WVU-CED Ability Grand Rounds-Improving Healthcare for Adults on the Autism Spectrum-(Zoom)
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Remote CART Captioning

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>> Hi, everyone. Thanks for joining us, I think Dr. Raymaker might have some issues connecting. She was on here. Give her a couple of minutes to get back, to log in.
I'd like everyone to please mute your lines as well.
>> Hi, Dr. Raymaker.
>> Hi. I'm sorry. I got disconnected. I don't know why.
>> Okay, good. I am Melina. So I'm going to be helping you, trying to facilitate for you today. So I do not have the latest version of your presentation. Do you have that? And would you like to take over sharing the screen when we're ready?
>> Yeah. We'll do that.
>> Do you need a few minutes to get set up, or are you ready?
>> Actually,--
>> Actually, I got all said up. I had everything set up like a half hour early.
>> Great. Then I'll go ahead and introduce you. That way we can get started.
So, thanks, everyone for joining us. Today we have Dr. Dora Raymaker from Portland State University, joining us. Her presentation, titled Improving Health Care for Adults with Autism Spectrum has been very well -- they had a lot of interest had this one. We've glad to have her with us this month.
Um, Dr. Raymaker is the Co-Director of the Academic Autism Partnership in Research and Education and Associate Editor of Autism in Adulthood. Thank you. We're happy to have you, and glad this we could get this worked out. I'm going to hand it over to you.
>> Thank you.
>> So, um, so thanks again, so much for having me. As Melina said, I'm faculty at Portland State University of Research Institute and Co-Director of the Academic Autism Partnership in Research and Education. AASPIRE. I conduct research with the autism and mental health. My focus is a social intervention research. I do employment and mental health research. But I have been for autistic adults-- you'll hear about the work that AASPIRE has done.
My work with AASPIRE I straddle both worlds as PI AASPIRE, I came to AASPIRE as an autistic self-advocate. So kind of in between. I've been a long time, kind of human rights advocate as you can see from my baby picture. So my whole thing is science for social change.
Just a quick note of language, in this talk, I'll be using identity first language with respect to the

people in autism spectrum. I know many of you have been taught to use person first language, or person with autism. But the autistic community feels like the deaf community the way we get called. In general, I advocate for person centered language which is to use the language that the person themselves actually wants. I'm happy to answer questions about this in the Q&A at the end of the talk.

So today, I'm going to give an overview of AASPIRE and community based participatory research so you get where the context of this information comes from. And then I'll get into health care disparities and barriers to health care for autistic adults followed by ways to understand and reduce some of those barriers. Finally I'll show you the AASPIRE toolkit and accommodations tool that you can use in your practice with your patients or with the people you support or maybe with yourself, if there's anyone, in the audience who is like,-- so just some things about where this comes from. So AASPIRE was founded with my partner, Christina-- who is the medical doctor and public health half of our collaboration 14 years ago when she lured me into a conversation with promises of reading autism papers because she knew that I was interested in science. We read about maybe three of those before the issues became really overwhelming. That autism research was not very useful or relevant to our lives. There were some really bad research designs because the researchers didn't understand what the experience of being autistic was like. It was stigmatizing or marginalized us in some ways or maybe had the potential to cause harm.

Fortunately community based participatory research is an approach to science that was designed to help with issues just like those. So CBPR is an emancipatory research that was developed with public health. It's been a around for a while. It takes approach to science. So the idea is that community partner service coresearchers with academics in all phases of the work to figure out what you're going to study all the way through disseminating it through the communities. And the lived experience and community knowledge of the nonacademic partners is valued equally to the academic exercise. Autistic adults including health care providers, clinicians, and supporters were involved with all stages of this health care work that I'm going to be talking to you about today.

So we've now been working on health care projects for 14 years because that's the place we started at. Over multiple national tutors of health, with a lot of learning. And I am really proud of who we are today and what we've done. These are by no means of pictures of everyone who has had their hands in this work. It shows a fair number of them. This is from 2018 and 2019 when we had in-person retreat. This work that I'm talking to you about is collaborative and collective and all of ours.

So yeah, it's been going on, we've been actively doing this, funding, in a funded context for ten years now. There's a slide in the end that has the citations for all of this. I assume you'll be given the slides. You can email me and I'll send it to you. I'll send you the actual papers also, if you have trouble with payrolls.

The first study we did was survey of autistic adults, non-autistic adults with disabilities and without disabilities. That study included a survey of barriers to health care. We then did a qualitative study to better understand the experiences of autistic adults, their supporters and providers in health care to better understand and explain the disparities we saw in the first survey and to get new information about what we might be able to do about this.

We used this and the expertise of our CVPR team for the toolkit. Recently we conducted a larger project or integrating the toolkit into various health care settings. As part of that we surveyed providers in their confidence in providing care it adult autistic patients. I'll be talking about the findings and recommendations that are from those studies.

We also have new patient measures for assessing health care interventions and we had a lovely scholar who was with us last year from Australia. She led a qualitative study about hospital experiences for autistic adults. I'll share a bit of her findings. But that's not as much the focus of this today.

So this is kind of just the disparities and barriers to care.

So as you probably know, autistic adults have worst health and health care outcomes than the general population which includes more frequent, co-occurring physical and mental health conditions, higher rates of mortality and morbidity. Health care utilization and cost. Lower, use of preventive services, more on health care needs, lower satisfaction with patient provider communication, and more barriers to just receiving care even in the first place.

And that's not just us at this point. That's a large body of research that has been done that has explored the basic bigness of the problem. We're talking mostly about barriers and ways around them. I'm going to go into detail of the work we did on understanding them. So in our health care disparity study, we included a measure of barriers to health care that have been originally developed with the cross disability community. It was a community partnership at Oregon science university. We developed as a team to include items that are autistic community partners-- -- so the survey, broadly included items around emotional cognitive, health care system provider attitude, communication, sensory, socioeconomic support type barriers. We have short and long form measures available. Which exhibited some good initial psycho metrics and responsiveness to change. They could be useful in intervention testing or even as a broad idea for what is, what barriers are being experienced by someone.

Using a long form, we surveyed 209 autistic adults, 55 non-autistic without disabilities and without disabilities. And we matched forever age and gender. The autistic sample selected greater number of barriers than the other groups.

So these are the top ten-- um, barriers for autistic adults. The top one fear or anxiety was-- that was selected by more than a third of the autistic sample. That was actually the top barrier for the non-autistic spams as well. But for the people without disabilities, it was only by 10% of the sample. You can see there was a 20% difference in even what was the biggest barrier. Or people even having a barrier in the first place.

So the next in order of how many people selected them were not being able to process information fast enough to participate in realtime discussions about health care; concern about cost, facilities causing sensory issues, difficulty communicating with providers, not understanding how to use the health care system. Sensory issues making it too difficult to communicate, social isolation, embarrassment, and worry that the stress of interacting with the health care system will cause a meltdown.

The issues with quality health care access for autistic adults isn't just barriers that reside with the patients on their end. There's also increasingly documented issues with health care provider knowledge and self-advocacy on their side. AASPIRE created an adult advocacy scale to measure confidence based on the qualitative studies and the expertise of the clinicians in the group. We used it on 143 internal med and primary care providers across different settings.

So the results which were consistent across setting practice, and practice type were that, only a quarter of the providers felt confident communicating with adult autistic patients. Only 53% were confident performing exams and procedures. Only 40% were confident, accurately diagnosing non-autism medical issues. 38 were confident that they could help their autistic adult patients to stay comfortable and only 14 to 15% felt confident identifying and making accommodations to improve health care access for their patients which is where hopefully some of the tips we have come in.

So how patient barriers provider barriers and system barriers interact is something that's, being-- works in this population-- there are multiple models out there that are similar to this. This is from our qualitative study with patient factor, such as communication skills and sensory sensitivities, body awareness processing speed, atypical communication challenges. That interacts with the level factors, how knowledge al people are about autism. How correct and incorrect their assumptions are about individual patients and their abilities.

Their ability to accessibly communicate their openness to providing accommodations and their skill and integrating a patient supporters when they exist. It all exists within the context of the broader world where their system level factors including stigma and discrimination, availability of supports to the person, the health care system that exists within and all of that kind of as a lump leads to the success of somebody's ability to have a good health care interaction.

So that was a whole lot about the problem. I kind of-- a kind of numeric sense. But I would like to focus now more on getting a deeper understanding of what's behind these numbers. And looking at some of the solutions might be to getting rid of them.

So the first big category here is about communication and interaction that's going on between the patient and the provider.

One of the things that people autistic patients experienced and their supporters also experienced was there was a hypotension in the healthcare systems for faulty assumptions about the patient.

So for example, some people who were nonspeaking, felt that, that translated into providers thinking it meant that they were also non-understanding. So this person said, just because I have difficulty expressing what is going on with me, does not mean I'm stupid or making things up. On the other side, people who have fluid speech aren't always communicating adequately. So this patient said, usually when I demonstrate a large vocabulary or fundamentals, my needs around communication are ignored. My choices is to pretend to be less intelligence or to be confused, or stressed out.

Patients talked about needing a specific node in order inform hundred in these stressful communications. This patient says, I prefer and find it easier to communicate in text. With every doctor I speak to, they wave the note card and look at me to ask the same question answered.

I wish health care providers would read the notes I made for them. I wish they would be patient as I pause a lot and stutter when I am overloaded.

So here are some tips that we have for dealing with those.

First is for providers and offices to get really explicit individualized information on the patient's ability it understand spoken language, to speak back, to read and write, if they use any alternates to speech to communicate what they're preferred mode of communication is even if they're able to do multiple modes. Their ability to use the telephone. A lot of us have trouble with telephones and you can't assume that they can be used.

And the degree to which communication normally varies based on environmental factors or stress because it may not be consistent depending on what's going on. And then for the provider and office staff to use the effective communication mode for the patient, even if that means it's not what the provider usually uses.

Another communication related thing that we heard a lot about was the need for literal and precise language. Where language pragmatics, so the social use of language can sometimes be a bigger barrier for this population than the vocabulary itself or the sentence complexity.

So this is a quote from somebody, a supporter of an adult child who related they asked him on a level of one to ten where is your pain. First time he said, how do you weigh your pain? I don't weigh my pain. And this is from a patient. How do you feel today? Can you describe your symptoms? I can somewhat answer this but not fully. The starting point, not the endpoint. Specific questions related to symptoms are good. Does your side hurt? Are you keeping food down? And we heard a lot about anxiety of people who didn't feel like they could answer a question, particularly a general question precisely enough. And that really heightened people's anxieties.

So here are some tips around language. Of course be very concrete and specific which sounds obvious by is actually very difficult for people to do especially providers who have been taught to open patient interviews with general questions. It's almost like they need to be retrained to do things in a different way.

Avoid figurative expressions and figures of speech. Avoid broad questions. In some cases some people may need mostly closed ended questions or ones that patients can answer with a "yes" or "no." Or they might answer better if some samples or instructions are provided. Showing patients a list of symptoms to choose from can be helpful. Giving examples of the types of things people might experience and have the patient tell you if they also experience them.

Reminding patients that it's okay not to know the answers to questions or not to be exact, help with that anxiety about specificity. Give patients direct and concrete examples when discussing your plan. Direct patients to resources about health conditions and treatment options if that would be appropriate.

The language, of course is not just what we say. It's what we do. We heard a lot about people having difficulty processing body language or self-regulating or managing stress. That would make providers or office staff make assumptions about them that weren't actually the case. For example, lack of eye contact or-- the office is sometimes misconstrued. Sometimes it's a way to manage the stress or pay attention it a difficult topic. This patient says, don't assume no eye contact means we're not listening or being deceptive. It's a way we behave to regulate stimuli and not be overwhelmed too much at once.

So some tips for that, don't try to force a patient to make eye contact. This happens to me a lot. And is very unnerving. Don't assume a patient is being rude or trying to signal something if they're pacing and not making eye contact. Sometimes they have to be told explicitly, I'm going to act like this. It's not what you think it means. And letting patients behave in self-calming ways to be able to take in information. Allowability and giving permission to do that can help.

I don't remember the processing speed issue was the pretty much the number one barrier after that common fear that kept people from being able to participate in their health care.

So slow processing, of course, impacts communication. But it's also related to responses to sensory stimuli. So indicating that something is tender or if you can feel something before the provider moves on as well as the ability it make decisions quickly in high stress situations.

So this is a quote from a health care provider we talked to. "it might take a while for a patient to effectively communicate. It takes them a bit, extra amount of time to process questions, process information, sometimes the responses are, you know, going to be delayed than say the typical patients might. For instance, if the patient receives questions or information to describe or identify their conditions or symptoms, they might not be able to answer right there. They might need to go home and think over it and be able to answer the next session or even call in and describe it."

Some strategies for that, uh, just realizing and making space for giving patients time to answer, process what has been said, making sure explicitly, are you ready to move on? Do you need more time? Giving patients extra time to process the things they need to sense before they respond. Have you had enough time to tell, do you want me it keep pressing? If possible, schedule longer appointments. I know that's not always a reasonable tip. But-- encourage patients to prepare notes in advance about what they want to discuss and make sure that providers and staff carefully read the notes that patients bring to the visit. It's not just there to-- write down important information or instruction so patients can review it later outside the office. It appropriate, direct patients to detailed resources about their health condition so they can review them at their own time and if necessary give patients time to make decision and communicate at a later time or schedule a follow-up for it.

They may also need to talk it over with a trusted person.

So the next kind of big group after communication stuff is sensory issues. And everyone has sensory issues in health care. Many people don't like fluorescent lights. But not liking that for most people, doesn't make it impossible to talk to your doctor. So it's important to understand that these sensory issues are not to be brushed aside because everybody experiences them. It's a different level.

So this person, um, this is actually one of my favorite quotes because I think it's just a really good description of an experience related-- I have just traveled to the office in a very loud bus or train. The lights in the office are very bright and exacerbated by the white walls. Sometimes the waiting rooms are crowded and I cannot filter out the background of people talking. I feel diss oriented by being led down long hallways. I'm not able to bring my concerns because it's all I can imagine to what the doctor is saying so I can respond to his questions.

So sensory issues, some ways around some of those, when possible, if somebody is light sensitive, use natural light. Turn off fluorescence, make the lighting dim. Try to see the patient it in a quiet room if possible. Have one person talk at a time.

Avoid unnecessary testing of the patient, for example, to express concern. Warn the patient before you're going to touch them so they can prepare and they know when in the expected. And encourage patients and supporters to bring objects to reduce or increase stimuli.

So you know, the office can be noisy at 3:00PM. Bring some headphones. It's bright in here and I can't do anything about it. You may want sunglasses, things like that. Sensory items.

So there was a whole lot of people have-- um, the sensory things extend into body awareness, pain awareness and other aspects of sensory processing other than just being sensitive to the stimuli.

This includes difficulty discriminating abnormal from normal body sensations, pinpointing the location of a symptom, describing the quality of a sensation. Some of us have really hugely hyper or hyposensitive pain thresholds. Some of us have difficulty recognizing normal body stimuli such as hunger or the need to you're nature. And here are two quotes about that from different autistic patients.

I don't know my own body. So when I feel all of these different sensations everywhere, I don't know which is the real problem and which is just sensation. The problem is it is difficult for me to isolate specific sources of pain and identify duration and intensity. It's sort of like the equivalent to white noise.

So unfortunately we haven't really figured out great ways around this. One is just to be aware that it's a thing that could be happening, awareness helps. Consider the possibility that differences in body awareness might be affecting how the patient rocks or describes the symptom or how they respond to their illness. It's possible you may need to do additional testing or imaging because the information from the patient's experience might be limited.

Okay. So the next kind of big category is need for consistency. We know why that's important. This patient says, meeting new people is difficult. I was always shuffled to a specialist, it was extremely scary and anxiety provoking. So before a visit, some things that staff can do is let the patient and supporters know what it likely to happen during the visit. Avoid rescheduling appointments if possible and notify patients as quickly as possible when the schedule changes, prioritize their notification. You can give them pictures so the patient or supporter, take pictures of the office or staff to get used to it. When the patient checks in, let them know how long the wait is likely to be and give warning if there's unexpected delay. I know that you can't often tell. You can't say, well, exactly, we are running exactly 20 minutes behind. But even saying there is an uncertainty that we're running behind and we actually don't know by how much could be five minutes or be an hour, that's something specific that people can hold onto, and they know then what the range of expectations is. So there are ways that you can give something specific even in an uncertain situation.

Um, so some-- this is not true of every autistic person. And nothing that I am describing here is a universal experience because again we are all aware of the heterogeneity. But some people have concrete or visual ways of thinking, some people have trouble with the abstract nature of time and time questions.

Sorry, my cat is telling you she has never been fed in her whole life ever.--

So you can help patients answer questions about time by linking to important events in their lives. This is around the time of your birthday. Do you remember? You can work with the patient to explain time based recommendation. For example help them set an alarm to take the pill or an action of doing something-- if it's somebody who has a well established, rigid daily routine link their treatment actions to the things that are already happening in their routine.

For visual or concrete thinkers, you can offer diagrams, pictures, models and also create or have your staff or the supporters create or work with the patient directly for them to create themselves, visual schedules or visual instructions for recommendations.

And then there's this whole area of quote, executive function that kind of keeping things organized, keeping track of things, sequencing things which a lot of us struggle with and get really, the people's ability to navigate a complex and difficult health care situation.

Here to are two experiences that come from patients. So this person relates with my autism it's difficult for me to understand and follow all the different appointments and procedures I have to schedule. And no one will help me because people magically become competent at these things before they turn 21. This is getting into some of the transition issues. Another person says, it's like having a list of 100 things you have to get done right away which you must memorize orally in the five minutes you spend with the doctor and execute without error even though you don't understand half the things you need to do.

So some ways to help with that are to write out detailed step-by-step instructions for the patient to bring home. Much more detailed than you would for other patients. Show patients what you want them to do while they're still in the office. Have them practice. Have office staff help the patient schedule their follow-ups, referrals or tests. Use the staff to provide support. Have someone show the patient how to get to other places in your office or medical center.

Sometimes navigating through space is too much even if it's down the hall and two doors over. Have office staff contact the patient or their supporters after the visit to make sure they've been able to follow-up. Sometimes again in the things-- flying at you too fast in the appointment. You get home and you're like, wait what happened? The patient worksheets or dairies to keep track of things and give them detailed information how to communicate with office staff during office visit. You can't assume all the steps, when I should call, how should I call
Overcoming anxiety about the-- get explicit and have a plan. (Reading Record)
So all of those things, you know, sensory issues, communication, body awareness, all of those things that I just kind of ran through are factors when exams and procedures are actually being done.
So here are some additional tips that we have for accommodating exams and procedures.
So first is just to explain and tell the patient what you're going to do before you do it. I'm going to, I'm going to lift up your arm. I'm going to press this cold thing to it. All of these things before it actually happens. And with times. I am going to press it to you for 30 seconds. Show the patient equipment before using it. If possible, not always possible, but you can let patients do a trial run of a difficult exam or procedure, practice it first. Tell them how long things are likely to take. They know then how much they have to hold themselves together during an uncomfortable situation or at least have some idea of consistency or when in the going to end.
When the patient-- warn the patient before doing something. Limit the amount of time they might be undressed. This is the tip we got that someone was sensitive to heat and cold. The coldness of being undressed was impacting their ability to relate to the doctor. Give patients extra time to process things, they need to see, hear, or pole. We talked about that. Allow the patient to skit, lie or lien or something for people who have motor difficulties. Let the patient use a signal they need a break. They might not be able to communicate it normally. (Reading Record) they might not be able to communicate outward but respond it a prompt. For some people there's nothing you can do and anesthesia--
Not every autistic person has difficulty with blood draws. Just like not every non-autistic person does. Those who have difficulty with blood draws it's a big deal. So some things that we heard helped people is to group blood tests so that you can minimize the number of draws, lying or leaning or things, numbing-- being very patient, using a calm voice, not doing anything startling.
Some people like having a detailed explanation of what would happen including how many tubes of blood you need.
Consider antianxiety medication for some people. Give-- this is going to sound contradictory. We're talking autism. Some people like plenty of advanced warning so they can prepare themselves emotionally for the coming needle. But other people were like, no, what you need it do is distract me so I don't know when it happened. A lot of these things are highly individualized. That's part of why I like to talk about the underlying experiences and what the general issues that we're trying to accommodate are because, uh, this is like, um, like reasonable accommodations in the workplace under the ADA. These are all things that are negotiations between the patient and the providers it it's individualized and specific. These are starting point. There are things that we have heard help other peoples and-- and yes. So --.
So that is-- is happily, even though that is a huge amount of information that I just dumped on you, you do not need to memorize it or taken furious notes because it's actually online in our AASPIRE health care toolkit which I'm going to walk through a little bit next. So I'm going to

get out of that and I'm going do a little show and tell.

Here is the front page. It's got one slide for patients and supporters. One side for health care providers. On the health care provider side, there's a section caring for patients with the autism spectrum which is all the information that I just gave to you. through that last section. There's also some information on adult diagnosis. Some legal stuff, resources and links to things that patients might want to use.

And then over on the patient's supporter side we have these sort of do you know loadable checklist and monarch sheets to help people manage their appointments and follow-up care and understanding what do I need to do and have together in order to schedule an appointment? There's a health care navigation information about how to, how to do things-- before, during and after the visit. Some health stuff, some HIPAA stuff and extra organizational stuff. So that's all here. There's PDFs that can be printed out if you don't want to use the internet. And then there's this personalized accommodations report.

So, uh, briefly sort of switch back to here.

So before-- right around the time that I started working with Christina on these projects, I went to-- I had an appointment with a neurologist about migraines. And I wrote up this, like, highly detailed list of accommodations that I needed in order to get through this appointment. And it was, you know, beautifully spelled out, three pages. I write well so it was all polished. I gave it to the neurologist and she looked at it and tossed it aside, completely unread. And the appointment blew up and it was terrible. And Christina, um, shared-- she's an internist, and she shared an office with an intern shift. She said, I work on this autism health care project. He said, it's great. Let me tell you an experience that my wife had. This autistic patient came in with 25 pages of accommodation needs. And you know, she took one look at it. It was like she didn't know what to do. It was overwhelming. And as they started talking, it became clear that his wife was the neurologist that I had gone to see. So the whole purpose of this autism health care accommodations tool was, how do we translate things out of this highly specific patient way of communicating into something that is going to accommodate the health care provider who is so busy and overwhelmed that it almost turns into a disability in itself.

You know, we started laughing about this project because it almost felt like more disability accommodations were needed for the provider than for the patient at some point in getting this report out. So what it does is a patient-- or a patient and their supporter would fill out a survey about what's going to help them access health care. And there's a little translation program that turns-- checked off into more succinct provider speech with their jargon and reform at it into a report. We worked with a bunch of providers to try to find something that didn't immediately overwhelm them and make them want to throw it to the side like my experience with the neurologist.

This is what it looks like for the patient. It's just a very simple check box survey. You can actually pick more than three suggestions. This is an older version on my slide.

It will be prompted with the questions. What can make you make good decisions about your health and health care? You pick out three suggestions, whatever you want and these are things like, give me extra time to make decision even if it means I need to come back. Given a person I trust detailed information. So these are various accommodation things.

So just to give a little sample of what that ends up looking like. It starts out with a-- with a cover letter. Letterhead. It's got customized information with the patient's date of birth and their name. There are some things to help people schedule or help with transportation that would go in there.

Then it's got a section on how the person communicates and communication accommodations. Then it's broken down into the sections of recommendations for specific things that happened within the health care setting.
There's a section on how to understand the person's unique-- the way that their autism traits might express themselves in the office, any sort of triggers, meltdown triggers to avoid. It's got a section broken out for the staff. That will go to providers. The providers don't even need to see this part. This is for the front office staff, for some of the sensory stuff, blood draws.
There's a page for provider information because providers-- supporter information because we heard from a lot of people that providers didn't actually understand how to use the supporters. They would sometimes look to them at times when they should be talking to the patient or talk to the patient when they should have been talking to the supporter. This includes what role the supporters are supposed to take.
So that is what that ends up being like.
This is my fun bonus. I told you we had a scholar working with us. She did a project on hospital experiences and put together this sweet, little video. That I'll play. And then I will do questions.

>> In 2019-- [Video playing].

We interviewed 22 participants, including adults, their supporters-- based on the findings, there are-- communicate in accessible way. Ask your patient about their communication preferences, in clear and concise language. Consider using pictures, or writing things down. Use closed ended questions if you can. They're easier for an autistic person to answer. Do you need anything else is help. . Reduce sensory stimuli. Many autistic people-- [Off Mic].
-- [Video playing]. It was too much.
Provide routine and certainty. Explain procedures and timelines if possible. Any certainty you can give your patient can be helpful. However, if there is uncertainty, tell them so. Especially difficult for me as an autistic person was the uncertainty of the timeline. During hours visits between doctors, I was constantly afraid that the staff had forgotten about me. When possible, allow your patient--
[Video playing]

>> So yeah. Autistic adults experience disparities in health and health care including barriers different from others. But you can help with reasonable accommodations and we have some tips, a starting place and the accommodations record are report that can be used to help. So thank you. And, to the AASPIRE team and participants who give us that information. I am the associate editor for autism and adulthood. If anyone has articles, consider submitting. Also that might be research articles. But we have a section for providers, autistic people, supporters call insights that you can contact me if you're interested in insight.
And here's my contact information. So I'll open it up now.
>> Wow that's correct was a lot of really good information. I was making notes, throwing all different kinds of things, how can I share this toolkit. This is wonderful. Our families need this so much. So thank you for that.
I'm going to open it up for everyone on the call. Does anyone have any questions for Dr. Raymaker? And please remember you may be muted.
>> Would you periphery stop sharing my screen? Or should I leave the slide up?

>> Sure.
>>
>> That way you get my face real big.

>> Okay, it looks like we have a message in the chat. This is a wonderful training, thank you so much.

>> Hi, Melina, it's grace.
>> Hi, Grace.
>> Hi. So this superintendent-- well, this will lead into a question. One of my colleagues who is a speech therapist shared a great resource about, how we model communication. Because I was thinking of AAC devices. Whenever we're asking people to use a device, but we're expecting them to do it with our spoken language instead of modeling with them and communicating with them using that same device, so I'm wondering if Dr. Raymaker has any tips or resource for learning about augmentive communication devices or possibly sign language so we can communicate with people in their preferred method. If that makes any sense.
>> Maybe-- as a speech pathologist, I'm sure you have access it way more resources than I do as a systems scientist that does services work.
I can-- I can interestingly speak a little bit from personal experience because the neurologist story I related-- I'm one of those autistic people, depending on what's going around, more or less functioning and at the time I was relying heavily on a speech device that was outputting-- it was doing a text-to-speech. And that was one of the things that the neurologist couldn't handle. So I kind of feel there's a preparation that providers need to have of like, this is going to be slow. And you need to be respectful. Because the providers are going really, really, really fast. And everything to them is a big rush.
And I know that this isn't their fault. It's the way, one of the many ways our system is broken. But I think it puts people who are using speech devices or letter boards or picture boards in a huge disadvantage because of how slow it is.
So I don't think you're going to be able to get most providers in a typical primary care setting to use a C back. If it's a very dedicated provider and it's a long-term relationship maybe. I would focus just on getting them to respectfully give people time. I don't know that we're there in the place where the model back is even possible. Which might be pessimistic but--
>> Thank you.
>> I don't know if that addresses it.
>> No, thank you so much for your answer. Um, it means a lot. And I'm really thankful for this training because it's not only sharing information that is becoming more published. But it's also making aware and also driving more toward that acceptance. So thank you very much for this training and for your answer.
>> Yeah, and I do think that the more-- it's one of those, systems are very, very slow-- complex systems, the more complex, the slower it takes to change. It's not like you can implement a policy and everything gets better.
I think that the norm we normalize, asking for accommodations in health care and the more we normalize how to have adult patients be in the community health care settings, all of that works towards improving the situation over time.
>> Great. Does anyone else have questions for Dr. Raymaker?

>> I do. This is Elizabeth. It's nice to meet you. I just finished my MSW this spring and got a job at the CED. My professional pathway that I'm trying to forge is more on the autism in the adult arena. So I want to talk about-- there are a lot of services for adults in West Virginia just like there aren't a lot of services for adults anywhere in the spectrum. What national level organizations do you recommend that we at the CED can reach out to or me somebody who is trying to build that more both locally and at the state level to look for resources that either don't exist yet or might exist.

>> I mean, I'm sure that you already know all of the big groups like, you know, the autism society of America. And the AUCD. If somebody had asked me that question, in a different text, oh, contact your local AUCD.

I think some of it-- as you've rightly pointed out doesn't really exist. This is a place where I can kind of plug the community based participatory research model. And especially as you're connected to AUCD, sometimes building these certain-- this is kind of the pat that I'm on. And I work in school social work-- I'm not a social worker, but you're in my world. You need to get resources in order to develop, implement, and test out services. And that's a place where I see an ability to get money and resources is to, if you can partner with social workers who are doing research, the national institute of mental health, are willing to fund interventions for adults. And I was recently, it's not that recent anymore. A couple of years ago, our program officer at the national institute of mental health put together a conference for everyone who had been funded through the NIMH to do research for adults. There were 17 of us. The hole history of NIMH, only 17 Principal Investigators had gotten money to do intervention research. So when people come to me and say, why isn't there more research happening? It's-- I see it as not enough Principal Investigators to do this. Like the pipeline is inhibited just by the research side of it.

So I think as a more community oriented or provider oriented MSW, working with AUCD researchers or researchers who do intervention research, taking advantage of-- there's an NIMH mechanism to change your research, current senior research path into adult services, they're actually looking so hard for people to fill this gap that they will fund a senior researcher to train themselves.

So if you can find people within the AUCD who might be interested in going in together on-- doesn't have to be big. It could be like the organizations for autism research which I review them. There's applied autism research. There are places out there where you're partnership with the research entity could enable you to create some of the stuff to fill the void if you have such ambition.

>> Yes.

>> One possible path open. Community campus partnerships are a great thing.

>> Thank you.

>> Sorry, I was muted.

Okay, well, we have-- I want to be considerate of people's time. So I want to mention a few things that are in the CHAT. A lot of people saying, fantastic work. Thank you so much. A lot of people are interested in online toolkits. Some other resources about the Job Accommodation Network, so, um, I definitely think that you might have some follow-up questions after this. But I really want to thank you, Dr. Raymaker for presenting with us today. And, um, this training has been recorded. And it will be uploaded on the CED's website for those that have missed or are unable it join us. So I think that the resources that you shared will continue to be passed on. So thank you very much.

>> Thank you. Thank you all for having me. And you can just email me with any thoughts. I'm around.
>> Great. Thank you so much, everyone. You guys have a good day.
>> Thank you.