**Cognitive Access and Inclusion in the Independent Living Movement**

**April 14, 2016**

**Presented by Julia Bascom**

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| Tim Fuchs >>Good afternoon everybody. I'm Tim Fuchs with the nation council on independent living. I want to welcome you all to our latest IL-NET tell conference, creating cognitive access and inclusion in the independent living movement. I have a bit of a cold today and I hope I'm not too hard to understand. I'm safely quarantined in our offices here in Washington. So today's presentation of course is being brought to you by the IL-NET training and technical assistance prajs for CILs and SILCSs. April in little rock Arkansas with support provided by ACL, the administration of community living. As always we're recording today's call so that it can be archived on IRLU's website. That means that you or your colleagues will be able to access it free of charge, within 48 hours, usually much sooner. We'll be breaking several times during the presentation, three times actually, to take your questions. There's a few ways that you can ask questions today. If you're on the webinar screen, you can ask your question in the chat box, and you can type your question in the text box underneath the list of attendees. Don't forget to hit enter. You can type questions and comments any time during the call. We will wait for the Q and A breaks to address them though. Also, if you just on the phone today and if you're on the phone and prefer to ask your question live, you can press star-pound to indicate that you have a question and we'll take those questions in the order that they're received. And finally. One last option, if you're on the CART captioning today, I'm logged in the chat there as well, and you can type your question in the CART chat and I'll voice those questions for you on the call. You want to have the PowerPoint. If you're on the webinar you're looking at slide 2 and that will display and change automatically for you. So really only for the folks that are just on the phone or just looking at the full screen CART, you want to make sure to have the PowerPoint open or printed out. If you don't have that handy, it was included in the confirmation e-mail that was sent to you with the connection instructions. And if you didn't see that or maybe a colleague registered for it, you can e-mail me and I'll be happy to send a copy to you. You want to have that open today as we go along. It's going to make the call a lot easier to follow along with. And finally, my last piece of housekeeping before we open today is just to remind you and ask you to please fill out the evaluation at the end of the training. Our forms are short and concise but we really do need your feedback. We want to know what you think of our calls. There's a live link at the end of the training, the end of the PowerPoint so you can actually click on that and wait until the end because it will take you away from the webinar. If you're participating in a small group, that's great, but I hope each of you will fill out an evaluation so we have individual responses. So thanks for that and without any further adue we're going to get started. I want to introduce our presenter today and that's none other than Julia Bascom. She is deputy executive director at the autistic self-advocacy New York here in Washington. We have the pleasure of working out of the same building we're on a separate floor and I have loved working with Julia since we've moved over here. It's just been fantastic and I'm so impressed by the work that they do. And as you'll see, their name and their focus on autism might not communicate you who beautiful cross-disability they are and you'll see that in Julia's presentation today. And just before I turn it over to Julia, I'm going to -- oh, and you see here on slide 3, Julia has been generous enough to offer her contact information. If you all have any follow-up questions. And on slide before before I turn it over to Julia, I want to walk through the objectives quickly for today. Today we will all learn common access barriers for people with cognitive disabilities, the common areas of overlap between the access needs of people with cognitive disabilities and other disability communities; ideas for expanding access in centers for independent living for people with cognitive disabilities, identifying weighs Ciles can become more inclusive of this community. And strategies that create cognitive accessibility that can improve communication so that's quite a full agenda and I'm going to click to slide 5 and turn it over to Julia to continue. >> JULIA: Thanks so much. So we're going to dive right into it since we have a limited amount of time today. I wanted to start with some quick background information about cognitive disability, but before I do that, I want to underscore Tim's point the network focuses on autistic needs of adults but we foe us on disabilities. We've been really impressed with the network of sils and the roles that they play so we're seeing this as a natural overlap between our communities and wanting to build and expand on that. To start with for the background we're going to talk about what is a cognitive disability, where is the disconnect between communities of people with cognitive disabilities and the rest of the disability community and what can we do about it. I'm going to switch my slides now. Cognitive disability is a really broad term. There's not a great term for a community of people I'm talking about. Sometimes this community is called the DD community or the community with people with developmental zabts. Of course there are people with cognitive disability who don't have developmental disabilities. So I'm using the term cognitive disability for this slide for lack of a better term. When I talk about cognitive disability, I'm including autistic people, people with intellectual disability, a lot of people with mental health disabilities might find themselves in this community, people with learning disabilities, some people with traumatic brain injuries or some people who are aging end up in this community whether they develop dementia or the natural processes of aging and so on and so forth. It's an disability that affects your brain and ability to think, basically. The other term I'm going to talk about is neurodiversity. It sort of originated in the autistic community but it's taken on a broad meaning. It's short for neurological diversity. There are lots of different ways to be a person, there are lots of different ways to have a brain and they're all good and they're all important and they're all a natural part of human diversity. There's a line in the DDS that you'll see echoed throughout other writings that says that disability is a natural part of the human experience. And neurodiversity is about taking that idea and connecting it to people with cognitive disabilities. Despite this overlap in framework and approach, there's a lot of disconnect between the different communities. There are a lot of different language preferences that can trip people up. The autistic community, like the blind community and the deaf community so on and so forth really prefer identity first language. So autistic people tend to say I am an autistic person rather than I am a person with autism. However family members feel strongly it should be a person with autism. People with intellectual disabilities as a community tend to believe in first-first language in saying I'm a person with a disability. And you can see that disconnect really originating from different histories that we've perhaps had as communities. I think we all know and understand that the disability community has a lot of shared history and a lot in common. But you see different people having different subsets and experiences. And for autistic people, a lot of the stigma and bias that we encounter, and which can often be quite legitimized through the school system, is focused on normalization and erasing signs of autism. And so for those reasons, validating our autistic identity can be very important to us. People with intellectual disabilities have had horrific histories in state institutions for a long time so when the people-first movement ended they were very, very clear as self-advocates that they preferred person-first language, that we really wanted to make them have to say that we were a person before talking about our disability. Related to those different history, I think some of the disconnect between the cognitive disability and the rest of the disability community have to do with the fact that we interact with different systems. In terms of services and health care and so on and so forth. So for various reasons many of which are not particularly good, most states serve the DD community through one system or through one set of waivers, and another community through another and subcommittees are served with more different waivers and different systems. Obviously there's a lot of crossover and it's very difficult to say which person would fall into which category and why we have these categories at all in the first place. I think people's experiences with those different systems can also impact the disconnect in terms of the outreach and finding people and also in the experiences that you have in different systems. And also how you organize around those systems and what issues you focus on. There are also, you know, issues of different access needs. We see a lot of disconnect where someone might need very physical accommodations and accessibility features that I as an autistic person don't necessarily need but I need different accommodations around speech and the learning that's used in the room I'm in and so on and so forth that other people with disabilities might not need so that creates a disconnect. And we also have disconnect in terms of just the cognitive ablism and the inner community hierarchy with disability. I think really in any community. However, there's a lot of things that we can do. To adjust this. Obviously we're talking about it, we can share information about different stabilities, different ways of accommodating people, different access needs. We can broaden and expand the definition to be more inclusive of people with all disabilities and we can make sure we're prioritizing and engaging with the whole community. At this point I think I'm a little early Tim but I apologize. I have a question and answer slide here and I realized I'm on slide nine I realized I foerkt to say I was changing my slides. >> TIM: So again, you can press star pound if you have a question on the phone, or of course you can type your question in the chat box. Either on the webinar or on the CART screen. And we'll give folks a few seconds to see if any questions show up. We've got plenty of time for Q & A during this call. Three 10-minute breaks. So a whole third of our call for questions, so don't be shy. First, Julia, just a comment from the Michigan disability coalition rights that they appreciate the discussion of identity first and person-first language. I'll give just 10 more seconds to make sure no more questions come in. And if there aren't questions yet, that's fine too. It is early in the call and we will have two more Q & A breaks. Same folks say cognitive decline is not a normal part of aging. >> And that's true. And I'm not just talking about what we typically talk about as cognitive decline but also an increase in disabilities that many people experience, hearing loss or vision loss, for example, as well as we see a lot of overlap with cognitive disability and some of the needs the aging community might have around accessing technology, for example. >> TIM: Okay, good. Thanks. I don't see anyone else typing and there are no questions on the phone. So Julia, I'll go ahead to slide 10 and you can continue. And folks, we'll have plenty more Q & A time later in the call. >> JULIA: Great, thank you. On slide 10 at this point I'm going to go through a few different aspects of accessibility and for each of those areas of access and accessibility I'm going to talk about some common barriers that people with disabilities might encounter, some ways that those barriers miilt overlap with barriers experienced by people with other disability. I want to preface this by saying that there is a lot of variety and diversity within people with cognitive disabilities so nothing I say should be assumed to be true for every single person with a cognitive disability. There is's going to be a lot of variation and experience. I'm going to slide 11 now. Let's start by talking about sensory barriers. A lot of cognitive disabilities, particularly autism but people with learning disabilities and intellectual disabilities, for example, encounter a lot of barriers around sensory processing. For many people with cognitive disabilities sensory processing might be al tered in some way. So flash photography can be a huge barrier and people with epilepsy. So flash photography can be life threatening, it could cause migraines or panic attacks. Noise level can be a huge issue. This is something that's often not taken into account in organizing especially when you're trying to corral a large group of people. It can be a huge barrier to participation, again, the autistic community but for other meem with disabilities as well. Side conversations can present a problem. If you're having a meeting or a conversation and there's a main conversation going on but two or three people are breaking off to about something else or exchange some information or figure out whether or not people want coffee or whatever, that could make it impossible to understand what's going on and participate for someone with a cognitive disability. Microphone feedback is a huge problem again for people with sensory processing impairment. It can be very painful, it can disrupt's a person's ability to participate, it could reduce their ability to function the rest of the day. Crowds. Lots of people with cognitive disabilities have scent sensitives and lighting can present a big barrier for some people. There are lots of people with sensory processing disabilities, fluorescent lights can be distracting depending on the person. Obviously a lot of this overlaps with other disabilities. I'm increasingly seeing cross-disability space making sure that they have processes in place, people who have chemical sensitives and so on and so forth. A lot of what I'm talking about around crowds, side conversations and noise levels can be applicable to people who are deaf or hard of hearing. So there's not a whole lot of stuff in this list that I think is necessarily new or unique to people with cognitive disabilities. For a lot of people with cognitive disabilities, they may also have an additional disability going on that will amplify this as well. As a lot of people have fragrance-free policies. It's relatively straight-forward for an event to have a no flash photography people. Maybe you post signs reminding people. Pretty simple stuff. You know, there is's sometimes are noises that happen that are inevitable in the work that we do, but it can be a simple okay dation to just warn people that for example you're about to move furniture and there's going to be something, as Tim mentioned, we share a building with NCIL and we share a building with a number of other tenants and we have an agreement that the other tenants will warn us if they're going to harmer a picture in the wall or the building will warn us if they're going to be testing fire alarms. At events there's going to be a lot of noise or crowds or social interaction, we encourage events to hold some space in reserve for sensory free or respite space where people can go to regulate their senses. Quiet areas, at events these are called quiet rooms. We actually discourage people from using that wording because often times in schools or in institutional placements, a quiet room is a room that's used for restraint and seclusion. It's useful for parents with small children. This isn't just going to be used by people with cognitive disabilities, but to increase access overall. A lot of people with sensory disabilities move sarnd as a way of accommodating themselves. So they'll pace or do other movements to let their brains focus on the sensory that they're needing. So another way to okay date that and cognitive disabilities in general is to encourage movement. To see at the beginning of the meeting people are free to move around, to get up and pace the back of the room, whatever you have to do in order to participate. It can take people a little while to trust that, but once people are affirming that at every meeting, that could go a big way towards increasing access. It could also be useful to adjust expectations for different events and figure out whether or not what you're planning is really necessary, if there might be another way to do that, and also to adjust expectations of the people you're interacting with. So we have, I think, common expectations, in terms of social communication, that someone who is moving around a lot or fidgeting isn't interested in what we have to say or isn't engaged or paying attention or really participating in what's going on. And that's often not really true for people with cognitive disabilities. So it could be really important to adjust our internal expectations for what it means for someone to look like they're paying attention. We have a saying in the autistic community of I can either look like I'm paying attention to you or I can pay attention to you. That's common for lots of people with common disabilities. Something that can be a little more ambitious is to avoid using fluorescent lightbulbs since they're inherently painful to people. We don't control the light bulbs in our building, for example. There are filters that are available that you can put over a fluorescent light to sort of mute that impact and that's helpful for some people. And in addition, one of the side effects of just sensory processing disabilities is that things can can very overwhelming and chaotic because you are taking in information and what you're getting is distorted. It can be useful to provide a schedule to participants of what's going to happen and to follow that schedule. So people have a way of creating order, and it can help people figure out what information to pay attention to and what information to prioritize. And again, I'm talking about sensory information more than anything else and all the input you receive as you're processing sights and sounds and everything else. I've seen one thing that I forget to put on this slide. Treat mic feedback very seriously. If there's feedback that should be resolved before anything moves on. To people with that sensitivity, it's roughly the same level acceptability emergency as for getting a ramp up to a podium. It needs to be taken very seriously. I'm going to move on to the next slide now. We're talking about social communication. This can be a little bit tricky, but we'll get into that. So a lot of cognitive disabilities impact people's social communication. It might impact a person's ability to initiate a social interaction, which can make people seem aloof or disinterested when they're really not. It can impact turn-taking someone might have a hard time figuring out when it's their turn to interject or if you're working with children how various common games work. It can -- social communication disabilities can impact name, remembering people's names and facial recognition. It could make using the correct pronouns very difficult. I'm not just talking about using the correct pronouns who are speem are transgender, but for everyone. Where you meant to say I instead of you or you instead of I. Keeping track when multiple pronouns are used in the conversation. A lot of people with social communication impairment find it difficult to interpret sarcasm, and that can be true of people who make sarcastic statements themselves. The ability to read body language can be impacted, and so also can the ability to give body language that matches what the rest of the world would expect. So someone might have body language that isn't really reflective of what they're trying to do or how they feel. And the last -- actually, certainly not the last barrier. The last barrier we have time to talk about today with regards to social communication is social capacity. And some of these people are autistic, who have social capacity, less ability to handle large amounts of interaction with people or lots of relationships and lots of social demands. And that's important to realize and recognize as well. Social communication doesn't necessarily overlap with a lot of other disabilities that aren't cognitive disabilities. Certainly you'll see people with other disabilities who also have cognitive disabilities experiencing social communication challenges. One of the unique problems about social communication disabilities is they're so easily misinterpreted because they're not common to the rest of the population and they tend to rehigh on taking something the majority of the population does instinctively so often people don't realize they're interacting with someone with a disability. They think someone is rude or disinterested or self-centered and so on and so forth. So it can be really difficult but really important to interrupt that thought process to find out if you're dealing with a jerk or dealing with someone who has a disability that's impacting how they come across. There are actually common solutions to this. One solution that started in the autistic community but is starting to trickle out into other events has been something called color communication badges. These are badges that people can wear, kind of like a name tag. They're colored coded so you'll have a stoplight, red, green, and yellow. And these are used to handle problems with initiation and conversation. So green card, if I decided to have my card communication badge on green, a green card would indicate that I'm open to social approaches, but I'm having a hard time initiating things. So it would essentially be something please talk to me, please start a conversation with me, even if I look like I'm not participating or interested. Yellow badge would indicate that I'm in this social situation and paying attention to what's going on, might even being talking to someone, but I can't handle interacting with people I don't know right now. The red badge might mean I'm here, I'm listening but I can't talk right now but please don't talk to me unless the building is on fire. Those can be really useful pieces of sort of accessible social architecture for a lot of people with social communication disabilities and they're useful because they destag ma tiiz. A lot of people might have a limited ability to interact or might be only to interact with people you know well in the situation. And with these color communication badges you won't be able to control what interactions you're expected to have so people might be unable to participate in general without that system of signalling. For people who have problems on figuring out when it's their turn to talk, it can be really useful to have talking objects, a talking stick or a water bottle, the things you use at summer camp to indicate whose turn it is to talk. That can be really helpful. Often, especially I think in intersectional activist spaces, there's a focus on paying attention how much space we're taking up and how much we're talking and for a lot of people that's not possible. So it could be useful to have a really obvious visual system to track whose turn it is to talk right now rather than having that be on an individual. Name tags are a huge lifesaver, for me personally especially, for people who have trouble remembering names or recognizing faces, reviewing just a standard practice of having everyone around the table introduce themselves before you start something even if you think this group has met six times before, surely we all know each other's names, that's not necessarily true. In terms of interpreting sarcasm, it can be useful to either indicate that you're being sarcastic or to be willing to explain if someone asked you if you're serious or not. I wanted to add that listing people's pronouns on name tags can be helpful for people who have particularly difficulty keeping track of pronouns. Direct communication can be helpful. A lot of times due to how social conventions work, people can feel really hesitant to explicitly say I'm not okay with you doing this or I expect you to do X and Y. And so people try to be more subtle. People with social communication disabilities aren't necessarily going to be able to interpret those messages or realize that you're trying to say anything at all. So willingness to be direct can be really helpful and sometimes it's ultimately what's necessary. We often find that in situations where people aren't willing to have that direct communication, they sort of end up falling back on just gradually excluding the person and that's not a good solution. Certainly not an inclusive one. Again, in situations with a lot of social interaction that can be fairly overwhelming so having a schedule what's going to happen and the socialization is going to break down if you're doing a workshop or a meeting or something like that can be useful. But it's only as useful as your willingness to actually follow the schedule. So if you have a meeting agenda and it lays out five different things that are going to be covered and then 20 minutes into the meeting you're clearly at the end of the agenda and are talking about entirely subjects, some of the community with disabilities might not be able to participate anymore. Might not be able to follow the conversation or figure out how to insert themselves into the conversation or understand the underlying points that are being made. This issue in particular can be talked about for a long time because it's very counter intuitive in people without social communication disabilities at time. But in the interest of time I'm going to move on. -- it's telling me to share my screen now, which is not what I want to do. >> I imagine we'll see the PowerPoint. Just a second. There we go. >> JULIA: There we go. I'm sorry about that. The next slide, slide 13. Here we go. A relatively small percentage of people with cognitive disabilitieses use AAC. Using augmentative alternative communication. AAC users can be part-time or full-time. Obviously a lot of people with physical disabilities and other disabilities also use AAC. Some examples of AAC would include sign language, someone typing, someone writing messages out by hand, someone who uses a voice output device with pictures symbols, someone who uses preprogrammed messages, a scanning method or Morse code or something like that. There are a lot of different forms of AAC but essentially it's a very broad term and it indicates someone who uses methods other than speech to communicate. AAC users, AAC can take longer than speech to compose a message, and composing that message might be more cumbersome for the user and harder to understand for the audience. A lot of people don't know how to integrate people who use AAC into broader conversations. There's some pretty easy things that could be done, however. Most humans have multiple modes of communication. Many people, for example, speak orally, they send text messages, they might use emoticons or other symbols and they might, I don't know, post pictures to Facebook. That would be an example of multiple modes of communication. A good way to include AAC is to make sure however you're trying to elicit communication from an audience or a group, you're open to multiple modes of communication. So providing information through social media and through printouts, for example. Having people in a meeting talk about their ideas and do that color dot method that some people use, for example. Keeping in mind that we all use multiple modes of communication I think is a really big part of that. Sometimes interpretation will also come into play here and for that the roles are pretty similar around talking to the person, not the interpreter and so on and so forth. Good meeting facilitation can also be a big part of this. So, for example, if you're asking for an opinion, you might say I have this question about how you feel about this funding proposal. I want to go around the room, Greg, you're going to be -- and Greg knows that he has time the next four people are talking to compose his message and have it ready to go. Methods like that are important. And also just be willing to wait and to take time to really pay attention to what the person's communicating and the process they're using to do it and to show respect for that can be really important. If you have an AAC user on the panel, it's important to mic that output device so people can hear them. It's important to coordinate between the device and the CART provider, for example. Sometimes the speech can be difficult for people, including people who themselves have cognitive disabilities to understand. And so it's important to be willing to ask people to repeat themselves. To make sure that the CART person is able to interpret this and so on and so forth. There's an AAC user who works in the federal government and often when they give panels, there's CART at the panel and whenever this person speaks, the CART just says [unintelligible]. That's not acceptable. This is something self-advocates are really figuring out how to navigate in general. How to include people who use AAC into the broader movement and into conversations. A lot of it just comes down to being willing to listen to the person and figure out what works for that particular person. Lots of AAC users will know this about themselves. So just ask them what they need in order to be able to communicate and participate. I'm going to switch slides again. We're on slide 14. Telecommunications. This is something that's going to have a lot of overlap with other disabilities. Having difficulties with auditory processing. It's very, very common in people with cognitive disabilities. I'm seeing a comment about audio issues. Should I pause for that? >> We'll try to help Michele out. Thank you, Julia. Your audio sounds good to me. We'll see if there's anything we can do on our end and help her troubleshoot that. You can go ahead. >> JULIA: Okay. People with cognitive disabilities can have auditory processing issues where it can be hard to figure out what we're hearing. Many phone calls, and webinars including this one, obviously might rely on people who use verbal speech. And for people for whom that's difficult or not something that they can do all the time, that poses a barrier. It can be more difficult to follow and interpret a conversational flow. Over the phone or over a webinar and figure out when it's the right time to interject yourself into that conversation. Many, many people with cognitive disability find phone calls to be essentially inaccessible in and off themselves. Thankfully there are a lot of solutions to this, many of which you are all quite familiar with as CART, using text-based chat instead of a voice chat on Skype, for example, or e-mails or instant messaging instead of phone calls. Often I know if I'm going to be on a conference call with five different people, I might try to be in the same space as the other people so at least that end of the conversations will be easier for me to hear and interpret. I have visual support marked here and I have no idea why. When you're having audio only for people to identify themselves before they speak so they can keep track. And sometimes the solution really is to team up with individuals. So you might have someone who's listening to the conversation and providing their comments in a text format or another format and another person who's voicing for them, for example. Or a person who knows that the conversation itself can be difficult so they're facilitating the conversation and making sure everybody has a chance to talk or directly saying I think that maybe Julia or Bob or whoever has something to say at this point, making sure everybody has a chance. A lot of this, particularly for this area, crosses over with other disabilities. So the issue is not so much coming up with new methods of access as it is realizing it affects a broader population than people might be used to. I'm going to move on -- oh, gosh. I did it again. One moment. And we're back. I'm on slide 15 now. This one is a little more complex. Making meetings and presentations and workshops accessible can take a little bit of work. Some people with cognitive disabilities might have a disability that impact their ability to pay a tension for a long time, to process information or large amounts of information or information presented in a certain way. Difficulties understanding and learning new concepts and also difficulty with the social communication barriers that we talked about that are really an important part of many, many meetings and presentations. This is largely a cognitive issue, we don't again see a lot of overlap in the disabilities, although there are certainly other people with disabilities who also have cognitive disabilities in these areas. There's a little bit of specialized knowledge of how to make meetings accessible to people with intellectual disabilities or cognitive disabilities. I believe I have some of those more detailed resources listed at the end of this presentation and these are the resources that have been developed by self-advocates with cognitive disabilities. But as a bref overview, there are a few things that can generally make meetings and presentations more accessible to people with cognitive disabilities. Again, providing and following a schedule can give people really useful tools structure the information they're going to hear the experience they're going to have and help them stay attract and figure out what's going on. In larger presentations it can be useful to have small groups to discuss the content that's being presented to come up to make comparisons between the content that's being discussed and more concrete examples to participants' own lives. Planning presentations around the fact that people have different learning styles can make a lot of sense in making sure to not rely only on visual or auditory methods where one style of presenting information to give people lots of different ways to wrestle with the questions being asked in the meeting and come at it from different angles. Long meetings and long presentations present a significant access barrier to a lot of people. So focusing on having short meetings or short presentations building breaks into the schedule or having different things going on, so maybe there's a lecture for 20 minutes and then a break and a small group activity and back to large group. It could be a way to chunk. Again, getting permission for people to move around, can allow people to regulate themselves and process information more easily. There's also quite a bit of guidance around providing using accessible language and providing accessible information and I've got some of those resources at the end of my slide. But I think particularly for folks who are stuck here with me in Washington, we have a tendency to use jargon and talk about things in the most complicated way possible and that's not helpful for most people, let alone people with disabilities. So using language that's more simple, not language that's dumbed down or babyish, but language that's concrete and clear and direct can be really important. And really helpful. In thinking about how you structure the information you're presenting, making sure you're moving from concrete to abstract, providing all of the necessary information that's needed and so on and so forth and really structuring how you present things can be really helpful. Again. This is really a whole topic in and of itself, but I believe I have more information at the end of my slides, and if I don't, shoot me an e-mail and I can send you some of the resources that self-advocates have developed on this. And then a last and really powerful set of barriers are the attitudenal barriers that can come with a lot of spaces. People will say that, including other disabled people, who will say that cognitive disabilities aren't real, that you can't see them, you don't really understand them. And there are also people who would never say those things but who still implicitly have that set of beliefs. A lot of cognitive disabilities aren't visible when you're interacting with a person or they're not visible unless you really know what to look for. So people might not -- they might see this person at disability events, identifying as a disabled person but they might not see the disability and that could color the perception of the person an the seriousness of their access needs can be impacted in perception. Lots and lots of spaces will say I might have this disability but my mind is fine. And that can be really hard to hear as a person with a cognitive disability and certainly says some troubling things about inner community bias. A lot of people don't like to be talked to like they're two years old or like a dog, but people might say don't talk to me like I'm intellectually disabled. And the reality that people with cognitive disabilities also don't like being talked to that way. So it's important to pay attention to what we're saying versus what we really mean and to make sure that we're not excluding and implicating people in that. There are a lot of really important conversations that are had about how disability service provision is structured and the various ways that that's foolish and unhelpful, but it's not really helpful to imply that intellectual disability or developmental disabilities aren't real things or don't really mean anything. The meanings are pretty clear, they're available in statute, they're available in definition. And it can make conversations that are otherwise productive, hostile. And again, like I said, a lot of social communication disabilities can be difficult to identify and they don't realize they're interacting with another one which can make them perceive as a person that's rude or standoffish or other things which isn't helpful. At the same time having stigma within the disability community about other disabilities isn't a unique issue at all. There's certainly stigma within the community with people with cognitive disabilities about each other let alone about other people with disabilities, and we also see people with less visual disabilities facing a lot of these things. So it's not a unique issue necessarily. And really the solution is to be mindful about who we're including, who we're excluding, who we're treating as real and valid and legitimate and making sure our own attitudes and our own preconceived beliefs aren't holding people back or excluding people and that can be difficult to do but it's something that we all really have a responsibility to do, especially as a disability advocate. There's another somewhat related access issue that can be difficult to articulate but relates sort of to power dynamics. Different groups can certainly do this to each other. You might see for example someone with a disability thatistics their speech struggling to articulate a thought. In add vrt eventually establish a power dynamic that excludes people with cognitive disabilities. Certainly you see people with other disabilities talking to people with more apparent cognitive disabilities in ways reminiscent of bad special ed teachers. And realizing that sometimes things that could be very well intentioned could end up excluding people. Some people have more perceived legitimacy and the importance is being mindful of that. There's also a good way to address this is to work directly with self-advocacy groups on ways of ensuring accessibility and inclusion for everybody and prioritizing the accessibility and inclusion of everyone. I'm now on slide 18. I forget to mention I moved slides earlier. I apologize. The fact that sometimes needs and access are conflicting. No one is necessarily doing anything wrong and it's important to realize that sometimes the access needs with people with cognitive disabilities could conflict with each other and people with other disabilities and to see those ation an opportunity for problem solving rather than deciding who gets to participate and who doesn't. Slide 19 now is a question and answer slight. I think these slides are a little quicker so hopefully we won't be too over time. >> TIM: It's only 4:00. Time is on our side. We've got a few comments and questions that came in. But before I go to those, let me remind you all, star-pound if you have a question on the phone. Or you can type your question in the chat. Either the webinar chat or the CART chat. Okay. So let's see. We had a comment and a question from Annette. She said that some of the social communication challenges that you mentioned, Julia, can also cross over to different cultures. So, true. And an important comment. And then Annette also asked, going back to slide 11. She said you mentioned CFF and they were wondering what that was. Could you go back? >> JULIA: Yes. I think that was left over from an earlier version of the slide. I think I was mentioning crime fatigue syndrome there. I think it was me typing that instead of talking about chemical sensitivities as I tried to talk about as the slide progressed instead. I want to thank you for making that point over communication cultures as well. One thing I left off the slide was eye contact. Eye contact could be a significant challenge or really painful for a lot of autistic people but the rules about eye contact are also difficult -- different cultures we see a lot of people with different cultures facing things that people face as being interpreted as rude or disinterested or dishonest because of cultural norms about eye contact. I'm going to go back to slide 19 now. If there are other questions? >> TIM: Thanks Julia. We'll give some time to see if there are any questions. In the meantime the comment from the folks at Michigan disability rights coalition says excellent information. Thank you. Thanks to you all. And again, we've got -- we've still got more content to go through, another Q & A break. Don't hesitate I'll give about 15 more seconds here just to make sure there aren't any more questions. You can press star-pound on the telephone or you can type your questions in the chat. We did look into the audio issue and it was not on our end so please do let us know if any of the rest of you are having issues. And we did try to help the participant that mentioned that. I'll go ahead to slide 20 and Julia, you can continue. >> JULIA: For the last part of the webinar I'm going to talk about cognitive accessibility and about outreach as I mentioned we were going to get into. So on slide 21, we're talking about cognitive accessibility. In the context of meeting the, presentations, the information you present, the materials you develop and so on and so forth. So we've sort of narrowed down what we're looking at. Cognitive accessibility looks at things like language complexity, the presentation information and your intended audience. It often really does just come down to whether or not you value the participation of people with cognitive disabilities as well as other groups such as people who might be English language learners, people from a variety of different backgrounds and so on and so forth. Let me see on the next slide. On slide 22, one of the easiest ways to address is to look at whether or not your materials or presentations are using accessible language or inaccessible language. This is challenging especially for a lot of the advocacy that we do that can be technical or policy-oriented. It can be helpful to realize that a lot of the concepts we're talking about are not rocket science. People wp disabilities deserve real jobs for real wages is not something that took a Harvard graduate to come up with. How we talk about it can get complicated but remembering that core underlying concept can be really helpful in simplifying and clarifying our language and there are a lot of examples for given policy issues. Some guidelines would be to avoid jargon and other inside terms. Avoid acronyms. If you have to use acronyms or if you need to use jargon and technical terms, it can be helpful to provide a glossary if this is a paper or to provide, if this is a presentation, sort of a bank of words, maybe up on the wall or something. Where you're writing down acronyms and what they mean as they come along. This is something that a lot of self-advocacy groups will do, so it might be useful to reach out to local groups to see how they handle this in particular. As a general guideline, keeping things on an 8th grade reading level or lower is certainly not a catch -all, but it can solve a lot of issues around convoluted sentence structure and really advanced vocabulary. Obviously I'm not doing the best job of prioritizing those things in my own presentation. This presentation was a little different in a variety of ways if I was aiming it at my fellow self-advocates. Using concrete language and examples can also be helpful. So if I'm talking about medicated policy I'll talk about the structure of a waiver but I might also connect it to a real-life person who's having that experience with the waiver and how that plays out in their life and I would go back to this is the proposed language or funding increase would do and for this specific person that would mean this, this and this. To help people anchor the information that they're getting. A lot of this stuff is similar to general best practice around presenting information and writing readable documents. That a lot of I think communication professionals are relatively well-acquainted with. And this is one of those things where doing this doesn't just help the people with cognitive disabilities that you're trying to reach and include, but also people who are interacting. Have clear information is always helpful pretty much regardless of the person. Let me go to the next slide, 23. And again, accessible information is really not about watering down information or dumbing down information. It's about getting to the core point of what you're trying to say, making it concrete. And really thinking about how you present and structure that information. I think scaffolding can be a really good analogy. You're creating ways po support the information you want to share and to lift people from one level to the next to the next in terms of their understanding. Providing accessible information might also mean using multiple modes and alternate formats. For example, my organization is developing our ability to provide accessible policy information. So we recently prepared a document about guardianship and supportive decision making and we talked about different options that are had for supportive decision making around the world and we produced one version of that document that was written at an 8th grade level but that was pretty straightforward. It didn't have pictures or anything like that. And then since we wanted self-advocates we had a lot of visuals. The concept of multiple for mats. Whoever needs to access your information can access your information. If you have a text-only version, you needles an audio only version or at the very least a version that can be read by a screen reader, so on and so forth. A lot of people with cognitive disabilities miid use screen readers to supplement their own literacy. So it might be useful to think about who you're marketing to as well. A lot is just best practices. If you if you want people to understand you, you want to make sure the information you're providing is clear. And concrete and useable. I'm on slide 24. We're switching approaches slightly. And talking about some general strategies for outreach. Prioritizing inclusiveness and accessibility for everyone within your organization is a really important place to start. Without that your outreach is a useful result people might be interested in working with you, spend time with your organization, go to some meetings and you realize even though the good intentions might be there, in reality this isn't something we can participate in, this isn't something that's accessible to ask. And as a result stop participating and not feel as inclined to participate again in the future if they were approached again. So really, taking stock of the current situation and thinking about what needs to be done to make things truly accessible and inclusive is an important first step and that involves thinking through and breaking down those attitudinal barriers and really thinking about do I really see people with intellectual disabilities as people. Do I really see people with mental health disabilities as members of my community and so on and so forth. Just to make sure that, again, what you're doing is going to be really inclusive. And then, you know, specialized outreach isn't necessarily needed. But incorporated very explicitly including cognitive disabilities in existing outreach can be very powerful. People don't always realize, I think that the independent living movement is for people with all disabilities so being clear about that and making sure that you're explicitly articulating that can have a big impact. Youth outreach is something that's an important avenue, I know something that's not new to you by any means. It's something that the community with cognitive disability, the people with cognitive disabilities is also taking a look into and reaching out to and connecting to those youth can be really powerful, I think particularly with this new generation of youth who have grown up with the ADA and sometimes with a different experience in terms of inclusion. Obviously states have existing self-advocacy groups, whether they're called people first or speaking for ourselves or some other similar title and it's good to connect and see what shared priorities we have and perhaps collaborate on policies that overlap. A lot of chapters are focusing on voter education, voter outreach, voter registration and also obviously on the same funding issues, but general funding issues and so on and so forth so there can be a lot of natural overlap just working on those issues. I'm seeing a comment from Michigan disability writes about having people on staff who have cognitive disabilities as being helpful. Yes. That is a really good point. And I think that's true with any outreach you're doing. So hopefully that's something that can be really naturally included into that process of looking at what's going on in your CIL and figuring out what you're doing in terms of inclusiveness and access and what you might want to do more or less of. Move on to the next slide. I mentioned local self-advocacy groups. There's also a DD network in every state. These can all have slightly different names in each state. Disability right centers and so on and so forth. And I don't necessarily know the different names that are used in each state. However, if you know what they're called the DD network partners. So one of these three. You'll be able toz put you in touch with the other two and that can be a really direct way to access advocates with cognitive disabilityings and start building those relationships and building that overlap. At the end of the day this is about movement building. We want to see overlap and outreach between these communities because we need to build the disability rights movement that really does build on our power as a community to affect the kind of change we need to see and to have the impact at our local and state and national level that we need. I gave a version of this talk to our own chapters about the importance of reaching out to CILs and building that coalition and that crossover. So it's very much something that goes both ways. Ideally it should be something that's instinctive. I'm on slide 26. Mostly these are resources about plain language and about ways to include people with cognitive disabilities in meetings and presentations and so on. There are a few different documents here. Again, I've got my e-mail on one of the very first slides as well. If you want more information or more resources. I'm on slide 27 now, so that's final questions and answers in the evaluation. Do we have more questions at this point? >> TIM: Let's see. So one last we minder, even though I know you all know. Is to press star-pound if you have questions on the phone. In the chat on the webinar on or on the CART screen. We've got 19 minutes left. So plenty of time for questions. We may not need it all but please let us know if there's anything we can help her clarify. So again, star-pound on the phone or you can type your question on the chat. In the meantime, I'm going to give you all a commercial for a call that we have coming up on the 19th that we're doing with Christopher and Dana Reeve foundation on resources that they have, both through the general foundation and also through the process resource center for the centers for independent living. So if you didn't see that announcement let me know and I'll make sure to send it your way. And again, this call, as with all of our calls, will be archived on ILRU's website so you can share it with colleagues. So if there are friends, board members, staff members, maybe your boss or someone else that you think could benefit from this presentation today, you can share it with them. And again that's always posted within 48 hours and usually much sooner. All right. I'm not seeing any questions. Which is surprising, but that's okay. Let me just highlight this evaluation form. Again, make sure to hold down control when you hit it or wait because it could take you away from the presentation. But please do fill it out. We'll also send you a thank you, at least to the person that we had on the registration form with a reminder of the evaluation tomorrow so be on the lookout for that. And again if you're in a small group, that's fine. But I hope that each of you as individuals will fill out that eval. If there are questions that you think of maybe later today or in a month, don't hesitate to reach out. As Julia mentioned her e-mail address jbascom and myself my e-mail is very easy tim@ ncil.org. We would love to hear from you if you have questions or thoughts after the fact. Thanks so much to all of you for taking time to be with us today. We really do appreciate it. I know it's not easy to find an hour and a half of your day to take and I really do appreciate your time. Thanks so much. This is such an important conversation. For us to have and I really appreciate you taking the time to put this together and being so willing to present with us and this is going to be archived now for all the CILs to be able to access. So thanks so much. I hope to hear from you in the future and have a wonderful afternoon. We'll talk to you soon. Bye-bye. |  |