

Association of University Centers on Disabilities (AUCD)
You are important to me: Help your DSPs be the best they can be
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>> Hello and welcome, everyone. Thanks to you for your patience. Welcome to "You are important to me" help your DSP be the best you can be. My name is Anna Costalas and I am the Resource and Dissemination Manager here at AUCD. We would like to thank all of you for joining us today! Before we begin I would like to address a few details. We'll provide a brief introduction of the speakers, following the speakers' presentation there will be time for questions. Because of the number of participants, your telephone lines will be muted throughout the call. However we will unmute your phones one at a time during the Q and A at the end. Press star and pound on your phone. When using your microphone on your computer, you can raise your hand by clicking the little icon with the guy who's raising their hand and everyone mute your phone. You can also submit questions at any point during the presentation via the chat box on your webinar console you may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please know we may not be able to address every question and may combine some questions. This entire webinar is being recorded and will be available on AUCD's webinar library. There will also be a five-question evaluation survey at the close of the webinar. We invite you to provide feedback and also provide suggestions for future topics. There's a little box above the chat area that says handouts. You can select that and download the presentation slides.

Now, please join me welcoming Dr. Diane Jacobstein.

>> Thank you and hello to everyone and welcome. I'm from the Georgetown UCCED and before we start I would like to invite you to join the special interest group. There will be a meeting on Tuesday November 13th during the AUCD annual conference. I would like to welcome our speakers, Kelly Hartman, the president and CEO at Insights Consulting, Inc, a company named to the top workplaces in Indianapolis for nine years. She's co-founder of outside the box, a day program known for its innovation, and has served the Indiana association of behavioral consultants since its inception in 2001. In her near 30-year career of supporting individuals with developmental disabilities, she has always maintained a focus on individuals' capacity, not their disability. In her passion to help people achieve better outcomes in life, she believes in building on what a person can do through teaching a nonaversive person-centered approach to personal success. Through her very real training

style, miss Hartman is best known for her sense of humor and helping us see things from a different perspective. Mary Ciccarelli is a professor of clinical medicine and pediatrics at Indiana school of medicine and director of the center for use and adults with conditions of childhood. She has developed a unique approach of engaging staff on the health and wellness of the people they support. Her approach will keep it simple, direct and effective. John Dickerson spent 42 years with the Arc, the last 32 as executive director of the Arc of Indiana. Most recently he formed Quillo, an innovative platform designed to inspire, engage and educate staff at all levels working with people with disabilities. Quillo is based upon the personal well-being and positive -- upon personal well-being and positive psychology. John will share the concepts he has learned in nearly three years of research and testing. Let me turn it back over to you.

>> So since we're ready I believe the first person to speak is John.

>> Thank you. I appreciate so much we're doing this. For the first time together in different parts of the country and in different parts of Indianapolis. So thank you everyone at AUCD for helping us and inviting us to come in and talk. I'm going to kick things off and talk a little bit through the very general side of what we've learned on the DSP issue. And I want to go beyond DSPs and talk about the staff working to support people throughout our system, wherever they may be. And we're going to do a little bit today, just as an introduction, about how we improve the training of managers of DSPs, discuss some emerging client health and wellness issues, and discuss emerging behavioral health issues, and also talk about, in my area, establish a culture of work force well-being. And I'm going to be, which is rare for me, on a strict timeline, because I really want to hear what my two colleagues are saying because they're two of my favorite people in the world, on what they're dealing with in their thinking about what we're doing and needs to go. As you see the screen, I want to do a check-in with folks, with some data from the University of Minnesota RTC. Do we have any folks from the university of Minnesota on? 70% of our workforce are women. The interesting thing, that was true 30 years ago. 30 years ago they were predominantly the second paycheck in the family and now more and more they're the primary wager. 40% are recent immigrants within the last five to six years to this country. For our workforce a \$400 unexpected bill is a financial crisis for them. And I raise that because we talk about our staff and where they're at. We've got to be conscious of what's going on in their lives. 60% are considered underbanked. They may have a checking account with a debit card, but they don't use checks or have any savings that are out there, which makes them particularly subject to payday lenders when they hit that \$400 bump. A growing number of immediate family members have joined our workforce, and they are direct staff for their family members. In looking at Indiana, where I've looked at the most on this data, if we don't capture good data on this, I believe that as many as 20% of our work force in Indiana are immediate family members of individuals they are caring for. And that's just an important thing to think about when you look at our workforce. Again, many of our folks get in trouble with payday lenders and transportation and day care could be critical parts of their lives that can break down at any moment. Nationally we're looking at about a 50% turnover with most moving from one agency to another, as opposed to leaving and going into a \$30 an hour job in industry. And wages are important. Make no mistake. I want to make this really clear. We've got to raise salary and benefits for our work force. It's essential. But in the last three years I've learned there's so much more we can do that while we continue the battle for raising wages, we can address for folks. So I'm going to ask you guys to think if we can't do this interactive, but I want to ask each of you to think of the very best staff person you've hired in the last six months. Who is that person? What do they look like? What are their skills, where did they come from? Because wherever I talk about workforce issues, people immediately turn their minds to the problems, the people that have left, the people that haven't worked out so well.

But we've not -- we don't think about the very good people that we've brought on and how do we deal with them. So three takeaways that I'm going to work with you on in the next 17 minutes, is thinking about the communication we have with our staff. And be more mindful in what we're doing. Secondly, how are you building your culture in your organization? And thirdly, how are you hiring and promoting the right people? You'll see nothing that I'm talking about here is skill-building, talking about compliance, health or safety. All those issues you're required to train your people on. All of that is important. I'm going to be talking to you about things that are very different, that will help determine whether people stay and grow within your organization, or they leave.

When I talk about mindful communication, one of the things we learned in our research, is that 80% of our communication with staff and managers is done by smart phones. It is either a text or an e-mail, or a phone call they receive. When we asked the people, both managers and staff, to self-define their communication, 70% said it's predominantly negative. They're only hearing from managers when there's a problem. And so as recently talking to 600 managers of residential programs in Chicago, and I asked them how many of you have already had a phone, text or e-mail from somebody back home about a problem that came in. Everybody raised their hand. I asked them how many of you got a text, call or e-mail about one of your staff that did something extraordinary yesterday. Nobody raised their hands. So when we think about mindful communication, it's the context we live in, which we all understand is very negative. 60% of Americans have quit listening to the news because it's so negative. The world we live in is driven by problems. So our experts in psychology and business psychology said to have a good relationship with your staff, a good business relationship, you have to start with the goal of a 3-to-1 positive to negative communication ratio, or 3-to-1 negative to positive. A psychologist said something to me you've got something good because you only have 50% turnover as a national average. When you think about mindful communication, we ask people to spend 15 minutes a day looking through the extraordinary in the organization. How do you break time away to look for the really good things that are going on. How do you tell your team about their success? The five dime exercise is a great one. The ideas that you put five dimes in a pocket or one side of your purse. And every time every day that you give a positive message to someone, you take one dime out and move it to the other side. And see how long it takes you to give five unsolicited positive feedbacks to folks. Go back and look at your e-mail and texts, and think about how they're received with folks, and you think about how you communicate today is different than how you did it five years ago. What we're talking about with mindful communication is, when we talked to staff, do you know what the first thing they said to us, when we were doing some interviews? They said are we in trouble? The only time we hear from folks is when we're in trouble. That is not leading to a culture that models our best behavior for folks. And everyone responds to positive attention. It may take several times to get them to realize what you're doing with them, but the idea that we've got to become more positive in our interactions with folks. And when you model behaviors, how are you looking at that with your own team of leaders? Do you talk about just the problem folks or do you talk about your all-stars? So one of my friends of mine is a young man that works in a hospital system in charge of housekeeping. Not one of the more glamorous, but very important jobs. And he describes the three groups of people that work in his operation as people on a boat. And you have the rowers, who just work their heart out on the oars. Then you have the sitters, they have their hands on the oars but they're not really putting their effort into it. And then the drillers, the people at the bottom of the boat drilling holes into it. Too often we spend time trying to solve the drillers' problems instead of praising our sitters into becoming rowers and he decided he was going to get the drillers off of boat. He took his employees in a little over an year moved from having an 84% turnover ratio to an 18% ratio

all by getting to know people in his operation. When we talk about mindfully communicating we've got to think about the people we're reaching out to and what is important to them. We communicate differently. We have to learn to live with cell phones as a way of life, as opposed to something we want to ban. But we have to find ways to use them correctly.

And so I'm going to switch gears here. We can spend an hour on the idea of mindful communication. Think about your own organization and think about how you communicate. So I'm going to ask you now, as we switch to the next section, about building your culture. I would ask you to say how much time do you spend developing the culture of your organization. What is it that you want people to think of as the key values of your organization, and how do you live them. When I ask that to a group, they'll often say well not enough or sometimes there's a really clever person who says I spend every minute of every day working on culture because that's what I do as a leader is what builds our culture. And that is so true. There's a reason Kelly's organization consistently is in one of the top ten businesses to work for. Not human services, but the top ten businesses to work for in Indianapolis. She's built a culture with a lot of daily hard work of what that is. Another way of approaching that is asking people what your cultural address is. What are the names of the streets, the two intersecting streets for your culture of where you live. And think about just two words that would describe where you want your organization to be. The last thing when we think about culture is asking the people that come to work for you at all levels, what brings them joy in the work that they do. And how do we do more of it. That is how we start building a culture and begin looking at the way we indoctrinate throughout folks, so they think immediately and know here's what we're about. And we do it one person at a time. This isn't about having a retreat on culture. Which isn't a bad idea. It's not bad to have discussion with your staff leadership, but what's more important is taking what you believe is your culture and living it every day with the folks you work with.

Now, our last section we often get asked about is how do we hire these folks. In the work force we're at under 4% unemployment. I often have people tell me we're hiring people we wouldn't have interviewed a year ago. We tend to look at the workforce as the problem instead of this amazing opportunity we have. When we start talking about hiring and promoting the right people, I ask folks to look at orientation. And when you do orientation, look at your agenda for orientation. Because what you're telling people, your first real exposure to them is here's what's important to you as an organization. If your orientation session is entirely about compliance, health and safety and rules and paperwork, that's what you're telling people that is important. Instead, you have to cover that, of course, but how do we instill with them a sense of mission in the organization? How do we extend to them this understanding that here's the team you've joined? Some of the best people I've seen start looking in every orientation class that say who are our future all-stars in this class that we have to mentor, encourage and keep them going. Keep a list of these folks and share them with managers. When you see these folks, we want you to mention something to them, mention something positive. Some of the exciting things people are doing on their second day on the job, everybody gets a positive stay interview. What are you liking, what are you doing, how are you find this working for you, how can we help you. One organization in orientation they brought everybody's immediate supervisor into orientation for lunch, and all they did is have lunch together. No agenda, just get to know each other. And then when they showed up on first day on the job, they knew somebody. When you start looking at bringing those folks along, then you look at who do you promote? Is it just based on skills, or I think you need to promote people who get to know their staff, their family situation and their kids. I visited an agency not too long ago, 800 employees and was interviewing a DSP. At the end of the interview she said I worked for this agency for six years, I love it. And I've never told anybody I have a 12-year-old daughter with down syndrome. When I shared that

with the executive director, he was shocked. Why wouldn't people just naturally want to share that information? So our leaders have to get into where they know the people and what's going on in their lives.

So one of the questions one of the agencies did in talking about this, is right at the point they're hiring somebody or promoting someone, they ask this question would I take an eight-hour road trip with this new hire. Why? Because on a road trip you learn about a person. You learn about what they like, what they don't like, how they want to change the radio, what they like to eat. If they decide they wouldn't want to go on a road trip with them, then they think maybe I shouldn't put them with our folks for eight hours. And provide that sort of a situation for them. One of the things we ask people to talk about, are you interested only in coverage or the character of the people you have. One of the exciting things I saw when we started talking about recruiting people is one agency changed one of their core competencies and asked each of their staff members, they say you know, you're some of the best people we've ever hired and you bring a joy to this job that is exciting. Do you know people just like you that are the best people that would like to come and work at a place like ours. 40% of the staff took them up on it, and that was incredibly successful and it was just by asking them. Not offering a cash payment, not offering them a recruiting bonus, which as I travel around the country I find really don't work in big numbers, because people don't want to bring their friends in for payment. They want to bring them in because it's a great place to work. And it starts with this idea of what brings them joy at work. And it generally comes back to not just seeing the paperwork is done on time, the reports are done, but how people grow and develop. And that is so critical as we look at it. These are folks that I've gotten to know that work with folks with disabilities. One came out of retirement. Ana on the far right had retired from AT&T and her daughter responded that she was bored at life and she said why don't you come do some rescue work. She is amazing and she loves it. The other fellow Allen has worked for an agency now for 14 years as a DSP and first-line supervisor now. But he still does DSP work because he's got this group of three guys that he has developed a relationship with and he knows the agency cares about them. So as we think about well-being, we challenge people to get to know what's going on in folks' lives, we want you to know about what's happening. I'm visiting an agency in New York City that they learned that one of their folks was having some troubles at work and didn't share anything because they brought in a 90-year-old mother to come live with them who had Alzheimer's and all of a sudden she was missing a lot of work and her supervisor wanted to fire her. Instead they went and talked to her and found out what was going on in her life and helped them figure out what they were going to do about it. If we are going to change the focusing on the well-being of folks, there are lots of clever ideas that folks have out there, and I've taken what is about an hour and a half presentation and built it down to about 18 minutes here. But the idea that you look at well-being. So we can't make people middle class, but we can help them out with tough things. We know about affordable housing. We know about kids who are having trouble in school. We now how to help people who get into financial problems. But how do we take that and translate it back to our staff. That will make us more relevant in people's lives. I wanted to end with this quote from Burton Blatt because we tend to get really interested in what we're doing today and think we've achieved the best we're going to do. He wrote this in 1956. He said to some degree all of the talk and behavior will not change. That is absolutely certain that we will change. What we profess now in one way or another, we regret later. The workforce situation we have is not a crisis, it's a wonderful opportunity for us to reinvent how we interact with our staff, how we use positive psychology to model the best of what we have. And have people aspire to that. And how do we take care of people from their personal well-being. I'm going turn it over now to Mary Ciccarelli, and, who's going take that to the next level as we talk about emerging trends in health care,

that we can engage DSPs and staff that will give them a greater relevance in what they're doing in people's lives. And the three things staff looks for in feeling satisfied with their work is one they want to see results that show that they have value in people's lives, they want to be acknowledged for what they're doing, not just called when there's a problem, and lastly, they don't want to be anonymous. They want to be recognized as someone who cares about the people we work with. So if we have a way to do questions at the end, I'll be glad to do that and share with you. This is more about the high level thoughts that you can move into and Mary and Kelly are going to get into very specific ideas with you and thank you for your time and sharing with us here.

>> Thanks, John. This is Mary. I think that what we're all trying to say today is that relational aspects of our work and the people we serve are important, and that's how we picked the title for the talk. You are important to me is that, it symbolizes both directions of the DSP staff themselves are important to their organizations, and caring for them in a relational way improved their ability to work within the organizations as John just told us. And these staff are also really important to the people they serve. So what I want to do is talk about the health perspective. The health perspective of the staff and the people they serve. And so let's think about how we think about health in a less-than-complicated manner. What are the simple things we need to do to take adequate care of our bodies to maintain our health? How do we think about what the people we serve feel and need from a health perspective. And so we might ask questions like what is this person telling me with their behavior, their words, their actions. What is this person likely to be feeling and sensing about their body, as well as about their staff and the world around them. And how do we use their brains, strengths and limitations to help them manage their health. This is the standard curve you see when we talk about intellectual disability and it's not important. The numbers really aren't important. What is important is how do people perceive and reason and what is their memory like and at what speed does their brain go, and when an individual can have limits in one area, they might not have the same limits in all four of these areas. And we have to think about each individual and what we know about them and what they're telling us. They may have trouble more with communication than money or self-regulation or understanding rules and socially engaging with others, or doing the daily activities of taking care of their own body. And I'm going to talk a little bit more specifically about the specifics of taking care of our own bodies.

I just like to use language that also thinks about what does autism mean. Because autism doesn't mean that you necessarily have problems with perceptual reasoning or memory or processing speed, but it does mean that you have some issues in your social communication back and forth between people, showing emotions, understanding relationships and interactions with relationships. It may also have issues with repetitive movements or communication or rituals or fixations, all of these are pieces of understanding this individual person. I know you've all already heard the expression, if you met one person with autism, you've met one person with autism. Because the way they manifest these different issues in their social communication and their daily behaviors and sensory intake and processing is very unique to each person. And therefore we have to walk a minute in their shoes to think about what is this person feeling and sensing, how do they understand what I'm communicating or demonstrating for them, how do they infer information from their environment and what can I do to better work together with them.

We've created a project at kayak, that's the name for our credit, it's CYACC, it's phonetically incorrect and you'll allow me that license I hope. The project we've created is thinking about health habits or daily activities that are necessary for maintenance of one's own body. And so let me walk through this step by step. We have people who communicate with us in a variety of different ways. And I guess this slide is maybe even out of place of

where I want it so I'm skipping it. Thinking about how people communicate pain is an important part of autism and intellectual disability as well. I like this particular tool called the Dis Dat assessment tool. It helps me think what does my person look like when they feel well or when they're content or what do they look like when they're distressed emotionally or behaviorally or environmentally and understanding this unique individual, by taking some time to think about what kind of movements demonstrate pleasure, contentment or comfort for this person. For some of us we're still and have a calm look on our face and are silent. And some of us when we're content we hum and main phonations of other kinds and rock back and forth and understanding the difference between those two really matters. I have some patients who I've met with various conditions that in fact make lots of noise and have lots of movements in their best of situations, when they're having a great time, and they actually freeze when something is terribly wrong and they're silent and they're motionless and that could mean that something really wrong is happening in that particular person, if I understand them better, if I've walked in their shoes to understand them better.

So now let's talk about how our bodies give us cues. As you're all sitting here right now, you can answer the following questions but I'm not going to make you do that. You can tell me how thirsty you are, you can tell me if you're feeling a little tired and you think a little jolt of caffeine will help you, you can tell me if your bladder feels full and you're going to run to the bathroom, you can tell me if you felt some rectal stretch earlier in the day and forgot to go poop and are now going to need to go sooner or later. You can tell me if you're eating something and now it's safe for you to swallow it. These are all body cues. You're hungry, you're full, you're hot, you're cold. All of these we take for granted if we don't stop and think about the fact --

>> Mary, it sounds like we've lost you. Sorry, folks. Mary has been experiencing power outages in Indiana. Let's just give it a second. All right. While we are waiting for Mary to reconnect, does anyone have any questions from John's previous presentation? Is Mary back?

>> This is John. Just want to do a little shout out. Because we talk about one of the folks on the call is a friend with Albatross consulting. If you haven't ran into Shannon, she has a wonderful presentation for staff that is how DSPs and staff will survive the Zombie apocalypse. It's right on point what we recognize in strengths and what we should recognize in folks. Just wanted to share that with folks as we look at that. In case it is coming, we want to be prepared.

>> It looks like Mary is on her way back in. Just give me a second. Mary, can you hear us?

>> I've got one question here while we're waiting.

>> Can you hear me?

>> Great, go ahead.

>> I'm in a build thanking has lost electricity twice now today so I can't see screens yet at all. So I think we're talking about -- so sorry. I think we're talking about body cues. Is that what everybody heard last?

>> Yes.

>> Okay. So I a little bit lost my train of thought struggling here with my computer. So this health habits is a way of thinking about what your body cues might -- how missing your body cues might require you to have rules instead of cues to help you take care of your health. Can you go to the next slide that's titled body cues, because I can't see the slides yet. And I think we talked about each of these. So you'll notice that the people in these slides are noticing their own body's needs. They feel full, their bladder is full, they're hot and need to drink something, their belly is full, they're feeling tired and probably should go to sleep. All of those things, if you don't pay attention to those cues, the secondary abnormalities might be that you eat very selectively and don't eat things you need or you don't chew well enough

and choke or you might be over or underweight because you don't listen to your hunger, or you have episodes of irregular bowel movements or menstrual hygiene problems or you don't remember to cut your toenails or recognize that you're smelly and need a shower. Don't get to sleep, don't stay asleep. If you can go to the next slide, I don't think I can do this at the moment but I'll try. Hopefully you're on the slide that says the fatal four, and that slide is a reminder to all of you that individuals with ID have increased morbidity and mortality from those four conditions and all of them are attributable to poor reading of one's own body cues. Aspiration often is about not chewing right, cramming thing in your mouth, having things of mixed textures that are hard to handle at the same time. Dehydration is not remembering to hydrate when you don't feel well. Constipation is not allowing one's self to poop and hold it in so you get secondarily constipated. Seizures, they don't recognize the sensory cues of their seizure auras or pre-warning signs and therefore run the risk of having more complicated symptoms because they can't sense and make people aware of it. Could you go to the next slide? And that's fussy eating. And fussy eating causes a lot of issues. I've talked about some of them already, particularly refusals of food or selectivity or textural needs or eating irregularly through the day because of not listening to body's habits and if we all actually override our own hunger pains and just eat because it's there for other reasons, we all fall victim to not being healthy. And we use in medicine the term "grazing." If you eat things throughout the day, you don't ever get full in this grazing manner, and then you are quite likely to not be at the right weight for your body. If you go to the next slide it talks a little bit more about toileting in the population and how common abnormal colons are in this population. You stretch your colon out so much that it can't squeeze things along normally. Our colon is a muscle and it needs to be able to not be overstretched like an overstretched balloon that has no elasticity anymore, but at normal size so it can contract and squeeze things along. And one of the most common problems that fosters constipation in this population is a colon that's out of whack, that's just not in shape. And so to think about how to help people with this, we have to actually know if they're going to the bathroom regularly and what size those poops are. And how hard or soft are they. The very -- not to be vulgar, but frank questions you have to ask people are, show me the size of your poop. Is it as big as a pencil, a sausage or a rock like this. You might want to know how easily it flushes. A hard poop doesn't flush easily. These are very simple skills in helping someone self-monitor their stooling regularity. When we think about hydration, what do we do to help people think about their hydration and how to make that better? The easiest way is to know how much people drink a day and how often they pee and what color it is. And a really great family suggestion that I've had from folks is to try using just a 30-ounce water jug every day as additive liquid to drink besides your usual meal liquids to help a person keep pace with drinking enough. And drinking enough means drinking enough to keep your body feeling well-watered. That affects our ability to exercise, that affects our kidney's ability to get rid of waste products, that affects our ability of the colon to move things slowly. No water in the colon leads to hard pooping again. Toileting aids. The point of this slide is not just about using visual aids who might not be good at hearing their own body cues, but also a reminder to think about how should they time when they should go to the restroom. If you're not good at sensing that your bladder is full, just creating rules that are easy to follow as habits, I go to the bathroom before I get up in the morning, I go after each meal, I go before I go to bed and I go and I try those times out of habit because I'm not good at knowing when I really need to go because I either receive sensory cues from my bladder or the way I understand and process them in my head. Next slide. Thinking about how much sleep people need. So what's the usual amount of sleep for an adult. A usual adult needs somewhere between seven to nine hours of sleep. Maybe as little as five and a half to six for a few rare individuals. That being said the lack of sleep plays a huge role in the ability to function in the

day. Having some routines and rules are important. If a person needs to not figure out am I tired right now, but instead when should I go to bed so I can get up at the time I need to get up, that's a complicated calculation for many people. So helping with the basic rule that you're the kind of person who does best with seven hours' sleep, therefore if you're planning to get up at 6:00 a.m. tomorrow you've got to be asleep by 11:00 p.m. tonight. And that rules help. I think Kelly made a good suggestion to me when we were talking about that, which is that rules aren't meant in these circumstances to be adamant rules. They're guidelines. Some days we stay up later. Some days we make choices to do something different and it's okay and important to be able to have the dignity to allow unusual days. But understanding in general what the body needs helps you figuring out is today an usual or unusual day and how are we going to navigate that. A few other things on this slide are just the basic principles of what you need to sleep well. You need regular and consistent habits about that and your bedroom has to be a comfortable place and caffeine certainly puts a monkey wrench into most people's sleeping. Heavy activity right before sleep doesn't help people relax. Light activity, relaxing activities do. Keeping away from the blue lights of i pads and telephones and television which are bad at signaling our brains to stay awake when we're trying to get to sleep is another important issue. I talk about melatonin a lot because it's a non-prescription solution for many people and it really has a very limited risk for everyone, in terms of as a supplement to helping people reset their brain's clocks. Next slide shows just some other additional reminders and visuals that we use to help people with setting up their rules and reminding them about their rules. The following slide about dental care does the same thing. And the last slide is a basic checklist that some folks use to help them monitor and feel proud about their activities. So in summary, hopefully I think you're all still hearing me but I don't promise what my phone is going to do, health habits are a way of creating rules to help individuals who may sense or process their body cues in a manner that doesn't help them maintain good health. And so that might include not eating regularly at set times in a day. Regularly set times. Most of us need to eat more than once or twice a day. Three times a day. Maybe four or even five times a day, depending upon specific needs. Our goal is to keep our weight in a healthy range. And if that's not happening and nobody is ever weighing us, we can't do a cross-check of whether we're eating in a healthy manner. We need to sleep in a certain amount of time so we're relaxed and well-rested and easily awakened in the morning. We need body hygiene. Somebody needs to be checking those toenails. If I'm not good at noticing that my toenails are banging into the top of my shoes. Toileting we talked about enough. Having a habit to checking and see if you need to go at some point throughout the day. Drinking enough liquid with reminders to do so. Checking in about how people manifest illness or pain, and learning how to ask them those cues or recognize those cues in them as well. Okay. That's my summary about health. I'm going to hand it over to you next, Kelly, to talk about behavior and then we'll accept questions at the end.

>> Hey guys. Have you unmuted my microphone? Can you guys hear me?

>> Yes.

>> Okay, great.

>> So my background is in behavior. And typically my training style is very interactive and I move a lot. So pretend like you can see my moving my hands and pacing because it's very different when I can't see you all. Typically when people see the word "behavior" and they work in this field, they do not think of it as a positive thing. When you think about behavior, as John and Mary have both alluded to, this is a lot more about just a targeted behavior that's in a behavior support plan. This is about how people feel, this is about how people communicate. So I like to tell people when we talk about behavior, we're not just talking about folks with health challenges, we're not talking about people with intellectual disabilities.

This is really about all of us, not just the folks that we support, but this is about each other and the teams that we work on. The definition of behavior is actually anything you do or do not do in response to anything that is or isn't happening. So it's how we act or react in response to any stimulation in our environment or lack of stimuli. So what we want to think about is how that impacts us in our lives. So we have situations in our lives that we might have behaviors in. Now, I understand that people also have positive responses, but because we're talking about behavioral challenges, and the things that we really struggle with in our work, understand that right now we're going to talk about what are typically seen as negative behaviors. Here's a list of situations you might have in your life. You might get in an argument with your partner or you feel bad or you remember a funny joke you've heard. Many of these situations lead us to have behaviors. Here's some behaviors that many people will say they have in response to these life situations. So you know, yelling and screaming and cussing. This happens at my house every once in a while. Slamming doors and throwing things, drinking, smoking and taking drugs. And while I don't encourage these behaviors, certainly they are behaviors that sometimes people use in response to situations. Biting your nails, withdrawing, sleeping, eating, laughing out loud and repeating yourself. The question I ask you is if you look at this list of behaviors that you see on the right side of your screen, the big question I always ask folks is what's the difference between these behaviors that you have in your life and the behaviors that folks we support might have in the same situations. Most people will say there's no difference. I will tell you that I believe it doesn't matter if you're working specifically in the mental health field or specifically in intellectual disabilities or folks who have co-occurring issues. I think we talk differently about our folks than we do about each other. So yelling and screaming and cussing becomes verbal aggression when you translate it into a behavior support plan. Slamming doors and throwing things becomes physical aggression. And onward. And so we have these labels that we use. Now, think about this. I'm sure many of you have children at home. I have 14-year-old twin boys, and I have never said to my kids when they were in the middle of a fight, Austin don't you be verbally aggressive with your brother. We only talk about verbal aggression and physical aggression as though it's a thing that you do if you are in a certain population. And the reason that's important, folks, is that I can go around through the 70-plus people that are on this list, and if I could see you I could label every single one of you. But labels only do one thing, and that is make us different from one another. The other word that I hate that we use in our field so much is community. When I hear people in my office saying we're going out into the community tonight or we have a community outing, I say what is the address of that place, because that place is happening. Everybody is going to the community. Truth be told, while I'm being funny to a certain degree, I've never again said to my kids or my partner, hey, you guys want to go on a community outing? I think we need to be careful about the language that we use, because it does nothing but separate us. I've had the opportunity to work with folks here in Indiana that were institutionalized and when I would hear stories from the late '60s and early '70s when people lived at a place called central state hospital I began to believe that maybe they were exaggerating but I continued to hear the same story over and over. And I think when people have come from a place where they were fed out of a bucket in barn enclosures, given clothes that were not their own, and went through this day after day, it makes me think a lot about how important it is for us to not make people feel different than us. And so understand when you use labels, if I say to someone hey, I'm taking you out in the community, what I'm doing is actually saying to people, I don't think you're part of my community now. And while it may not seem like a big deal to use the right language, I think when you see these pictures from the late '60s and early '70s when people were institutionalized as a standard, it is important that we take careful consideration of how inclusive we are, not just with what we do, but with what we say and how we act.

I think it's also important to understand that we did not institutionalize people because we were trying to be disrespectful or take people's integrity away. The quote that John used earlier from Christmas in Purgatory, it's really important to understand that as a society we did that because we thought we were protecting the community from these folks who we weren't quite sure how to interact with, and we thought we were protecting those folks from being in our community where they may not be safe. And so 50-plus years ago, we were very, very focused on health and safety. And what I encourage you to think about is what are we doing now that goes beyond that. And we'll talk a little bit more about how important it is to go beyond health and safety. The approach that we talk about most here where I work and here in Indiana is positive behavior supports. And so understanding that positive behavior supports is basically a belief that all behavior is a form of communication. It is an understanding that people don't randomly just have behaviors. If you're working with folks that have behavioral challenges, there's a reason behind that. We want to develop strategies to help people get what they want safely. We want to be preventative, proactive and supportive. Obviously behavior support plans in our approach should be individualized and we need to base what we're doing with behaviors on a functional assessment. In other words, the team has to know why the behavior is occurring. We have to get to that point before we can really support someone towards a better life. The next thing is to understand what positive behavior supports is not. It's not generic or aversive or restrictive, it's not the use of manual or mechanical restraints and it is not crisis intervention. Those things would be dealt with in a different way than a positive behavior support intervention plan. I'm going to give you guys five tools that you can use that will make your life a little bit better as a DSP or as someone who works with DSPs as we support folks. Number one, understanding that learning and living does not happen at the same time people are having bad behaviors. I worked with about 75 families and some psychotropic medication and it was amazing how many families said Billy doesn't have any behaviors when he's doing something he loves. Think about how much sense that makes. You're not living and loving and learning and doing things you want to do and having negative behaviors at the same time. So if I could give you guys all a little favor for coming today with a big red bow for participating in this, I would love to give you happiness. And if I asked you to raise your hand, every single person would say yes, I want that. What we need to understand is part of being human is we all want more. We all want to be happy. I'm going to give you a couple hints how we get there. First of all what we know from research is that happiness is more than being healthy and safe. I am not going to feel happy in my life unless I also feel loved and valuable. Think about this from your perspective, guys. This is not just about the folks that we support, but this is about the staff that we employ. It is important that people feel loved and valuable. So if you think about trying to keep these things in balance, it's difficult. Because life happens. For example, in the early '90s my mom was diagnosed with cancer and I spent a lot of time trying to feel safe, emotionally and physically again, because I was freaking out. And as I worked really hard at trying to get safety back in balance, then I got bronchitis and I felt really unhealthy and as I continued to pursue that, I realized then I wasn't feeling as loved because I wasn't in a relationship with people and I suffered in my performance at work and school so I felt less valuable. So these four things have to be in balance for someone to begin to feel a sense of happiness. Now, there is six areas, and this is all based on old-school Maslow's hierarchy of needs, but it's important to understand how this all works together, task areas that we work at are health and well being, emotional and behavioral skills, social and relationship skills, cultural and spiritual activities, and then we get into the higher level vocational and educational steps and fighting ways to be economically self-sufficient. These are activities of life that we want to keep ourselves involved in so that we don't have burnout, but to also think about how do we keep our folks involved in activities that are meaningful as

we kind of balance in these supports, many of us in residential support, we have to look at we're not the ones providing happiness. We're the ones amidst all the activities that help people achieve a level of happiness. What happens then is that sometimes there's an interruption in this, and a behavior might occur. When the preventative and proactive things are no longer effective, it's like someone goes into the Bermuda triangle. We want to understand, as someone with a behavior, we want to use the least restrictive interventions, more restrictive interventions and the course the last amount we want to use the most restrictive with the goal we want to get people back to life. Understanding the first tool is learning and living does not happen at the same time that somebody is having a negative behavior. So if somebody is hurting themselves, they're punching themselves in the eyes, you don't want to go up to them and say hey, don't you guys want to work on your relaxation exercises as a group, because they don't. They want to get through it and your goal needs to be using those interventions to get people back to life. The next tool I'm going to give you is it's important really to understand. You have to know why the behavior is occurring. And so let's say we have a targeted behavior. Someone is punching themselves in the ear with a closed fist. Just off the top of my head if I'm asking why is this happening, it could be three or four different things. It could be the individual is trying to avoid something, maybe trying to avoid a certain kind of sound or they're trying to stop auditory hallucinations. It might be that the individual likes how it feels so they're sensory seeking or they like the sound of the punching. It could be because someone is experiencing pain, maybe they have a headache or an earache and they're not able to tell us in another way. And the last one is maybe they just want attention. They want response from a caregiver because every other time they've hit themselves they learn they get attention for that. So it's understanding the why is very, very important. We have to know that no matter what the situation, in all four of these particular explanations for that behavior, we would respond very different for each situation. We have to know why the behavior happens to help the individual have a better life and support them in a way that they can reduce that behavior or achieve better outcomes.

Number three is understanding the individual's story and understand the role of trauma. What we have to stop asking when people have behavior problems is what is wrong with this person or why is he doing that. We really have to understand why we have to -- we start asking the question what is your story. I think it's really important to understand how relationship build suggest so important with our folks. You are not there in that situation to baby sit or provide simple supervision. We want to empower people to be the best they can be. And if these folks have had trauma in their past, that is something we need to understand. What we know about trauma is that between 34% and 53% of people with severe mental illness nationally have reported abuse, approximately 25% of the folks that we work with who are kids with disabilities have acquired that disability as a result of abuse. And what we know is more than 90% of all people with intellectual and developmental disabilities have experienced some trauma throughout their lifetime and of those, 70% of those folks report that it occurred repeatedly. Your role in working with these folks has to be an understanding that we want to know the story, but we also must know that people have to feel safe, physically and psychologically, for us to feel empowered. Again, this goes back to more than just health and safety, but understanding that people need to feel loved and valuable as well.

The next thing to understand, especially when you're talking about trauma, is how the brain works. And this is number four for you guys to have an understanding of. While the brain is very, very complex, and we're still learning every single day about it, what I like to teach DSPs is a very basic triune approach which helps you understand that all of us have in our brain an organism, an organism similarity, like all organisms where we all have instincts. So the very base of your brain, in the first part that develops is the reptilian brain. That is

where our instincts come from. That is fight, flight, freeze. The next system is the limbic system and that develops over your reptilian brain. And the limbic system is where your emotions are stored. And your emotions come from. And in the very last layer that develops, which is the neocortex, same thing as saying the new brain, is where rational thinking and language are stored. So the really interesting thing to think about when folks are having negative behavioral expressions is that where their emotions and instincts come from is not where their language is housed. And the words that come out of their house or sometimes the rational thinking that they seemingly have or don't have is not necessarily connecting to the same part of the brain where the emotions and instinct are. And when you look back at my third point of being trauma, this is super important to understand because when people have instinct to respond and they display situation or they freeze in a situation or they fight back, all of these things come from a very instinctual point of trying to keep themselves safe and again your best approach is to understand we need to go beyond health and safety and make sure people are feeling valuable and loved at the same time. Again, that relationship building, being so incredibly important. Now, if you're one of those people that is listening to this webinar and you're not looking at your screen, I encourage you to take a second to turn around and look at your computer because I'm going to talk about perception and I find this is probably the most valuable thing that I can share with you today. If you're looking at that picture of the rain forest on your screen, many of you are like okay, wow, that's great. Maybe some of you have begun to see the animals. And in this picture there are five animals. There's a serpent, a wild boar, a crocodile, a monkey, and I believe a tiger. And the cool thing is if you look at this picture and you now see the animals, and I show you this picture tomorrow, you can't unsee those animals. You will never be able to look at that picture again without seeing those animals. And so when you're brain, whether I'm talking to you about your role in supporting folks or if I'm talking about your role in life, just keep in mind that your brain cannot unsee this. It is a perception shift. Again, when I show people this picture, what do you think that is? It's a violin, a string instrument. And I ask you is it really. Some of you are turning your head right now because you're trying to figure out what I just did. But that is the same picture two different ways. It is a land formation and a reflection off of water. Again, you can't unsee the violin. This is probably one of my favorites because this is clearly a rock formation with water. However, it is a parent and a child in a peripheral situation. So again, it changes the way that you see things. Now I ask you what you see here. This is easier to do when I'm in the room but what I'll tell you that there is nothing there to see, but that's my backyard and people always look at me really seriously and think I possibly have that as my backyard and I tell them I won the lottery and I'm one of the richest people you've ever met. My question to you is do you believe that. So you guys have never met me before. I will tell you I have one the lottery and I am one of the richest people you've ever met because there is a big total of \$16 and I am the richest person you've ever met because those children in that picture bring great value for me. I've changed your perception by saying I've won the lottery, because I'm showing you there the evidence that that's a true statement. I take you through this perception exercise because what I want you to think about is how you see the folks that you support, and how you see your employees. Because it's really, really important. If you were to go in tomorrow and only see the amazing. If you go into work like today is going to be the best day but if you know Billy has been having a bad week, you're going to seek out those amazing things about Billy. You're going to seek out great things about the staff that might challenge you at times. And when you see that Billy is amazing and when he cares about how he looks in the morning or whatever it might be that is new information for you, keep in mind that when you see the amazing in someone, you cannot unsee it. It is impossible. To unsee things. Because once you perceive something a certain way, it will change how you see everything. And so I think it's really important to

understand that how you treat others, whether they're folks that we support or people that you employ, is really impacted by your perceptions. And those perceptions come oftentimes from our own experiences. It is a discipline that you can get really good at, ask people and be very, very active in understanding what they are most amazing at. I think the last thing to share with you is, this really simple quote that everybody's seen it on a card. But the truth be told is we know from research why you work in this field. I'm sure each one of us have had a die here or there where we sit around oh, man I can't do this anymore or why am I in this field. What we know is that you do it for three reasons in this order. Number one, you want to make a difference. You want to change people's lives. Number two, you want to be valued for making a difference. Not just changing people's lives, but you want to be recognized for that. Like John said, you don't want to be invisible. And the third reason you do this is for a paycheck.

I've had the opportunity to work with some amazing humans, both people that work for me and work on teams with us, as well as and probably most importantly the folks that we support. And what I've learned over and over and over again is that for all of us, to the world you might be one person, but to one person, you are very, very likely the whole world. And when you are very, very clear about your role in someone's life, I think that it will help you perceive them differently, and I think it will help make you more amazing in how you're able to support those folks. So the last thing we're going to share on this last slide is our contact information. I think I can speak on behalf of John and Mary both that if you have questions after this, you can certainly e-mail us. I do know that the handouts are up in the section where you can download the slides from today. I think at this point we are in a good place where you can ask some questions. If you guys have questions or anything additional that we can provide for you.

>> Thank you, Kelly. Folks, if you raise your hand, if you're using a microphone and raise your hand I can unmute your mic. You can also ask questions on the chat box. If you are on the telephone, you can press star and pound and I will unmute you.

Yes, this webinar will be recorded and it will be able on AUCD's webinar library and should be available by the end of this week.

Handouts. If you look above the chat box, there's a DSP presentation. If you highlight it, you can download the PowerPoint directly to your desktop. I also will include this PowerPoint when the recording goes out, which will go out to all the registrants and it will also be available on AUCD's webinar library.

>> Did you say you would also be doing an evaluation, right? Because certainly --

>> Correct.

>> We would love the feedback it's important that DSP have the opportunity to hear this information.

>> Yes. The evaluation will pop up on your screens when we close out and it's a short five questions and yes we will forward those answers to you as well.

I'm just seeing a lot of thank yous. Give it a second. Those of you who are not a part of the AUCD network, please feel free to forward this on to your folks if you are -- this will be available and free to share.

All right. Well, I would like to thank the awesome presenters once again. I learned a great deal. And for those who are attending, thank you very much. As I said, this webinar has been recorded and the transcript as well will be available by the end of this week on AUCD's webinar library. I put the web address in this chat box. It will also be e-mailed to all of the registrants. So you'll also get an e-mail with the slides and the recording and the transcript. If you have any questions feel free to e-mail us at AUCD. And presenter contact information is

on the screen if you would like to contact them. Thank you again everyone and please feel out the five-question survey that's going to pop up on your browser. Have a great rest of your week. Take care.