ASHLEY BROMPTON: Good afternoon. Thank you so much for joining us today. Again, my name is Ashley Brompton with the Center on Victimization and Safety at the Vera Institute of Justice. And I'd like to welcome you all to our webinar today. We are pleased to bring it to you as part of our 2020 End Abuse of People with Disabilities webinar series.

Today, the webinar that we're going to have, is going to be talking about meeting the needs of autistic survivors. You know, we have spent almost two decades now addressing the needs of survivors with disabilities, generally. And have learned a lot about best practices and how programs can best serve survivors with disabilities.

However, we feel very strongly that the best guidance and the best information comes from those with lived experience. Nothing that I, as an advocate, can learn or share will replace the lived experience of being a person with a disability, or a survivor. We believe that this work is impossible if you're not centering people with disabilities and survivors in it.

And so when we decided to do this webinar, we really wanted to focus on ensuring that the voices of people, of autistic people, were heard. And so we immediately thought of inviting Max Barrows to join us today. And luckily, we were able to get him. We've worked regularly with Max over the years. And much of our work would not be the quality that it is today, or as expansive as it is today, without him.

Max is Outreach Director for Green Mountain Self Advocates. And this is a position he has held since 2007. He mentors youth and adults with developmental disabilities to speak up for themselves and become leaders. He also leads the Self Advocacy Resource and Technical Assistance Center. Their technical assistance team, assisting local and state self advocacy organizations across the nation. He's also a member of our NoVo Coalition to end violence against people with disabilities.

On a personal level, Max has a very high interest in extreme weather. And he likes to watch college and professional sports. He is joined by my colleague, Kaitlin Shetler. Kaitlin has been with the Vera Institute of Justice Center on Victimization and Safety since 2018. She provides technical assistance for the Office on Violence Against Women's Disability grant program. And works on our Disability and Deaf Resource Center.

Before coming into Vera, Kaitlin was the Director of Disability Services at Lipscomb University in Nashville, Tennessee, where she led all aspects of disability services on campus, and serves as the Title IX investigator. With that, I'm going to turn it over to Kaitlin to share some foundational information for the conversation today.

KAITLIN SHETLER: Thank you so much, Ashley. I am really excited to be with all of you today. I've had so many opportunities throughout my whole career to work alongside autistic colleagues, and serve autistic survivors. So as a former Director of Disability Services at a university, I interacted with several people unsure how to effectively serve survivors with disabilities and marginalized identities.

I've often been uncomfortable with the way that services are built inaccessibly, without the thought to the individual needs of people navigating a world built for abled people. So I hope that we can use this time together to think about how we can unburden autistic survivors through increasing access and safety, in order for them to engage in service provision.

So Max and I have talked briefly around accommodations and experiences. And I really hope that we can leave you with some tools to use when serving autistic survivors. And I want to make sure everyone can see the PowerPoint before we begin. Perfect. Thank you.

OK, so I like to start with saying, what is this webinar going to do. What are you leaving with? When you leave this webinar, I want you to take this information back within your own context, whatever they may be, and find ways to integrate best practices presented today. So at the end of the webinar, you're going to know hopefully, what barriers autistic survivors face when they seek healing services. How service providers can better meet the needs of autistic survivors. And then hopefully, what types of accommodations are helpful to autistic survivors, and what considerations to undertake when communicating with autistic survivors.

Before diving too deep into this material, I do want to note the language I'm using in this presentation. So one of the guiding principles of the disability community is nothing about us without us. And as such, I think it is vital to hear what each community is saying about identity. Overwhelmingly, many autistic adults have shifted to preferring identity first language. Autism is not something people are burdened with, or something that they have to deal with, but an intricate part of identity and personality.

And in a world built to privilege this neurotypical experience, most autistic people have reclaimed the label that has been given to them and built communities addressing their marginalization. And we respect this collective experience with the language that I choose to use today.

However, I also know that people are not a monolith. There are people who prefer being described as having autism, or living with autism. And person first language is typically the most respectful and inclusive way of discussing people with disabilities. So I really encourage people to ask a person of how they identify when you connect with them through providing services, or working alongside them. Let's go ahead and do an interpreter switch before I begin.

So since we are looking at how to best serve autistic survivors, I think it's really important for us to talk about the impact of the victimization on people with disabilities as well. While we have a lot of research around people with disabilities and their experiences with sexual assault and domestic violence, we have little to no research at all on autistic survivors in general. So we can extrapolate data. We can make assumptions. But without research, it's very difficult for us to come up with numbers.

But since we have a really good picture of people with disabilities in general, and we know that autistic people are typically high risk for bullying and other negative peer and family interactions, it's not a big leap for us to conclude that there are also high rates of victimization within this community. For example, people with intellectual disabilities, which sometimes include autistic people, are seven times more likely to be sexually assaulted. That is huge. So we know that there is a problem. And we know that there are few services addressing it. And we have to figure out what does that mean for our services.

I particularly, maybe because I'm like a macro level social worker, I like to stop at the macro level. And then what I want to do is focus on the autism community, in particular. And I always find it helpful to discuss what needs to be happening in general, if your agency or your organization is committed to serving survivors with disabilities, which they should be. And this commitment applies to autistic survivors as well. And so I want to start with that, and then tailor our considerations to meet the particular needs of autistic people seeking these healing services.

I'm going to go through these considerations, and what I want you to do is think about them and think about how they relate to your context. So specifically, when thinking about survivors with disabilities, each consideration, how have you done this? If you haven't done this, I want you to think about, how could we do this? What does this look about coming? How do we come back and focus on this? How do we bring back what we're going to learn?

So when evaluating your organization for its commitment to serving survivors with disabilities, I think the first consideration is always going to be access. How accessible are your services? And this is going to mean evaluating everything. How accessible are you physically, emotionally, virtually, socially, and from intake to exit, and everything in between, are survivors with disabilities comfortable and able to use your services.

For example, do you have accessible parking spaces? Do you have accessible doors, bathrooms? Are your printed materials available in accessible fonts, or plain language, or large print, or Braille, or detailed pictures? Do you have a strong plan for securing ASL interpreters? Is the organization you're with welcoming of survivors with disabilities, as demonstrated through outreach materials and hiring practices? Is your website compatible with a screen reader? Do you offer the same opportunities to survivors with disabilities, as you do for those without?

So one of the best ways to assess, is using some tool to evaluate accessibility. So whether it's a checklist, or you decide to do a needs assessment, you can quickly figure out what barriers need to be removed. So that brings me to the second consideration of barriers. Once you answered the questions that I posed above, you might find that there are certain barriers that need to be addressed. Some might be quick fixes. Some might require full organizational change. And it's important to involve decision makers in this process.

So when you think about barriers, right, barriers can be anything from physical barriers, like not having ramps or wide enough doors, to additudinal barriers, like keeping survivors with disabilities away from receiving services, through discriminatory policies or practices. That can include even saying, oh, I don't feel comfortable working with a person with a disability, so we're going to make a policy that says, we can't serve someone with a disability. And that does happen.

And so even putting aside the legality of that, just looking at the barrier that that creates, and the further marginalization for people with disabilities. And it's important, I think, for us to recognize that excluding people with disabilities is always detrimental. There is no reason to keep survivors away, because you're uncomfortable with how to serve them. It's each organization's responsibility to effectively and competently serve all survivors. We know that disability is not only extremely prevalent, but there are also acquired disabilities from victimization, and that's practically the standard. So excluding survivors with disabilities, might as well mean excluding all survivors.

Our third consideration is communication. There must be the seamless communication between service providers and survivors with disabilities, as well as accessible. And part of this could look like offering materials and services in plain language, which is clearer and easier to understand. But it may also be not having a well thought out or planned coordinated referral process. So there's nothing worse than seeking services, and having to go to multiple different places before being able to access them.

And typically, when people have to do that. If they're going to one, or two, or three, or four different places before they find somewhere where they feel safe and comfortable, somewhere that's accessible for them, we know that they typically just drop out. They decide, we're not going to do this anymore. And that makes them even more vulnerable.

Fourth, we've got to consider the staff comfort and capacity. And this is where I sort of touched on attitudinal, but I think we've got to ask questions, how are staff responding when they interact with survivors with disabilities? Are they warm? Do they use appropriate language? Do they seem open to offering accommodations or addressing accessible needs? Do staff know how to address access needs? Do they have the resources to address access needs?

That was my experience when I was working in a university. We had people who wanted to, but there just weren't the resources, or there wasn't the training, or it was no comfort with figuring out how to best serve the student. And so I think we have to be really thoughtful about not only making the commitment like on the organizational level, but making the commitment between colleagues and people and in the staff level.

And then the fifth and final consideration, is actually around those access needs. So what do accommodations look like for survivors with disabilities. And accommodation is something that we put into place to provide equal access to services for survivors with disabilities. It's something that a person with a disability might need to receive equitable services, like removing barriers or evaluating policies that disadvantage this community. Accommodations may be as simple as securing interpreters, or they could be as complex as figuring out how to plan support groups in order to engage survivors with disabilities at the same level of those without.

And I hope none of this seems overwhelming. And hopefully, you are already doing most of this. But one of the ways that I found useful for conceptualizing this idea of systemic accessibility and safety, is pulling actually from the concept of universal design. So you may have heard of universal design before. Universal design tells us that the more we consider access at the organizational level, and the more that we work to change things, for lack of a better term, at the more molecular level, the more people we'll serve. And the more we'll impact the experience of survivors with disabilities.

So by doing these things before even encountering a survivor with a disability, you will be better set up to serve survivors at their most vulnerable. Universal design creates things that are accessible to most people by considering services and policies and procedures that are usable, inclusive, and accessible.

The thing that I want to point out here, as you consider doing all these things, you do this not because someone asked for an accommodation, but because these things are the most accessible for all. Because a lot of people don't even disclose their disability. And universal design allows them still to receive safe, accessible, and comprehensive services, which at the end of the day, is the goal for service providers working for survivors with disabilities, and also, just working with all survivors.

I went through all of that setting up the foundation of what happens when an autistic survivor seeks services. So an autistic survivor is going to have the same needs. The basic needs are going to be around the ones we just discussed. Do those first. Make sure your organizations and agencies are welcoming for all. And then you'll be better set up to serve this particular population. By addressing things like communication, the physical environment, the social environment, stimming, and accommodations, unique specifically to this community, you are equipping yourself to be the safest place for autistic survivors to engage.

Within these considerations, there are accommodations that can be made to remove barriers and enhance safety. And we're going to talk about those. If you use this as a brief checklist, you should be able to build out a fairly good plan for effective service provision. And we'll talk about effective communication and environment in a second. Accommodations, like social stories and visual supports, as well as allowing for stimming.

And when I say stimming, if you're not familiar with that term, it's typically the repetitive movement of one's body to provide self stimulation and regulate emotions. These things are vital to working with survivors. And there are important considerations in addressing the trauma response of any survivor, and especially, with autistic survivors who often communicate non traditionally, understanding that these are vital.

And I did see a question, will I be explaining social stories. I think I have it in a couple of slides down. But if I don't, remind me at the very end, and I'll give you an idea of what social stories look like in the context of providing services for survivors. No problem.

So what does communication look like when working with an autistic survivor? And I want to say again, at the very beginning of this, I said that no person is a monolith. And so I don't want to come in here and say, this is how you do it, and you do it well. We're going to talk to Max a little bit, and he's going to let us know what is most helpful for him, and in the experience of working with autistic people.

I am giving you some general considerations that have been expressed as being the most accessible for the community. What I don't want you to do is get stuck on these and think there is no room for being creative, based upon the person you have in front of you. If you think about best practices, you always meet the need of the survivor in front of you. And you don't make sure that you get into this pattern where you're just doing things to check off the list.

So this is in general, I think a lot of you may have different experiences here. But for the most part, this is something that you need to do to make yourself more accessible. Communication, communication, needs to be clear and direct. So often, this means that you do not use figures of speech or analogies or similes, if you can avoid it. In some cases, plain language is preferred. I mentioned that above, but telling you a little bit more about plain language, it's basically a communication that's understandable the first time it is read or heard. And I think all of us could benefit from that.

Because I know that anytime that I have to sit down to read something, if I have to go through it like two or three times to figure out what it's saying, I typically give up. And when we are giving information that is so important to survivors safety and access, having things in plain language can be lifesaving. And part of that is just being less wordy, avoiding the passive voice, offering definitions for concepts and words that are unfamiliar to those who don't work in rape crisis or domestic violence. That's important.

Expecting anyone to understand what confidentiality is or mandatory reporting is, or even what victim and survivor means in the middle of a crisis, is a lot to ask. When someone has a communication disability, this is multiplied 10-fold. So when somebody comes in the midst of their trauma, or processing trauma, they don't want to hear words that just seem like these inside words to the profession. They want you to explain in a very clear way.

Visual prompts, as far as communication are important, as well as numbered list, can be so helpful. So when you think about the information you provide, and you're going to choose between a paragraph versus a number bulleted lists, communicating through the list, is always going to be most helpful. I think that's a way for universal design as well, because I prefer reading lists than sifting through paragraphs.

Visuals also allow the brain to process information in different ways than just written or spoken language. Showing someone the cycle of abuse, versus telling them about it, can be more impactful, especially for a person who may not be able to focus through a long interview, and while processing their trauma. So this is also true for all people who experience trauma, especially true for autistic survivors.

And finally, with communication, laying out expectations and rules and policies is a very important thing to do. For many autistic survivors, knowing what to do and what the expectations are, give them a sense of stability and comfort. It is so difficult for anyone to read between the lines, but this is especially true for someone who has difficulty processing social cues. And I'm going to pause right now for an interpreter switch.

I want to talk about environment, because I think that this is a very important piece of working with autistic survivors. Environment is a huge consideration. There are many triggers that are unique to each person. But we have an idea of what can be helpful as a whole. For example, I like to use myself, I often get migraines as well as seizures from my epilepsy. So for me, and many who experience these things, lighting is important.

This is something that I share with many autistic survivors. So again, I feel like I'm really bringing this point home over and over again, when you make things friendly and accessible for autistic people, you are also doing so for people with other disabilities that may be different. I use this image on the PowerPoint right now, because a lot of these things are important to consider, touch, sight, taste, smell, sound, using low lighting, quiet voices.

One of the things that we did when we were trying to do like a low distraction environment, we would take a sound machine and put it outside the door. We wouldn't be able to hear the sound machine in the office, but the sound machine kept different conversations that were happening out there, from coming inside the office. And so it was a very helpful, very easy way to make people feel more at home, and really create a low distraction environment.

Having no fragrance policies. And then providing fidget spinners and stim toys, those are all easy things to do to make things safe and accessible for autistic people. When we, in particular, at Vera have in-person conferences, which hopefully, we'll have again sometime, we often offer a tactile table with stim toys and fidget spinners. And then we'll put pipe cleaners at each table and crayons, and coloring pages, because all of these things have been found to be helpful for neurodiverse people, regardless if they are autistic, or have ADHD, or any other developmental or communication disability. And it's even helpful if you don't have a diagnosis. And It's another example of universal design.

There are a few things that I want to pull out specifically around working with autistic survivors. And this first is the concept of masking, and what the implications here might be. This is especially important when thinking through healing services, like counseling sessions, referrals, support groups, because masking often keep survivors from actually disclosing their needs. Masking, the definition of it is, artificially quote unquote performing social behavior that's deemed to be more neurotypical, or hiding behavior that's viewed as socially unacceptable.

For example, an autistic survivor might come in for intake not knowing how accepting or accessible your services are of their diagnosis. So they try to control their stimming behaviors, and they work really hard to match your facial expressions and your tone of voice. And this has been proven to be exhausting, demanding, and detrimental to one's physical and mental health. Because they are so focused on doing this, they are not going to hear anything that you say to them. They won't ask for services. And they most likely are going to walk out and never come back. So masking can be a risk factor for continued victimization.

If a person feels they need to mask, they may not be comfortable seeking services. Their abuser may use that to convince them to stay with them. Oh, I really know what you need. You can be yourself around me. You don't have to do this. And it's a way to convince that person, or coerce that person to stay with them.

We already know, I think all of us, that there is no typical victim or survivor. And every person has a different response to trauma and victimization, and already services have to be set up to consider this. However, when working with autistic survivors, the response may be so different that staff don't know how to engage. This 100% comes back to the staff comfort and capacity that I talked about above. And it should be addressed before serving any autistic survivor.

Some examples of trauma responses experienced by autistic survivors could be freezing up, not responding to any kind of conversation. It could be laughing or joking, instead of engaging. It can even be stimming. And in this case, being able to adjust services to better fit the needs of the person, will allow them to disclose or engage in ways that they feel safe.

So what barriers are created by service providers? We've gone over many of these. These are the things that service providers walk into, things that they can fix, but they are just not aware of, or hopefully, not, but may not want to fix. Inaccessible services, poor communication, assumptions of what it means to serve an autistic survivor, and then stigma. And these last two are probably the hardest to recognize, because they have to do with internal biases. They aren't simple fixes, like creating plain language brochure. And honestly, I will say the best way to address that is to hire and receive training from autistic people. That is the best way to combat that within your colleagues and the people that you work with.

So some other ways of addressing barriers might be, having materials in plain language, visual prompts, fidget stim devices, low lighting, low or distraction free community, so maybe not talking in the middle of like a busy open area, bringing somebody back to just an office. And then these two things, the social stories and the planned transitions. Planned transitions would be letting a person know what comes next. So possibly, giving them a schedule, or a way for them to track with you what's happening.

Even in this presentation, in general, Ashley is moving my screen. I've given her a script. And she is following the transition that I am making. And so even something like that, we do that for a lot of things. And I think we just don't think about how to make that more accessible for autistic survivors.

And then social stories, social stories are used in a lot of different ways to help autistic survivors. And basically, these are just narratives that show either how a survivor can receive services, or how a survivor can engage in services. It's telling a story either visually, so you know, Ron walked into my office. Ron sat down. Ron filled out the intake form, and sort of walking through the story of what happened throughout the whole process. Or it could just be working with the survivor to actually write that social story.

And then culturally responsive, and I think this is just like we talked about, as far as the language piece, it's keeping track of the community being engaged in the community, and what the community has said their needs are. And you're listening, you're coming from a posture of I'm listening, I'm not the expert. I don't need to sit here and tell you I know everything. I'm listening and I'm able to receive that, and then use my privilege and my power to bring that to other people who are able to make their services more acceptable.

And then right before we jump to our interview, I have a couple more suggestions for effectively and competently serving autistic survivors. The number one thing would be for you to hire autistic professionals. So whether that's reviewing your hiring practices, or being very, very thoughtful about who you recruit from. Bring autistic professionals into your communities, and into your organizations to lead these conversations, and to help you figure out how to be the most safe and accessible services possible.

And then consult with autistic led, self led organizations and agencies. Trauma informed training for all staff, and then evaluate your barriers and accessibility. And then finally, partner with other organizations to coordinate services. So right now, I'd like to bring Max on to interview him regarding providing safe and welcoming services to autistic survivors.

MAX BARROWS: Hello.

KAITLIN SHETLER: Hi, Max. How are you?

MAX BARROWS: Good. Yourself?

KAITLIN SHETLER: I'm doing well. I'm doing well. Thank you so much for coming. I appreciate it. So I think you have great insight into the general needs of the autistic community. And I have a couple of questions that I want to ask, in order to help us better provide safe and welcoming services. I'm going to ask you now question number one. What types of accommodations might an autistic survivor request, and what types of accommodation should an organization be prepared to offer?

MAX BARROWS: That's a really good question. So as I thought this question over, here is what I came up with. So each person with autism experiences autism in different ways and at different levels. So we are all different, but there are some things we have in common. And I made a list of accommodations for you to consider. So you know, number one, being in a large group of people can be overwhelming. It is good to have separate rooms for small groups of people to use, especially for those who may experience sensory overload.

Second thing is, also, have a safe space in case someone gets overwhelmed, and also. Next, here's a bit of how I experience autism. My brain can only process so much like information at once. So when I feel that there is too much information that I am receiving, what can happen is this, a shield-- this is how I would say it. A shield develops around like my head. So don't try to shove like too much information, or too many words in my head at once. When that happens, the words or the information will just bounce off the shield and onto the floor, and won't mean anything anymore.

So when we are overwhelmed or overstimulated, we might not be able to process our thoughts, feelings, and surroundings, which can make us, you know, lose control of our bodies. And this is what I call an energy release. I know stimming is you know, the-- it really is like the correct way of saying it. Some people refer to it as a melt down. But I personally, have an issue with that term, because I think of like PowerPoint-- well, not PowerPoint, a power plant, a nuclear power plant you know, melting down. And I just don't see stimming or energy releases, as I refer to them, as like really that toxic. I kind of feel like it's a judgemental term. No offense to anybody out there that works in the clinical field or anything like that. But I wanted to bring that up.

So going on here, many autistic people love routines, so much so, that it may be difficult to change gears and move on to do something else. If there is an event or meetings, send people a schedule ahead of time, and tell us when we will be talking about, what we will be talking about, and how long we will be talking about each thing. This lets us plan ahead. And it helps us know what is going to happen and what to expect.

And I will also say to-- next point is like many autistic people have a hard time understanding auditory information. Give information in more than one way. That's what I would suggest is to do that. To give information in more than one way. Share your ideas in ways other than just talking out loud. For example, like, use images, like demonstrations, and provide written information.

You can use like a PowerPoint or drawing on a whiteboard while you are talking about something, and this opens things up, and lets people with different learning styles feel welcome. And if people feel welcome, they will want to share more. It's a way to engage people. And next points, there's a lot of them. Hang in there.

KAITLIN SHETLER: You're good. I'm loving it.

MAX BARROWS: Thanks. So my next point is for people who are sensitive to sound. It is a good idea for organizations to have some disposable earplugs or noise reduction ear muffs, as like a way to accommodate autistic people. And as their day, they may [AUDIO OUT] down [AUDIO OUT] For example, consider wearing name tags. This helps autistic people and others who have a hard time remembering faces or names.

And my next point-- I hope I'm not going too fast for the interpreters.

KAITLIN SHETLER: No, they look good.

MAX BARROWS: My next point is, a basic rule is that information should be in plain language to make sure everyone can understand what is going on. And my point after that, some autistic people need extra time to think. And can't think of what to say like that fast. So try to avoid activities where you are asking people to think of an answer on the spot.

Whenever possible, give people a list of questions ahead of time. This way, people who need to think about their answers can participate, and this is a way of being patient, because you are giving more time for people to gather their thoughts around what they may be asked, what we may, that I should say.

My next point is, I know it is popular to use, like it is popular to use like mindfulness or relationship building games, and many of these activities ask people to say how they are feeling, or touch each other, or look each other in the eye, or move our bodies around. But eye contact or being touched is not something that everyone feels comfortable with. And we might not have the words to talk about our feelings. So keep that in mind.

My next point, sometimes an autistic person gets stuck beginning or ending a task. For example, they might not know how to use sanitizer, but they may need someone to prompt them to start. And they might need like a suggestion or when to stop, and move on to the next thing.

Next, autistic people often pay close attention to detail, which may result in us taking more time to think about things. And it can be hard for us to make a decision, like in a restaurant. And not being about to decide what to eat. Another example of giving patience.

Next, we may have strong interests that capture our attention. This intense focus on one topic often does not make sense to neurotypical people. Next, I like my options explained to me, or we like our options explained to us and written out, and for me, like in an accessible way. If you can call me on the phone, for sure I am going to ask you to send me an email or text to give me like all the details in writing. And send out any information for a meeting ahead of time and preferably, it should be like one to two weeks prior.

And my last point on this question is, it can be helpful to have things that's can be common, like stress balls, rocking chairs, et cetera. And finally, as an accommodation, we must be allowed to bring a support person with us when speaking to you.

KAITLIN SHETLER: That's a very good point. Max, I'm going to pause for a second to allow an interpreter switch. And then we will move to question two.

MAX BARROWS: All right.

KAITLIN SHETLER: OK. It looks like our interpreters are ready. So I'm going to move on to question number two. How do you know if a place is welcoming to autistic people?

MAX BARROWS: Well, my way of knowing, or our way of knowing if a place is welcoming for people on the spectrum, is for autistic people, you need to know that we process our senses differently. And we might be extra sensitive to things like bright lights or loud sounds, and the list can go on and on et cetera. Noises happen all the time, even when it seems quiet. And what you want to do is, spend time in the place where you will be with the person. Listen for noises that aren't obvious, like lights buzzing, fans, or like or air conditioners, things like that.

I would also say like, well I mean like these sounds can be like very distracting. I will give an example of a sound thing that I actually went through myself. You know, when I was in a hotel room at a conference, I think it was a year ago, I was given like-- of course my benefit of just being on a high floor and stuff like that. But when I got into the room, I thought it was quiet, and then I started hearing like a weird like high pitched sound. And I think it was like coming from like the fan or the vent or ventilation system, as hotels always have.

And it just, at first, I was like oh, I'm sure that sound like be an issue for me, but then it just came to the point where I'm like, maybe this will be an issue for me. Because I don't know how I'm going to sleep through this or have quiet to process my thoughts and re-energize for the next day, that I have to do business. So it just came to the point where I'm like, look, I need like to have a change in rooms. So basically, I just talked to the people that were accommodating me, and I told them what the problem was. And I was very like calm and I was pretty straightforward about it.

And after that, they accommodated me. And I still had a hotel room on like, still on a high floor, which I like. And it was a different room, and the room was quieter. We figured it out with the hotel. And it all went smoother than I thought it was going to be. I was a little embarrassed at first, but I had to speak up. So there is an example of how some of these noises can also at times, get to me, depending on the situation. But I learned and I spoke up about it, and things were handled well, and I got what I needed out of that.

So anyway, some autistic people are hurt by certain noises, certain and loud noises. And if you are passing around a wireless microphone during a meeting, make sure the volume is not too loud. Feedback from the sound system can be a problem. I've seen this. And it also is with me, you know, when there's feedback too. It can also be very distracting. And it can hurt my ears just sort of can interfere with my sensitive sensory a bit, myself.

But that's the case that I've seen with other individuals on the spectrum as well. So keep that in mind. Some people with autism are frightened by certain sounds. For example, don't be surprised if a person asks you what type of fire alarms are in the building. I know that I was scared of fire alarms when I was little. And there's people I know on the spectrum that have asked about, or have been bothered by, the kind of fire alarms, like in their hotel rooms, or that they're around. So don't be surprised if that were to be the case when it comes to asking about fire alarms. That is a pretty common-- well, fire alarms can be definitely frightening noises.

Many people are sensitive to light. Natural lighting is best. If that is not an option, give people a say about lighting, if you can. Consider getting a floor or table lamp, or floor and table lamps in addition to or instead of overhead lights. And other things, I would say the group should come to an agreement about taking pictures. According to pictures, the flash can bother some people. So ask them not to use a flash. And also, people should ask before they take pictures of others, or people people.

And also, other things to keep in mind, some people are sensitive to certain smells. It helps if like, you ask people not to use anything with a strong smell like, cologne or perfume. This can help autistic people avoid sensory overload. And a person experiencing severe sensory issues can have problems with balance, dizziness, and communication.

Let's see. I want to mention stimming. I know that was a word that was used. And some autistic people do the same movement over and over again. And this, of course, is called stimming. You pointed this out, Kaitlin, a little bit. Anyway, it helps us regulate our senses. For example, like, we might rock back and forth, play with something in our hands, flap or hum, or even jump. And this can help us focus.

And you should let it be known that stimming is OK. And tell people that it's OK to stim and move around it. This helps autistic people feel well. And consider having someone show you where to go. Not knowing where to go can be kind of draining. For example, well not kind of, it can be draining. For example, where the bathrooms are would help, especially if in a place that isn't familiar. So that's what I have to say about that question. I know it was a lot, but.

KAITLIN SHETLER: No. It was all wonderful. So thank you so much. Max, I think we're going to skip to question give.

MAX BARROWS: OK.

KAITLIN SHETLER: I'm going to give you a second to find it.

MAX BARROWS: Well, I have it, yes.

KAITLIN SHETLER: You have it? OK. So the question is, what things do people say that make you feel accepted?

MAX BARROWS: What things do people say or do that make a person feel accepted? Well, I can tell you this, it is important to know that autistic people socialize differently. And the social rules that non autistic people came up with, may be challenging to follow for people on the spectrum. And they may not understand those social rules.

I have been doing a lot of Zoom meetings and I've noticed that some people with autism have a hard time controlling their body language or facial expressions. We may be less inhibited about stretching or yawning, or rubbing our eyes with our cameras on. And sometimes, we just forget that the camera is on.

Yeah, anyway, autistic people might find it hard to look at a situation from another person's perspective. Anyways, like I am mentioning this, because it can be confusing to non autistic people, or make it hard for us to socialize. I mean, a few other things to keep in mind, are like we might be more direct than other people. And some autistic people avoid eye contact, because it makes us feel uncomfortable.

And some of us have a hard time reading a person's facial expressions. And we might not be able to guess how a person is feeling. Now, this doesn't mean that we don't care about how you are feeling. We just need you to tell us how you are feeling, so we don't have to guess. On the other hand, there are some autistic people who are extra sensitive to other people's feelings, and so keep that in mind.

And just be clear about what you will do, if any information the person tells you, they need to know if you are a mandated reporter. I know I am, and I have to do that sometimes. And reassure us that we are in a safe space, and explain like what you mean by that. Here's what I would say is, it helps when someone has to tell you something that may be hard. Just say that like, if you have to share something that may be difficult, or they don't want to share, because it feels hard on them to do so. Because it may make them feel like bad for whatever it is they have done. If they've made a mistake or a situation that they've been involved in.

Reassure them that even though it's going to be difficult to talk about it, the reason why we should share this, is because we want you to basically feel that we are helping you. And we are helping you get through a situation that is not easy to talk about. It's to help you. You know, that way, you can reassure them that there is no rule that says, oh, you have to share this, because we said so. No, it's because you want to help them get through whatever it is they're getting. It's for their benefit. So just keep that in mind. I know that's helped me. You know, I'm positive that it helps others.

And it helps to know that we do not have to share everything that is on our mind if we don't feel comfortable. And as I mentioned earlier, just clearly let the person know that stimming is OK, and talking to myself, of course, and ourselves, and energy releases are all OK. And never pretend you understand what is said when you don't. Ask the person to tell you again what is said.

Don't try to finish a person's sentences or cut them off. These are other things to keep in mind, and just listen until they have finished. Talking, even if you know, you think that you don't know the end, or can say it faster. And limit the use of sarcasm or subtle humor, because it might leave some people out of the conversation. Speak to the person directly, not the support person or companion.

Always ask for giving assistance. And let the person know that you $that OK, I'm sorry. My mouth is kind of like-- I'm not working. OK. Just always ask before giving assistance, and let the person tell you what you may do to be helpful. All right. My mouth hopefully, can work for the rest of this. Bear with me. Treat adults as adults. And use the same tone of voice you use when speaking to anyone else. And you need to have a plan and practice what you will do when someone discloses abuse.

And finally, it can take a lot of energy to live in a society built for non autistic people. And remind yourself often that we might need to take more breaks so we can recover our energy, or recharge, as I would say, which is another way of saying it. That's what I have for that question.

KAITLIN SHETLER: That's so helpful. Thank you so much. I'm seeing a lot of stuff come through the chat. I'm just saying that this is wonderful, wonderful, wonderful, information. So helpful. So I think you are giving a lot of great stuff. I want to ask you, we can do question number seven, or we can just end, since we have 10 minutes. Do you know which one you want to do?

MAX BARROWS: Well, I'd rather have it be up to you, because like, I mean, I'm good either way. But this is not my gigs. I mean, I'd rather have it be, sorry, I'd rather have it be up to you.

KAITLIN SHETLER: OK.

MAX BARROWS: You decide.

KAITLIN SHETLER: Sounds good. I just read that we have some questions in the Q&A. Do you feel comfortable if I grab one of those? Or Ashley? Ashley just came on. So we can make her make the decision, Max.

MAX BARROWS: OK.

KAITLIN SHETLER: OK. Go for it.

ASHLEY BROMPTON: We have lots of questions in the Q&A that I think would be kind of in line with Max what you were already talking about. And a few of them are around virtual stuff. So you talked a little bit about Zoom, and how Zoom is different and autistic people might kind of interact differently in virtual spaces. Can you talk a little bit more about what makes you feel comfortable when you're using Zoom, and maybe meeting via Zoom, or having conversations Zoom?

MAX BARROWS: Well, I would say for me, if I'm going to present on Zoom, I like to know what I am going to be-- like what I'm going to be presenting on ahead of time, and know exactly what to say and how to say it, when I'm on camera, so I wouldn't fumble. So usually, like when I'm going to present, we go over things, and then I have material ready for me to present ahead of time. And sometimes, I have a script or talking points that will help me kind of hit on what I need to hit on.

And that way, I wouldn't you know, fumble to where I get embarrassed, and I basically lose track of where I'm at. When I have to talk a lot, which I sort of did, however, you were helpful Kaitlin of asking the questions so I would give my answers. That actually helps. Like when there's breaks in between when I'm presenting. So that way, I wouldn't go on and on talking. And also, like it helps me with making sure that I can go at a pace that not only is comfortable for me, but also comfortable for the people that I am presenting to.

Sometimes I can lose track of how fast I am going, or my speed, to where I can throw somebody else off. So I kind of look at it like my audience is accommodating me, just like I would be accommodating them. And in terms of what I hit on before, when it comes to being on camera, I make this mistake a lot. But sometimes I am not aware that my camera can be on, and then sometimes I may do something like with my body or a movement that somebody else may notice that in the moment, I'm not noticing.

And then when I get reminded of that, it's like thank you, even though yes, it is embarrassing that somebody else notices it. Because it's like energy, my body kind of sort of readjusting and energizing in the minute, and just dealing with the constant I would say, just overwhelmingness, while I'm on camera presenting or in a meeting or something like that. What I try to do, and I am going to get better at it, is I would probably shut-- sometimes I do this, but I shut my camera off. And I also mute my sound.

So that way, I can have a moment where nobody can hear me or I can just like take a deep breath. And in that moment, I can do whatever it is I can without embarrassing myself on camera, due to somebody else seeing something that I may do in terms of as a result of dealing with the overwhelmingness and stuff like that. But I'm not perfect in that regard. But it's something that I am aware of. If that answers the question.

MAX BARROWS: Max, that was really helpful. I think, as we're doing more and more like stuff on Zoom, and other virtual places, it's really helpful to get an idea of what that might feel like on the other end of those calls, or those interactions. I want to make sure we get to the other anonymous question, because everyone else I know, have a ton of questions. We will follow up with you via email, and hopefully get you connected to Kaitlin or Max to follow up on your questions. But there are a couple of people who ask questions anonymously, which means I can't follow up via emails. So I wanted to make sure that those get answered.

And Max, this is something that you do a lot of work in. It's around plain language. And the question is, how do you make really complicated terms-- so this person for example, works in the criminal justice system. And deals with really complicated terms. How can you make that more in plain language? Do you have like a quick list of tips, or resources that people can use?

MAX BARROWS: So the first thing that comes to mind in that is, I will just give an example. With this uncertain time of happening with COVID-19 or coronavirus, we have made information accessible for people with disabilities to understand what's COVID-19 is, or coronavirus. And what we have done is we have taken information that we have looked over, or we have found, and we break it down into the simplest way of explaining what COVID-19 is, and how to be safe.

And so I will say on my job, we did that when the pandemic hit the United States, and things started changing immediately. And a lot of the material that we have developed has been sent out all over the country, and even the world. And it's been translated into like 11 different languages. And a lot of people have been giving us feedback. Not just people with disabilities, but even people without disabilities said, like this is probably the most reliable information that you have provided, due to just all the complicated information being thrown at us about COVID-19 and what is going on with it and how to stay safe.

We have worked on things like this in terms of you know, with oh, like our Vermont health department on how to make information about staying up to date with their health, the health of people with disabilities. Explaining them in ways that can be very easy to understand. We look at materials sometimes, and we give feedback on what to say and how to say it, with organizations and also corporations that we've worked with.

So like, there's two things I can also think of too. I think plain language, basically, is just like when you take something that is just complicated and you break it down into it the most accessible format that you can. And just not using as much big words that may sound like you're talking, or saying a language that's not the first preferred language that somebody speaks. And just avoiding using like big words. And basically, you know, alphabet soup, or as in other words, abbreviations.

And then there's easy read. And that is when you take material, and you put it into like they say, like, oh, a third grade level of reading. So like an explanation of something can be put like into from like a 12th grade level down to a fourth grade level. Now, I know there's controversy with that term, because it goes into the whole mental age thing. But basically, taking a sentence that explains something, and like explaining it with just using less words to where it's at a level that can be easy to understand. So if that makes sense, and I hope it does,

I don't know the exact logistics on what I explained. But that's to my understanding of how that stuff works. And it is something to keep in mind when you work with people with disabilities, and even have people with disabilities involved in the work when you make things accessible in those kind of ways, when it comes to reviewing material, even working on material to break down in two ways that are understandable. So if that answers your question, I'm glad. And I hope it did.

KAITLIN SHETLER: It did. Thank you, Max. And thank you to all of you for attending today. This has been just absolutely amazing. Thank you, Max Thank you, Kaitlin. We couldn't have done this today without both of you working together to plan this and figure out a format, and really, getting us some of this really rich information that I think was really helpful. If you have follow up questions that we didn't get to today, feel free to email us at cbs@vera.org. Hopefully, one of my colleagues can put that in the chat box for us as well.

We are asking that you complete a survey. There is a survey that's being posted. It will be posted-- we'll probably post it a couple of times in the next minute or two. We ask that you fill that out. It will also hopefully, if technology cooperates, pop up on your screen when we end this session today. If you could just fill that out, it really helps us to know what you liked about this session, what you wish we could have improved upon in the future.

As a reminder, the recording of the session, as well as the PowerPoint and a transcript of the session, will be posted online hopefully within a week. We have to get post-production captions, and then we'll get it up as soon as we can to all of you. And again, thank you so much for attending and spending time with us today. And thank you the most to Max and Kaitlin for all your great work today, and to our four fabulous interpreters and our captioner who are helping us today. Thank you, and have a great afternoon.

MAX BARROWS: Thanks.