel and I'm seeing the conversations in chat saying they can no longer hear the Spanish interpretation.

>> ANITA AARON: I don't know how to fix that.

>> Priya: Just a comment for our interpreters. No worries, Anita. Thank you so much for pausing.

And just a gentle reminder that if you can slow down for interpreter, that would be fantastic.

Please continue.

>> ANITA AARON: Thank you. So being admitted to the hospital was only the second time in my life I had experienced that.

Never in a situation of no beds, no rooms (chuckling) and limited staff. I found that there was no one to help me get the call button and how to use it.

They told me I couldn't keep my mobile or my hearing aids and charger because they would be stolen.

And so those two pieces of technology were my keys to access along with my mobility cane.

The night didn't go well. Many things happened. For example, they were worried about my vision and the fact I was blind. And I was worried about knowing what my glucose readings were because that's one of the ways I used my mobile phone.

Nobody asked me what I needed, but I will say they were in crisis mode themselves.

They had many more patients than they could attend to. And people like me who needed special intervention, if you will, that began to change the next day when there were more staff. And they could begin to focus on what my needs actually were.

I don't know that anybody any time during that day asked me the question, "what do you need?" But they did try to anticipate. And they were very reassuring about that.

But it felt awkward to be in the hallway on a cot. It felt awkward to not understand where the bathroom was. It was a very awkward experience.

When I asked what the medication was they were bringing me, they said your doctor will go over that with you. But I didn't know who my doctor was because of this particular facility, they separate your primary care physician from hospitalization, and the staff there.

So I was later told that my doctor had been in and gone over my chart, had not introduced himself. Had made notations and walked away.

And that he was concerned by the fact that I didn't seem oriented to what was going on around me.

By the middle of the second day everybody, including me, was getting their act together. We were acting much more like a team who actually knew what my issues were and they were very seriously committed to helping address them.

One of the final things that happened as my vision started to come back on the second day was I developed Charles‑Bonnet syndrome which is visual hallucinations that tend to only happen in people who already have vision impairments.

I didn't know what Charles‑Bonnet syndrome was at the time I just knew I was seeing things and it was very off‑putting to me.

When I tried to express that to the staff it was clearly, they just thought I was, I guess, having some kind of neurological experience.

So although things got better, people being to react in realtime was really hard for the staff to have to deal with one thing after another after another. As I was being checked out, the nurse that was doing the check‑out, I say to him, "Is there anybody else sitting at the table with us?" And he looks around and then realized, oh, well she's visually impaired. She probably can't see that.

But I was asking him because images were coming and sitting down at the table with us. And so I was seeing these things, he was not seeing, and had no way to know.

So I really appreciate by the end of my stay, I really appreciated that staff and how they tried so hard to intervene in such a tough set of circumstances. But all in all I would have preferred they asked what was going on right from the beginning.

And I would like to have had more tools to deal with my feelings of embarrassment and demoralization and absolute helplessness.

Sarah, I think I'll stop there.

>> Sarah: Okay, that's great Anita. So I'm going to for the sake of time pass it ‑‑ can we have the next slide? This is great. I've got questions already.

But to pass this over to Jessica Gormley, who I've already told you is a co‑leader of the Patient‑Provider Communication Network. She's also the co‑director of our project.

And on the leadership team. And go for it, Jessica. And thank you so much Anita. Can't wait to talk more about that.

>> DR. GORMLEY: Thank you Sarah. And thank you Anita. Hi, everyone.

As Sarah mentioned my name is Jessica Gormley, I use she/her pronouns and I'm a White woman in her 30s and I have long brown hair.

You can actually go to the next slide. All right. And thank you Anita for sharing your experiences and shining a light on what's missing on the provider side of interactions and areas that absolutely need to be improved within healthcare interactions.

Knowing that communication access barriers span across a lot of different systems, sometimes as a provider ‑‑ and I'm a speech‑language pathologist by trade ‑‑ sometimes it feels overwhelming to know even where to start.

And there's some big system areas that need to be improved, and we will try to tackle those in a future Webinar. But today in this presentation, we're going to try and focus on what you as a provider can do today with any patient that you work with to support their communication access needs.

So we're going to give you some tools and strategies that can serve as a way to start conversations with the people that you serve, and also people that you work with to create an environment that supports communication access for all.

We need each other. And you can make a big difference starting with some seemingly small and practical steps.

As a quick review, Anita experienced some communication access barriers that are unfortunately very commonly reported in the disability community.

And I'm just going to highlight those here. So during that long night and that stay in the emergency department, No. 1, no one asked Anita about her critical accommodation needs.

Such as her hearing aids, her chargers, her use of her phone. No. 2, the information that was needed and that was known to other providers was not in the electronic health record, which made it really challenging to share information across staff.

No. 3, Anita was treated with a lack of respect and dignity because people didn't know those supports that needed to be used for effective communication.

And 4, providers engaged in little to no attempts to partner with Anita to address those challenges.

So kind of with those challenges, now what? What are solutions that could be used to support communication access?

You can go to the next slide.

All right. So we're going to share some general solutions and then as the presentation goes on, we'll have more examples about how we can implement these simple solutions.

First, always ask about what that person needs. Each person requires different strategies to participate successfully in different visits.

So just asking a simple question and taking that minute or two to make sure that you understand what they need is so important.

And Anita's example she needed items such as her phone, her hearing aid chargers, her hearing aids, and her mobility cane.

And she also needed a call light as well.

Next, once you know what some of those accommodations or tools are that the person needs, this needs to be written down and documented somewhere.

You could put it in the electronic healthcare record so that other people on your team can know this information as well.

It could be a huge time‑saver for you and your team in the long run to make sure that everyone has the information right at their fingertips and helps with the chart review process and for how to prepare for a visit, like, if you're in an outpatient setting.

There are also staff that don't have access to the medical records. So it's really important to make sure that those staff also are informed about what the person needs.

So in the hospital you might have some written communication instructions at bedside or that could be share nd a clipboard or when folks are getting ready to prepare for the visit.

All right. And then next, and once we know what the tools are that we need, they're written down. We also need to use them (laughing).

So this is really important that we are practicing what we're writing down. I'm going to share some general communication strategies in the next few slides.

But this is going to be very unique to the person that you're working with and the situation.

All right. And finally, one of the guarantees in healthcare is change. It's inevitable. People change over time, teams change over time, and environments change.

Anita shared in her emergency department visit, her vision changed, her physical status changed, staff changed across shifts and there wasn't even enough beds in the emergency department to give those basic needs.

When the unexpected happens, and more than likely the unexpected will happen, or when a plan needs to pivot it's really essential to make sure the trouble‑shooting process includes patients.

If someone only asked Anita in the moment what she needed or what her thoughts were, I bet she would have identified some simple and effective ways to improve the situation, before having to go through a lot of hardship.

And at the starting point, you know, we recognize as a team with the group on this particular project that it sometimes was hard for people in our network to know where to start and to go to No. 1 about asking about critical accommodation needs and identifying those.

So I'm going to show you on the next slide what tool that our team collaborated onto really help providers and consumers engage in conversations about identifying accommodation needs.

So you can go to the next slide.

So we created a tool. I'm calling it the Communication Access Tool. As one way to ask about and document xun kags accommodations.

The tool will be freely available on the Patientprovidercommunication.org website. And it may be a helpful tool for you to use with people with disabilities that you interact with in your daily work.

The tool starts by asking if a person has difficulty with five areas related to communication and access such as seeing, hearing, expressing themselves, understanding, remembering, learning and moving.

And since everyone has unique needs, this tool is interactive. So that if someone identified having a seeing and hearing as a difficult ‑‑ as difficulties, only those options related to seeing and hearing would drop down in the tool.

And they can check off specifics related to those areas for an outpatient or a hospitalization visit.

So next slide I'm going to show you an example of what this looks like. On the website for the sample person.

So first the form provides some general questions about the person's language needs, and preferred ways to receive information.

This is a screenshot of the patient‑provider communication intake tool and the next reads: I understand spoken information best when it is in English. And I understand written information best when it is in English.

First question is: When trying to reach me use... and check all that apply.

E‑mail, text message, TTY, video relay, speech‑to‑speech relay, landline phone, USPS mail, not time sensitive, patient portal, and other.

And in this instance, e‑mail and patient portal were selected for this particular individual.

You can go to the next slide. On the next slide there are a few more general questions about the individual's preferences about receiving information related to their health visit.

So question for a visual description, this is a screenshot of the patient‑provider communication intake tool.

And question 2 reads, I understand best when I get information (check all that apply). In picture, in writing, accessible formats, explains to me, shown to me, including reading aloud.

And in writing and shown to me were selected in this instance.

Question 3: When viewing films and videos I need:

Descriptive narration, audio description, captioning and sign language.

And no options are selected for this particular individual.

And question 4 reads: During the visit I need accommodations for:

These are five domains: Hearing, seeing, speaking, understanding, remembering, and/or learning and moving.

And for this particular individual, speaking is only selected.

So now since that question No. 4 speaking is identified, using the interactive tool it's going to open up a bunch of options related to just speaking.

So they don't have to sift through other areas that don't relate to their needs. You can go to the next slide.

So for this particular example, this person uses communication accommodations related to expressing themselves.

Additional questions related are specifically what kind of tools do they use? For visual description the examples offered are a ‑‑ the screenshot is I use gestures, speech, or it might be difficult to understand me using my speech.

Sign language, a familiar person to provide communication support, communication board,i.e.; or a letter, word, picture, or translator board. Writing, speech generating device. Phone or tablet with communication app, voice amplifier or other.

In this case speech‑generating device is selected along with speech. In that it might be difficult to understand me.

You can go to the next slide.

So those are about the tools that that person uses. And then there's also a section as this person is preparing for an outpatient visit of what strategies that that provider would be ‑‑ should use in order to make it a successful visit.

For a visual description, this is a screenshot where the text reads: I ‑‑ oh, sorry.

I need for outpatient extra time to communication e g ask questions, confirm understanding.

And then questions in advance e g forms, questions providers ask in my appointment so I can prepare my responses.

So in this case both of those options are selected. Since the tool is interactive, every time it's completed, once all the questions are done, a unique print‑out will be available so this individual's choices can be saved in a PDF format and e‑mailed and scanned ‑‑ you can scan it into a medical chart or share it with other team members before the visit to help in preparation.

So this is just one example of from the team that has worked on this particular project that we have determined as a one strategy that you could guide those conversations with providers, especially if you're new to having these sorts of conversations with people with communication disabilities.

Once again it's one way, there's lots of other tools out there and we're working on our website to highlight more and more of what's available. But this could be one way to use those tools.

You can go to the next slide, and I'm going to share a little bit more about some of those other steps and strategies that we were talking about in the past.

So just generally, for general communication strategies, once you identify needs, of course, we want to make sure that we're doing what that unique individual needs for their visit and what they identify. But some general best practices is to always speak directly to the person rather than their family member or companion.

Ask them what they need to be successful. Check with persons to make sure their needs and goals have been accomplished.

Just because you ask one question and you identify the needs doesn't mean that's where your job ends. It's a continual conversation. Remember, people change, things change, and it's important that we're checking in to make sure we're receiving feedback from patients and people to make sure that what they need has been accomplished and ways that we can improve our services as well.

You can go to the next slide.

Another important consideration and thing to do is that you just use those identified strategies, tools, and technologies to achieve communication success.

Sometimes providing an accommodation might mean bringing something into the visit that is ‑‑ that might be new to your use or expectation, but it's not always about bringing things in. As in Anita's experience, it can be as simple as not taking tools that are known to be effective away, as in her hearing aid chargers and her phone.

Those were essential tools, and just by letting her have those with her, that could have really improved that whole experience on her first night in the emergency department.

Another thing to think of is to make sure that you're planning and allowing for adequate time for the appointment and interaction.

Especially if you might be doing something for the first time yourself, like, working with a new tool or a new service that you've never done before. Give yourself that time and space to try something new.

And also make sure that you're givening that individual the time and space to engage in those conversations and that feedback and ask questions that they need asked and responded to.

And you can go to the next slide. How can you learn more about your communication access possibilities? So that was one area, speaking and expressing.

There are so many different combinations and unique things that a person might need to benefit from a successful visit.

And here in the patient‑provider communication team and in this particular grant team, we're constantly trying to compile a list of existing resources about how you can support people with communication access needs.

And in all of these different domains: Seeing, hearing, expressing, understanding, remembering, learning, and moving.

Things are constantly changing, and we're trying to constantly add to the website and it's all freely available. A lot of the content is download‑able so you can put it in a clipboard or an iPad so you can bring it with you as reminders.

There's also information about resources, about current laws and regulations guiding communication access. And really practical examples about how people who have been in a similar situation has learned how to use these strategies in real life.

And we're continually adding more information as time goes on. You can go to the next slide. All right. And one just kind of ending for my part is if you're interested in becoming more involved, we would love to have your feedback.

And the goal ‑‑ one of the goals of this project is to refine this tool that we created and continually add content to the website. And we have just our viewpoint, our lenses that we have looked at the world, our experiences.

It's really important that you are including as many people as we can within this process. So if you're interested in rating the tool, giving us contact information to give feedback or sharing resources you found helpful or stories about how you have taken communication access to the next level, we would love to hear from you.

So feel free to e‑mail us at the end of the presentation or put information in the chat.

I think that's all that I have for this presentation. I am going to turn it over to on the next slide to my colleague Rachel Santiago, who will give you a little bit more examples about how to support communication access in her space.

>> RACHEL SANTIAGO: Thank you so much Jess. Hi everyone. I am Rachel Santiago. I am a White woman with blond hair in my late 30s. Coming to you from Boston Children's Hospital today.

And I just want to say thank you for having me here and letting me talk about as a provider working in a pediatric institution and share a bit from that lens.

As Jess already mentioned, unfortunately, experiences like Anita's are not unique.

And people of all ages can encounter very challenging and unfortunately unsatisfactory healthcare experiences when their needs are not appropriately met or respect.ed.

I feel very fortunate to work at an institution that has done a lot of work in this area. And speaking to you as a healthcare provider, much of what I'll share today is through that lens.

I'd like to highlight some important takeaways to ensure that our youngest and most vulnerable patients also experience successful communication access, which they equally deserve.

So I think it would be helpful to just take a quick moment to imagine what it feels like as a child to visit the doctor or the dentist or to go to the hospital.

I for one was always very nervous. I always had a pit in my stomach. And I never let me provider begin without telling me every single step that was about to happen because it helped me stay a little calmer.

But imagine you have a communication disorder or disability. How would you make your needs known? How would you be able to tell someone how you felt during this experience?

Would you be able to understand what's going on around you or about your healthcare plan? How would you want your healthcare providers to treat you during these encounters?

I recently asked one of my patients these questions. He's now 21 years old but I met him when he was nine.

He's to had to spend a lot of time in the hospital, so I've seen him evolve through his healthcare experiences.

This patient of mine has cerebral palsy and spastic quadriplegic.

He used speech approximations to spelling with a letter board via eye gaze to a communication device he controls with his eyes.

I asked him about his experiences with new providers and what we would want them to know about him.

His No. 1 request was very simple, actually.

It was to take their time and be patient. I'm going to say that again. Take their time and be patient. It's so simple and so effective.

He said he needs them to not rush, but to get to know him and his needs.

He copes best when his providers talk to him about his interests like football. But also when they understand his very specific requests like which medications he wants by mouth versus by his G‑tube.

He told me he wants providers to know that he can talk, he has a lot to say. But he needs time and he sometimes needs communication tools to get his message across.

I think his requests are really quite simple and easy, but providers must take the time to ask him the questions and allow him time to give his responses.

So good reiterative from the things you've heard today, but please take your time to ask.

I think ultimately we need to remember when working with children they are not small adults. Their needs are incredibly diverse, and as we know their skills and coping needs, personalities, self‑advocacy skills, these are all evolving by the minute.

That being said, I have a few consideration to share. And again, it's a little reiterative, but it really matters.

Please always start by asking. Just ask.

Begin your encounter by asking about accommodation needs for the child but also for the caregivers because they are protected under the law for accommodations.

You might ask how does your child best communicate or is there anything we can do to help your child understand their care.

I think asking shows others that you really do care to know. We really need to ensure that children's communication access needs are upheld; children are very keen observers and can pick up on context in ways that we might not realize initially.

So again, speak directly to the child, to the person that you are taking care of.

Be sure to acknowledge them, keep them part of the conversation in an age‑appropriate or developmentally‑appropriate way. That means not speaking over them or just to their caregiver.

At least without their permission. If a child utilizes any aids or tools, be sure they have reliable access.

It's no use if their tools are under a stack of pillows in the back of the room, of course.

And that also might mean consulting or getting other providers involved to assist, for example, speech‑language pathologists, occupational therapist, child life therapist and so on.

Please document these accommodations in the health record. The communication access tool is one amazing way to capture this information. But if it's not disseminated appropriately, it may not reach the people it needs to.

And of course please treat your pediatric patients with respect. Knowing a child has a communication access need should never reduce your interactions with them.

We should not be making assumptions about their communication, and we need to find out about accommodations and provide them.

And not add an added burden to families to translate for their child.

Especially important during acute situations and emergencies when we don't have time to plan ahead. Because these experiences are already overwhelming for caregivers too.

So treat your patients with the dignity and respect they deserve. Thank you so much. I would like to kick it over to Tami now.

On the next slide.

>> Thank you Rachel. I am Tami Altshuler, I'm a 45‑year‑old White Jewish woman with long brown hair and wearing a black shirt. I use she/her pronouns. I'mgoing to try very hard to speak slowly, which is an important thing for this Webinar.

I am a speech‑language pathologist and clinical specialist in patient‑provider communication at NYU Langone Medical Center in New York City.

My role focuses on ensuring communication access for patients during their hospitalizations.

Rachel spoke on the pediatric experience, and I'll now focus more on the adult side.

The patient‑provider experience occurred several months ago. How even when an accommodation need is identified on the spot and not immediately available, the patient and their healthcare providers can work together as partners to develop practical solution‑based actions.

A woman with significant hearing loss arrived at our emergency department or the ED we call it. With stroke‑like symptoms and immediately communicated her need for CART, which is communication access realtime translation.

A service that provides realtime transcription of spoken words into text.

Typically, she requests CART in advance for outpatient appointments and procedures to ensure the accommodation is in place.

However, due to the urgency of her medical condition, she was unable to do so.

In the ED providers followed all the appropriate steps to get CART, they called language services to request it.

Then language services reached out to their CART vendors, and unfortunately the vendors were not able to fulfill the request due to lack of availability of captioners.

The patient was admitted to the hospital. She grew increasingly frustrated by the lack of CART, which made it difficult to interact with her entire care team.

And when I arrived at her bedside for a standard speech and language swallowing evaluation which all patients with a stroke diagnosis get.

I observed her nurse writing out information about her medication ons a dry erase board.

Both the patient and the nurse shared how come ber some this process was.

The patient said this didn't meet her communication needs and in her words her needs were being "cut short". And she believes the nurse wasn't fully sharing information that she would have if she was communicating with her verbally.

I provided the patient with a departmental iPad, we have several to loan out.

And it had a speech‑to‑text app which allows providers to speak into a microphone and display the spoken words as text for her to reed.

The patient found this to be a reasonable substitute for CART during those bedside interactions.

But she emphasizes that for any procedure or new treatment, anything that would require consent and more complex information, she would still need CART.

And the speech‑to‑text app was certainly more efficient than just writing on a dry erase board, but there are concerns about its accuracy, especially in handling different accents and dialects, which are common in New York City.

Also background noise, which is very common in a hospital setting.

Medical jargon and the fast‑paced of speech which is typical of doctors and nurses, so New York City doctors together, that's quite challenging.

But a key takeaway from the story is a flexibility and collaboration and providing effective communication accommodations in healthcare settings.

So even when the ideal solution of CART was not immediately available, the patient healthcare team worked together to find an alternative that met her needs.

In the moment.

This demonstrates the value of patient‑centered care where patient's voices are heard and their input is integral in finding solutions.

However, it underscores the need for continuous improvement in accessibility as even the substitute solution had limitations.

So ensuring timely and accurate communication is critical to patient safety, satisfaction, and quality of care.

For improvement in communication access and accommodation needs in healthcare settings, it is essential to foster that collaboration between patients and healthcare providers.

This approach engages patients in the decision‑making process about their communication needs, and ensuring they feel empowered to express their preferences and concerns.

By implementing these problem‑solving strategies, providers can better understand the specific barriers patients face and tailor services to meet those needs effectively.

It's really important to create a responsive environment where patients and providers work together to enhance accessibility and improve those healthcare outcomes.

And I am going to turn this over to Sarah. I think.

>> Next slide. Okay. It's time for ‑‑ thank you, thank you Tami, thank you Rachel, thank you Jessica, and thank you to those people who have put in some questions.

Please do so. I want to start with Sheela. Her question is a perspective from someone with multiple disabilities and is a patient, and as also advocated for others who have gone through events where they are patients.

She has experienced something that I think most of us have, which is not being valued by medical systems, and treated as broken.

But not as people who know our own body, minds, and abilities.

So her question to the panel is ‑‑ and I think some of this comes out in what you've already said.

What must we do to make the systems understand that we know ourselves best? Who would like to take that? I know you all could.

>> RACHEL SANTIAGO: I can comment, at least. This is Rachel. Turn my video on.

Just a quick comment. You bring up such a very, very important point. We're talking here about a medical model of care versus a social model of care.

And the medical model ‑‑ is kind of the old way of thinking of common approach of something is wrong and we need to fix it, as you've said Sheela versus a social model of something is different and we need to be accommodate to be inclusive and equitable.

I think despite maybe adopting a social model of care, this is a really huge systemic problem, and I think that there's much to be done. As a provider I try to do this through education.

I am not a person with a communication disability, but I do work with them every day. And we talk a lot about self‑advocacy.

But the burden should not be yours alone. And I think that message that's been reiterated a lot today is working together. I think providers or healthcare professionals really need to partner with consumers to adopt this social model of care.

So that we're really not doing what you have just said, looking at people as broken or something that needs to be fixed. So that's my quick comment on that.

>> So Sheela has a response to that. And she's telling us that she's totally blind and won't be able to communicate in written print on paper.

So there doesn't seem to be any real means to brinl the barrier of the assumption of a printed document regarding medical needs and wishes.

And how are we ‑‑ please address this in a meaningful way. I can write electronic docs, but how can these docs be changed in systems as they change in life?

This really directly, Anita your story, this is directly where you also ended up when you were thinking about what the barriers you face.

There was nothing in your health record. There were health records, some in the clinic and others in the hospital, but nobody could see them.

And except in those particular situations.

So one of the things I know Anita said was not seeing patients as partners in healthcare is obviously one of the reasons where this project is being addressed. We are trying to address this, but it's a tough‑y.

Anybody else want to comment on that? I'm sure others would.

>> DR. GORMLEY: I can ‑‑ I mean, my expertise is not in this area necessarily, but I think one consideration that I've really learned throughout this project is just the importance of digital accessibility, especially in our electronic medical record.

I know that our team has really worked in the small area that we have control over, which is our website, to really work on making sure that the tools are able to be accessed by screen readers effectively. And not in an annoying way for someone who is using a screen reader we want to make sure it's a pleasant experience and not adding more challenges to

Using a tool like we presented today. But I think that you point out a really important piece about as we're moving towards a lot of these electronic health tools, a lot of it is we need to make sure that those records are accessible in a lot of different modalities.

So I think that there's a lot of work to be done in patient portals and these big systems needing to design those patient portals and records for folks who have different needs in order to engage with those tools.

So I'm hoping that ‑‑ yeah, Rachel is putting a great tool here in the Disability Equity Collaborative is really making some nice strides in this area.

And pulling together what is coming down in terms of law for digital accessibility and how to make those implement‑able. But there's no ‑‑ this is a really big challenge. I wish we had more solutions or success stories of this.

And I know Anita if you have any suggestions or tips that you've had or anymore insight in this. Not to put you on the spot, of course.

>> I want to point out in the chat that Todd said, yes, equal access to digital tools for participants such as MyChart. And that's getting definitely to where we know want to make big changes, which is how much better medical records could be and need to be.

I know we're kind of short ‑‑ getting short on time. But I do want to actually go to another question that I think June has. Tami can CART emergency response time being part of the CART contract with a substitute solution? The second best fix been offered if you weren't involved?

>> I was actually responding to June privately. But yes. So No. 1, this was brought up in a language services meeting between language services, the medicine team, and rehab.

And we are looking into a virtual CART option that would be immediate access. So there is no issue with finding ‑‑ you know, with the vendor of finding an available captioner.

It's a great question. We're working towards a lot more on accessibility within the health system. I have personally ‑‑ we use Epic, which is our electronic medical record.

And I have now flagged this patient on a private list that I have for any time she's readmitted through our ED or for any procedures.

I see that she's there and I know she has this accommodation need. So if CART is not available, I can bring the iPad to her.

That is not the best fix, but once again, problem‑solving, it's the current fix.

And while we're working on a much better solution.

>> I have a question from Adina. It's a big one. Just like changing medical records is kind of a big one.

But Adina's interesting in asking how to adapt the tool for quick identification of communication access needs during other forms of direct service or applying in a larger scale policy?

In other words, what are some ideas about how to actually, I think, use the tool across settings, situations, etc. And I think this can be reflected not only in how providers use it, but how consumers of healthcare might use it.

>> DR. GORMLEY: This is Jessica here. I'll try and talk a little bit.

I mean this is such a good ‑‑ a place that we have more questions than we do answers.

One of the things that we've ‑‑ an approach we've taken as a team, and I think it's to start small. That is not a very set ‑‑ it doesn't feel good. But kind of starting small but seeing how it feels to start implementing it.

And that could be done just as a single provider, or a single unit or a single team.

And then check in frequently to see how did that work? How can we make this better. How can we change tools. How can we change habits that we're doing?

I think that that would be really helpful that there isn't necessarily a perfect, you know, road map yet of how we can track some of those things or start implements.

But I feel once we start doing it more regularly and kind of measuring our impact, I think we'll know from there how we can start kind of presenting findings. Sometimes me as a provider all I have control over some days is what I do.

I think just starting there can give really good examples of, you know, gathering your teams, trying things out.

As a consumer, starting to try out a couple tools or have a plan of how you would kind of share this information onto all of your healthcare providers and reflecting to see what went well and what went poorly.

And giving us feedback about how we could improve that experience as we're putting tools out there could be really helpful.

So I know that's probably not too useful, but we have plans in future Webinars to really think about how we can make some big system change and have some other viewpoints as well. Thanks, great question.

>> And as somebody with a significant hearing loss or impairment or challenges now at my age, which keeps getting worse, I have an appointment with a dermatologist on Friday.

And I'm going to take the communication access tool filled out with me. Because the last time I went they were playing music in the examination room.

And I couldn't understand what the provider was saying.

And I had to ask them to turn off the music.

So as a consumer of healthcare as well as a provider, it's going to be about advocacy on both sides, I think.

>> Priya: This is Priya, I wanted to jump in and invite Anita into the space. Anita, you are off mute. No worries if you can't come on camera. Just wanted to make sure you knew that you are in a position to respond to questions.

>> ANITA AARON: So I wasn't being heard earlier, so I assumed perhaps I was still on mute. That's why I haven't said anything.

I do think that advocacy on both parts is what builds a better relationship. When I make suggestions to the doctor or the clinic, provider, whatever and they make suggestions back, it makes for a better outcome.

And I've seen it in small ways and big ways. Like when I checked in on a particular department for a typical clinic visit, and the woman behind the counter asked me did I need assistance getting to the exam room?

And other times I've been the one that said, I will need assistance getting to the exam room.

It's just so nice on that very easy high‑level thing to know that there's two of you working on this.

>> That's great. I thank you Anita. And thank you all who presented and then participated in this discussion. We could go on. I see some other comments in the chat, etc. But we do need to wrap this up.

So we have a next slide, I believe.

We have two more Webinars scheduled. One in October that will focus on tools for consumers to use. And you got a bit of a preview on that just a moment ago.

And then in November, integrating tools that we are integrating the communication access tool plus resources that we will be developing to improve healthcare outcomes. And you will find in the patient‑provider communication website.

So please do join us on those.

And then the next slide, we are going to ask for your feedback. We hope that you will also provide us feedback regarding the tool when you go on the patient‑provider communication website and test it out.

And we would appreciate that. But it is now time to have our post‑Webinar survey.

And Priya, I'm hoping that ‑‑ yeah, okay. Priya, can you give the instructions since I don't really know how to do this?

>> Priya: This is Priya. Absolutely. For folks who are able to access the poll via Zoom, please feel free to answer the questions in the poll that just popped up for folks.

If the poll is not accessible to you via Zoom, you can click the link in chat to access it via a Google Form.

And as always, if anyone would prefer to receive this link via e‑mail, and that's more accessible to them, please let us know via e‑mail at Priya@disasterstrategies for that alternative format.

You only need to do one version. You don't need to do all three. So please choose the best option for you.

>> Should I read that maybe? Or not?

>> Let's give folks just a couple more seconds to respond to the poll on screen if that's accessible to them.

And then we can end the poll in just a moment.

>> Okay, I was just asking if we could read them the questions. But that's fine.

>> If you would prefer that, that is A‑okay. Yeah.

>> So No. 1 is: I can identify practices. I will start, stop, continue, or change. I'm not sure what that means.

And then the second one is, I can apply the information personally. Strongly agree, disagree, neutral, agree.

>> Just to continue with those questions. Question 3 reads I can apply the information to my work. And those options are: Strongly disagree, disagree, neutral, agree, and strongly agree.

And the last question is, I use and then (check all that apply) chat, question function, captioning, Spanish translation, and ASL interpreter.

We're going to give it another 5 seconds here for folks to finish their thoughts.

And now we're going to go ahead and end the poll. Back to you Sarah.

>> Okay. So I can identify practices. Starting ‑‑ so we have starting and continuing, a high percent.

I can apply the information personally. 58% strongly agree. And 17% strongly disagree.

I can apply the information to my work. 67% strongly agree. And neutral is 17 and strongly disagree is 17.

Finally, I use the chat most people 92%. Question function 25. Captioning 33. ASL interpreter 8 and Spanish translation 0.

Thank you for your responses. Any questions or discussions about the survey? Okay. I think it is wind‑up time.

And we're right on schedule. Any comments you want to make, June? June is on the Webinar. June is our Project Director.

>> No, I wanted to thank you all. I think we did a great job. And I also appreciate the listeners, and the depth of their questions. And they will inform our Webinar 2 and Webinar 3. Giving us some good things to integrate and I thank you. Back to you Sarah.

All right. I think it's wrap‑up time. Unless there's anybody that has any final words? Thanks to the interpreters, both the American Sign Language and the Spanish interpreters.

And thanks for your ‑‑ I suspect patience with us who are not slow enough in our speaking. And for the partnership for enabling us to be able to reach so many people in an inclusive way.

Thank you.

We've got a lot more work to do, and we're keeping on keeping on.

So I hope you'll join us and give us feedback.

>> Priya: And just to wrap up, thank you all to our presenters, our planning partner, our language access team, our funder Ability Central and all of you.

If you have any questions you can connect with Patient‑provider Communication at patient‑providercommunication.org or contact Megan at Juring@gmail.com and she can connect with the rest of the presenters as needed.

Thank you all so much for joining us.

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