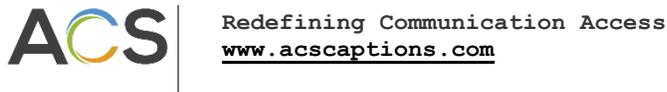


REALTIME FILE
 AUCD - STRATEGIES FOR ADDRESSING ANXIETY RELATED TO COVID-19
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(Please stand by for live captions to begin)

>>SPEAKER: My name is Louis Valdez and I'm your program specialist and I serve as staff support for the mental health aspects of IDD special interest group, a group within the AUCD network that promotes inclusion for all with IDD and mental health needs, we recognize the relevance and timeliness of today's presentation, especially during this global crisis we are all facing today. Thank you all for joining us today. Before we begin, I would like to address a few logistical details. A brief introduction of our facilitators, following the presentations, there be a time for questions. Because of the number of participants, your audio will be muted throughout the call. However, you can submit questions at any point during the presentations, via the chat feature. You may also send a chat to me directly. This entire webinar is being recorded and will be available on the AUCD website following this webinar. There will also be a short evaluation survey at the close of this webinar, we invite you to provide feedback and suggestions for future topics. Please welcome our facilitators, Karen Weigle and Jill Hinton. Karen is a clinical psychologist working with people with autism and other developmental disabilities, and their families. She is the associate director of the center for START services at UNH institute on disabilities where she facilitates program implementation, trains, and does research. Dr. Jill Hinton is a clinical psychologist, autism spectrum disorders and mental illness. As the clinical director, Dr. Hinton provides consultation and training to START teams across the country, and facilitates a monthly practice for START program clinical

directors. Welcome Dr. Weigle and Dr. Hinton.

>>DR. HINTON: Thank you. Nice to see everybody here, happy afternoon or morning, wherever you may be across the nation. I just -- I'm Karen Weigle and I wanted to let you know that we have three presenters with us today. Dr. Hinton and I do. And there are three clinical directors of START programs from around the country. And they're going to be sharing specific strategies with us today. Things that they have used within their START programs that have been very effective. And their names are Denise -- Alyse and Maggie Robins you will meet them shortly. Thank you for joining us, we appreciate them.

So today -- next slide, please, Luis. I was clicking it. Thank you. Today, we're going to very briefly talk about maybe a few differences in what we may see in anxiety for people with intellectual and developmental disabilities, the most of our time is going to be spent talking about different strategies for managing anxiety. And especially during COVID. So how do we do this? And how do we do this maybe remotely with people?

And then we're going to talk about fostering learned hopefulness and how that is related to anxiety and how that in itself is a strategy for managing and maintaining lower anxiety. Next slide, please? So I think that we're all fairly aware of anxiety symptoms, and what those may look like. Just put those up here to kind of remind everybody that they come in a variety of forms, right? So some of these things are cognitive and internal thoughts related to thoughts and feelings. Others are physiological. So sweating, pulse rate, fatigue, and yet, others are external, so things that we can see a person doing, maybe yelling or screaming or pacing. So there are cognitive, physiological, emotional, and behavioral effects of anxiety. And one of the biggest problems that we see through our work is that these particular symptoms are often overlooked or misattributed to something else. For people with intellectual and developmental disabilities, they're attributed as behavior problems without understanding the underlying cause of anxiety. So I feel like it's really important to address this, particularly now, with COVID-19 and how many of us, probably all of us, at some point, are experiencing some of these symptoms more frequently than we may typically.

Next slide, please?

So rates of anxiety in persons with intellectual and developmental disability are higher than in the typical population, so research among people with autism spectrum disorders, it shows anywhere from 3-5 time more likely to develop clinically significant disorders. And including anxiety and depression, most frequently. And for people with intellectual disabilities in general, if there's a study that looked at a clinical study that, there were 19.1% of people presenting in the past year with

anxiety and 31% of people reported having experienced an anxiety level 2 disorder during adolescence and lifetime. Pretty high. Next slide, please.

Just want to remind you, as we are listening to today's strategies and ideas for how to help people better manage their anxiety, that there are effects of development. So developmental delay may impact how anxiety presents in different people. So for people with intellectual and developmental disabilities, they may present, some of those symptoms and signs may present more similar to those in the research that we see around neuro typical children.

So it may become -- I don't particularly like the word tantrums, but I put it in my slide. (Laughing) but it may appear to be aggression or irritability, freezing sometimes, when people won't engage, are not doing as they typically do or refusing to certain things, sometimes that is anxiety freezing. Crying, nightmares, clinging, seeking out more reassurance. I know a lot of people that we know often want to go to the hospital or call for emergency services because that is a way for them to achieve some feeling of safety and security when they're highly anxious. Another thing that we want to remember is that all of us experience cognitive disintegration and deterioration, the more anxious we are, so we're less able to think and process. And it makes us less able to carry out every day functions. And when you already have developmental delay, the deterioration may be more pronounced and more obvious. Also, sometimes

we regress and engage in some regressive behaviors and primitive behaviors.

Next slide, please.

Right now, I'd like to hand this over to our START clinical directors. To each brother deuce themselves, so that you can see their faces. Denise, do you want to jump on and brother deuce yourselves, please?

>>SPEAKER: Hi, I'm a licensed clinical psychologist and one of the clinical directors for New York START on Long Island.

>>DR. WEIGLE: Thank you, Denise, Maggie.

>>SPEAKER: I'm the clinical director for NC START central and I'm a licensed creative arts therapist and drama therapist.

>>DR. WEIGLE: Thanks, Maggie. Alyse?

>>SPEAKER: Hello, I'm the other director for New York START on Long Island and I'm a licensed clinical health director.

>>DR. WEIGLE: Okay, you guys, take it away.

>>SPEAKER: All right. Next slide, please? I'm going to be popping in and out a few slides here, but we wanted to start by addressing some best practices for addressing anxiety. Specifically for individuals with IDD. And while a lot of these on this slide here, will not sound -- be very surprising to anybody, on this webinar certainly, they are really profound and important during this time of COVID. And so as clinicians, we are all meeting individuals where

they are, but this is particularly important in light of the anxiety that's being produced by the COVID pandemic. As Dr. Weigle showed, people are experiencing anxiety in a broad spectrum of degrees and sometimes that can look very physical. It can look emotional. Or it can look like different kinds of presentation that you haven't seen from that individual before. So it's particularly important that we pay attention to the way that the individuals anxiety is manifesting, so that we're actually addressing it from the standpoint of how they are personally experiencing it. So it's also important to meet them where they are, because there's a variety of reactions to the COVID pandemic. For some individuals, the idea of sheltering in place and knowing about the virus is what is producing anxiety and feels very overwhelming and for some individuals, the ability to be in their home feels quite comforting and what is anxiety producing is the idea of opening back up into the community.

So as we are working to address anxiety and look at ways to support individuals, we need to keep all of those factors in mind. In support of individuals with a variety of different communication styles, looking to incorporate both open and closed questions is important, it allows time for individuals to process, it allows and ability to empower individuals to both share their own experiences but also help kind of guide that information, anxiety is such an abstract concept that sometimes support is needed and helping identify what's actually happening for somebody. And with that providing visual supports while working through and we'll have a number of different strategies that we'll show and how to use visual supports, is a really important tool for people to be able to identify what's happening and then what they want to do about it. We'll talk through strategies and how to -- how to line those up so that people, as they become more stressed and have a harder time thinking about the processes and what they can do in that moment, for support they have a visual right there ready to help support their needs. We need to be able to adapt to that individual's level of emotional understanding, again, a global pandemic is pretty challenging for anybody to wrap their heads around and so coming at it from with communication in mind, with developmental level in mind, and what kind of communication style is important is really a key factor in allowing there to be time to process, to sit in silence to let people have some time to take in the information that you are providing, and then respond to it in a way that is meaningful for them. And then, through all of this, we want to provide opportunities for communication, through a broad range of modalities, this is a really important time for people to be able to fully express what it is that they're experiencing. So providing options for art making, movement, engaging the bodily reaction to the anxiety that they're experiencing

is really important. Visuals, writing, and augmentative connotation devices, it's most important that we're validating the experience that everyone is having. Again, people may have a broad range of experiences and it's something that really important that we are thinking about in terms of how they are responding to different concepts of sheltering in place, and what that means related to their past-lived experiences as well.

All right. Next slide, please?

All right. The other thing that we wanted to talk about before looking specifically at strategies is just considering vulnerabilities for individuals with IDD, when we're thinking about how to implement support. So first up, communication. Can be a pretty significant challenge for somebody with IDD. And there can be a broad range of ways that that presents itself. Dr. Weigle talked a little bit about how the decompensation under stress can look more pronounced for somebody with IDD

and a lot of time this is comes out in the way that they communicate. So as stress goes up, individuals may have a harder time using words to communicate what they're experiencing, especially related to anxiety, which is such an abstract concept. So a lot of the communication comes out in other forms. And it may look like externalized behavior presentation, or it may look like a very physical illness. So we want to be mindful that we have a broad range of communication strategies

to be able to support that individual in the work that we do when we're working with anxiety. There's also a lot of associated conditions and feelings related to anxiety in general, and to the change in the world that we're all experiencing.

It is not unusual for individuals with IDD to already feel isolated and lonely, and adding on top of that the experience of losing opportunities to be out in the community and in a meaningful engagement adds to the feelings of hopelessness, decrease in feelings of autonomy and other types of mood disorders that we see, so we need to keep these associated conditions in mind as we're also looking to support anxiety.

And then lastly, another vulnerability, keep in mind, is the executive functioning piece that somebody with IDD may be experiencing. So first, thinking through challenges related to impulse control, as stress goes up, the ability to control impulses also goes down. And when you are anxious, sometimes the thing that makes you feel better is to act. That means that people might need some extra support in finding ways to engage that need to act in a way that

is communicative and safe. We also need to remember that working memory is -- can be challenging for somebody with IDD and so we may work on strategies to support anxiety and that can look like it's working really great on a Monday. But as the challenging couple of

days go past, on a Wednesday or a Thursday, the work that was done has to be reiterated, that working memory can moving it into the long-term memory may not have taken place because of the level of stress that that individual is under.

So when we think about putting strategies in place, we need to make sure that we are acting as that executive functioning support in every session, in every interaction when we're looking at implementing strategies for anxiety.

Next slide.

>>SPEAKER: Hi, it's Denise, and I'm going to be speaking about some behavioral strategies for managing anxiety. And then I'll conclude with some case examples of individuals where serving in our region. As Maggie discussed in our work with individuals with IDD, it's really important to consider their vulnerabilities, including any cognitive limitations or impairments in communication, and of course, to meet individuals where they are. And given some of vulnerabilities -- individuals with IDD, especially for those with more severe forms

who may not be able or capable of benefitting from strategies that rely more heavily on verbal abilities. And in terms of kind of the first step, might be to manage the environment. So, you know, in fact for individuals with IDD, it may be important to start by kind of creating that calm, structured, predictable, environment. And as the slide here says, anxieties is contagious, so often when we're around someone who's anxious, we can, actually feel that tension. And start to become anxious ourselves. It's important to create that relaxed, calm, environment, and, you know, it's of course, the last thing we ever want to say to somebody is stay calm or just relax. But there are things that we can do or suggest that may help to create that relaxing atmosphere. And of course, that's something that is really important now, during COVID-19, because so many people with this shelter-in-place orders are kind of stuck home together and so creating that environment

all the more is important. So maybe having a morning check in. Making a plan. Or a structured schedule for the day. That may go a long way in minimizing the overall level of anxiety in the household. I won't delve into that too much, Alyse is going to be speaking about that a little bit -- speaking about that a little bit later on, but creating a physical space that ebb showers safety and well -- ensures safety can well-being, consistent with the trauma-informed approach is really important.

The same thing with taking space, so providing opportunities for a long time, or everybody to take a break and retreat a bit.

And again, with the stay at home orders during the pandemic, that's especially important to kind of devise those ways for people to separate. Since anxiety can be contagious, it's also important to emphasize caregiver self-care. Especially since many individuals

with IDD often are reliant on others, and maybe working closely be it either with family, or staff, for aspects of their care, it's important when they're interacting with those caregivers that the caregiver, that their own anxiety or tension is kind of well-managed because they're very likely to pick up on that. So to really encourage caregivers to make sure some of the basics, with self-care, sleep, hydration, exercise, and making sure that they're taking breaks during the day. This can be especially challenging, I guess, in both settings, be it a group home, there's staff, but there are also many individuals to attend to.

And perhaps in all of the individuals, may be evidencing anxiety in different ways. But perhaps rotating staff in and out, working with particular individuals, making sure that they're taking their breaks. So on and so forth, to try to allow for that time for self-care. And during the shelter at home, in families, it was a little tricky, especially when people weren't able to kind of get out and begin to return and interact with one another.

Families may not have had the supports that they have relied on previously, you know, whether it be in terms of community rehabilitation or perhaps, family supports that helped and so they really -- it may have just been parents or maybe even a single parent in some instance, you know, kind of providing that care. And so there, it's a little trickier to ensure that self-care. But that's where I think having a schedule or a plan for the day may go a long way. So that way,

if the individual, maybe, you know, in the morning is going to watch a movie, or play a game on a tablet or whatever it is, that they'll be occupied for a time, I think that the trick is, if you can plan that, that then the caregiver may be able to plan to use that time, you know, either to maybe spend some time reading, doing some yoga, calling a friend, whatever is important to them. But it really does require that kind of planning ahead that way. And finally,

mindfulness strategies for care. -- for caregivers, I wanted to emphasize that. In our region, we're doing some research on trauma and so we were looking at mindfulness strategies and, you know, actually, you know, in terms of the breathing, grounding, those type of strategies, they can be very helpful and go a long way and there is research suggesting that when caregivers take care of themselves and they're engaged and mindful

strategies that they actually are better able to manage, you know, aggressive or challenging behaviors in the individuals that they serve. Next slide, please.

So in terms of some of the behavioral strategies for the individual. As Karen spoke about earlier, when we look at anxiety, a lot of times, anxiety is experienced in very physical ways. It's a physiological response. And it can include increased heart rates, sweating, muscle tension, pacing, and of course, all of that stems from the

chemicals that get kind of dumped into the bloodstream. And that's, you know, readying the person for that fight or flight response and that occurs when the sympathetic nervous system is activated. So physical activity can be really important. Exercise, movement, yoga, that can really help kind of use up that energy. And, you know, in the past, I actually worked with individuals and who had fear of flying. And we used to tell them, which of course, wouldn't go over very well now, since 9/11, but we used to tell them that when they're flying, there you are on the plane, and all of those chemicals get dumped in the blood readying you and you have that energy, what do you do with it while on this plane ride? We used to suggest that they go into the lavatory and kind of run up and down, or to use up that energy. So that can be a good way and really, just even 10 or 15 minutes a day, of exercising, goes a long way in reducing baseline levels of anxiety. And that's important because if baseline anxiety is high, then little things that happen, the individual is going to be more sensitized to that. And more likely to react. So the more we can keep baseline anxiety down, the better. So again, movement and exercise is a good place to start. And then the next several strategies, you know, with respect to breathing, grounding, mindfulness, they really address anxiety by activating the para sympathetic nervous system, and, you know, the importance of that is, that you can't have the para sympathetic and the sympathetic kind of activated at the same time. So by engaging in activities that activate the para sympathetic, that has that impact on that fight or flight reaction. So diaphragmic deep breathing, perhaps balloon breathing, I often use that in working with individuals to help them and that's something that I'm going to be really emphasizing when I discuss the case examples, is really how to Taylor these strategies to the individual you're working with. And find a way for them to kind of connect to them. So if it's somebody, you know, you could use balloons or if it's somebody into sports maybe a basketball and imagining that, you know, they're blowing up that or inflating that basketball in their stomach. There's also lions breath breathing, that can be kind of fun, where you take a deep breath in through the nose and then it's exhale, I'm not going to demonstrate that now, but I do want to mention that that's this the references and I know that Alyse is going to speak about it a little bit more, we do have a YouTube channel where a lot of the activities that I'm -- or strategies that I'm touching on, there are videos there that actually can be used with the individuals you're working with. Progressive muscle relaxation, mindfulness, focusing on ways to calm the mind. Grounding. So whether it's rubbing your hands together, holding a pillow, or a stuffed animal, and then there's the -- I

thought I would highlight this one, because I know in the -- in my region, I hear from a lot of our coordinators, and coaches, that this is a favorite, so the five, four, three, two, one, game, so name five things that you can see. Four things that you can feel. Three things that you can hear. Two things that you can smell. And then one good thing about yourself.

So that's one that, again, focusing on the senses can be very grounding. And then, finally, soles of the feet meditation and that strategy has been used quite a bit in terms of helping individuals with IDD with respect to dealing with anger provoking or frustrating situations. But we have actually found some applicability with the COVID-19 outbreak with that, and the idea is that they would think of something that is anger

or frustrating, or anxiety provoking, and as they're thinking of that, they then would switch their attention to the soles of their feet. And it is also a part of it is, then, using deep breathing, together with that switch, and the idea is kind of taking their attention away from that upsetting situation and bringing it to a neutral location on the body.

Next slide, please.

Okay. So by now, you've noticed my corny slides, and all of the pictures. And there's actually a method to my madness that way, so a number of years ago, I attended a conference focusing on anxiety in children.

And the presenter really discussed the idea that it's important to find a way to -- especially when working with children, to find a way to give them something to hang their hat on. So to speak.

And so, you know, maybe using metaphors or things that they enjoy or something that's going to stick. So the idea being to just try to lead a child through a breathing or an exercise or, you know, something of that nature, and unless they're really connected to it, they're not going to remember it. And it was really interesting, the way that the presenter did it. But he gave those of us participating a way to hang our hat

and so it was something that has stuck with me, it's got to be 20 years ago. And so I hope today, even though I can't go through that kind of exercise that he did with us, I don't have the time during this presentation. I hoped by -- with my corny pictures, that would leave you with that idea of giving the people that we're serving something to hang their hat on that will connect them to the strategies that we're using.

So for the first example, the morning relaxation exercise with Jack, one of our coaches in working with Jack, noticed that really, he responded a lot better to strategies that focused on breathing and movement. And Jack's family comes from a very close-knit family. They have a great love of the beach and the outdoors. And during the coaching session, progressive muscle relaxation was used. And

it really helped, the coach was aware to set the tone of is session. And really just lowered everybody's anxiety level, including the mother. And so the mother then was encouraged to lead the exercise for Jack each morning. And gradually, the whole family kind of got involved, since they are very close-knit. And again, it created that same thing that occurred in the coaching session, it kind of created that relaxing, calm environment and set the tone for the day in the home and that really went a long way.

And, you know, I want to point out that again, getting back to that anxiety is contagious, you know, having the whole family participate lowered everybody's anxiety level. And I think that's also important for individuals that reside in group homes. That that can create a calmer environment for staff and individuals alike. And I think that the other important thing is that then the individual that maybe we're working with isn't kind of singled out. That it's really normalized where it's something that the whole house is doing. So I think that that's another important point.

The other thing that really helped Jack was some movement. And so working with him, the coach used animal yoga. Again, I think that if we tried to have Jack, just kind of follow along in yoga, there might not be that same engagement. And so what she used was kind of his love of animals and so it would be stand on one foot like a flamingo, which was tree pose. Or breathe in deep and puff out your cheeks like a puffer fish.

And that really engaged him. And then, in terms of Michael, and the anxiety monster, so, you know, for Michael, and again, you'll see as I talk about some of these, that each of the individuals is a little bit different. And so it's again, tailoring those strategies for them. For his, his anxiety manifested physically, and hot hands and a confused head. And so he was asked by the coach to give his anxiety a physical name. And he chose Thanos, the bad guy from the avengers movie, one of his favorites. He could label

his anxiety as a monster, he can use that as a queue for the community and rehabilitation staff that he was experiencing anxiety. And as we spoke about it earlier, not only do individuals with ID have the communication deficits, and the executive functioning deficits, but during times of anxiety, those are further compromised. So if, you know, we could give Michael this way of kind of communicating that he was anxious, it made it easier for him. And then what he would do, the mom or the staff

would empower him by reminding him how the good guys captain America, or Ironman, that the good guys always win. And that was enough for Michael to kind of have him kind of get over that plateau and then his anxiety would diminish. And then there's Sam, with nurturing the wilting flower. And so for Sam, here is an example of somebody rather than that fight or flight, where there's all of that energy, Sam tends to shut down when he's experiencing anxiety.

And so he shows more of that freeze response. And so during that time, he's not able to verbalize his anxiety or his need for care, some kind of attention. And so the flower was used as a metaphor and that he feels like that wilted flower, who needed some TLC, you know, a little water, a little sunlight. And then, that was taken further and provided with imagery where he was asked to take a deep breath, so he could smell the flower. And describe its scent. And then that was the way to get him to take those deep breaths without simply sitting and saying, okay we're going to take deep breaths now, and then, again, it really engaged him in that and he came to, call that flower breathing. So that's Sam.

And then, finally, the soles of the feet meditation with Allyson, like I said, initially, we were working with Allison around frustration and anger which we believed often was triggered by kind of retraumatization or history with trauma. Once COVID set in, she returned -- she was living in a group home, she returned home to live with her mother temporarily. And she began to experience more anxiety and as did the mother.

and so there, we started to use it more around the anxiety. So she would rate her anxiety and tension both before and after. And then the coach there would have her think about things that were anxiety-provoking, and when she experienced that anxiety, have her switch her attention to the soles of the feet. And if we could just go back a slide, I'm sorry? So the soles of the feet, here, with the clown faces, I just wanted to point out, that, you know, sometimes for the people we serve, it may be a little abstract to have you think about the soles of your feet. So what we actually did initially, was we used stickers on the soles of the feet. To help her think about that spot. And you can advance the slide now, please.

And that really helped her and how to learn how to focus the attention and what we were suggesting. And so switching her attention there and taking the deep breathing, and so it kind of -- you know, it's almost like an imaginal desensitization of sorts and helping her to manage, learn how to manage the anxiety that way. And then, that generalizes, not only is it the practice of it, but she could be prompted by her mother to use that during the day if she was experiencing anxiety. And just a quick note, in kind of speaking with the coach about this, when she would ask Allison to rate her anxiety at the end, Allison would say, oh, it's a two. But she didn't really seem to own it. And so the coach really had to say to her, is it really a two? It's okay, you know, what do you think? Could it be a three? And the point that the coach made was that in working with individuals with IDD, they become so accustomed to having to kind of just, you know, tell people what they want to hear. And so this was, you know, a way that the coach worked with her, that it's okay, giving her permission that, you know, what? Maybe it

didn't go down so far this time. Maybe it still is a 3. And we can try something else. But, you know, again, I just thought that that was an important point that it is unfortunate but that many of the individuals we work with do

-- you ask them how they're doing, everything is fine, you know, just telling us what they think we want to hear.

Next slide, please.

>>SPEAKER: All right. I'm just going to add a little bit to that, and in terms of thinking through strategies and the why behind some of them. Part of what the strategies we want to look at for addressing anxiety for individuals especially during the COVID period, is we want to increase expression of feeling, and correlate it with some type of coping strategy. Because as we talked about as that stress level or that anxiety level goes up, your ability to remember and recall

what will make you feel better in that moment, goes down. So as people and I -- certainly can -- I feel this as well, if you start feeling anxiety, that anxious feeling, you get anxious about your anxiety. So there's always kind of this cycle of it leading up and until you can find something that provides a grounding space to bring you back down a bit.

So with that, we want to look at how to correlate visuals that help people identify their mood, but also what coping strategies would they like to use in that moment? So that if communication of language is something that is not within your grasp, at that moment, due to the level of anxiety, you still have access to those coping strategies through the use of support, from a visual or somebody who's there to help support you.

We do that in lots of different ways, utilizing something as simple as a stoplight system, something that we use in our program frequently, so people are able to tell us, yeah, I'm in the green right now, I know that I can do all of these things to help me feel better. But also, if they get up into that yellow, where things are not feeling as good, they don't have to tell you with as many words, I feel anxious, and it's making me nauseous and scared.

They can say, I'm in the yellow, I need my squeeze ball. So we're correlating what strategies are helpful in the moment. We can also utilize these things with strategies with scales, like a 5 point scale. We can use those in different formats like a boiling thermometer, so you know as things are getting harder, here are the things that I can use.

And it's also an important time to use a scale like that, because emotion can feel very big and instead of sometimes finding the nuance between I'm a little bit anxious and this does not feel good to full blown crisis can be hard to identify, especially in words. So it allows somebody to say, I'm at a 3, here's what I need right now. We also want to allow some space and time for processing. That's

consistent with how that individual process is. Somebody may be feeling very anxious but due to those communication deficits, or executive functioning, you may not hear about it for several hours later. So having things and strategies in place like a journal or using mood trackers throughout the day to touch base with somebody, just ask them, briefly, where are you on your stoplight system right now? And gives you A heads up that even if they may not look like they're in that yellow to red zone, they may be heading there and feeling that way, if we can put something proactive in place, it allows that person to come back down to the green.

We also want to think about how the impact of trauma is so prevalent during a global crisis that we're experiencing. So when we're thinking through strategies, we need things that are in place too that help build resilience and increase in self-esteem and self-worth. If we think through trauma informed approaches, thinking specifically of an individual, we serve right now, who has a long history of neglect and the feeling of being shut into his house is a very overwhelming concept for him. So quarantining in this environment feels like -- and is in a lot of ways another trauma for him. So having something that he can reflect on each day, through a positivity journal, has been really helpful. It helps identify what went well today. What did you do that helped somebody else? What's one great thing that you recognized for your -- that you did today? So that it allows a chance to step out of some of the ongoing trauma of being in a shelter

a shelter-in-place setting and actually give somebody an opportunity to recognize what they can contributed to society in that day.

All right. Next slide, please?

Along with that, oops -- along with that, implementation of ongoing strength spots and opportunities to recognize when somebody is doing something well, when they are in flow, and when they're using a form of positive psychology that identifies how people have positive emotion, relationship meaning and accomplishment in their life, PERMA, we can identify those things, even when we're experiencing something as intense as a shelter-in-place

during a quarantine, and it's important to see those things and identify them throughout the day, because otherwise, anxiety builds on anxiety and we're focused solely on the feelings that have kind of a negative connotation to them. Going through and seeing somebody do something kind for somebody in the moment is a really great grounding technique because it also brings you right back to the moment to say, I did just do that thing, I was really helpful and kind. And so just a very simple way to provide grounding for that individual.

Having agreed upon options and choices for emotional support is really helpful in reducing anxiety as well. So identifying things that work when that individual is doing well so that they can utilize

them when they are struggling is a really important way to support that individual's executive functioning. So having things like reminder cards, visuals of their stoplight system, up so they can see what to do in that moment.

Practice these things when things are going well so that it is easier to recall when things are a little more challenging, because it's not the time to learn them, it's the time to use the things that you know help you in that moment. We've also seen that just as anxiety builds upon anxiety, that focusing on a very concrete and timed approach to using some of these strategies has been helpful for some individuals. Sometimes sitting in anxiety or not feeling good can kind of spiral into itself. And so for some individuals, and Alyse is going to talk about some of the DBT strategies, identifying a set amount of time to focus on sadness or anxiety and then helping guide and moving into a different activity, has been really helpful. Otherwise, we get into a pattern of ongoing expression of anxiety, without getting back on track into a more positive day.

Which then can positively go back to that strength -- use of strength spotting and focus on PERMA in the every day for that individual. And then, it's important especially when people are feeling anxious, to think about what is behind some behavior that may feel challenging as the caregiver or the provider, right? A lot of people are looking for connection, are looking for attention right now. And the phrase that, you know, we often hear, is somebody -- they're seeking attention, attention seeking. With a kind of a negative connotation to it. But there's a lot of information behind the fact that somebody is looking and needing something in that moment. Next slide, please?

So we want to think about what is behind attention seeking, especially during a crisis that we're -- the individual is in, and the global pandemic, are people looking to connect? Is that what they're needing in the moment? Is communication a real challenge? And they're looking to be more fully understood? Or are we looking at making sure that we're creating trauma-informed environments in approaches so that that person does feel protected? Oftentimes that need for attention

may come from the need for attachment for feelings of safety. Next slide, please.

Okay. And then lastly, I'm going to hand this over to Alyse, but we -- both of our programs have been utilized adapted DBT strategies specifically to address anxiety and expressions of suicidality over the past few months, these are utilized to promote this reframing of really challenging situations and also look at the way that your current emotional state is impacting how you're thinking about something.

So our thoughts, lead to different feelings, which lead us to act

in a certain way, and if we can help guide somebody through recognizing what those different pieces look like, we can help in the next time when somebody is feeling overwhelmed about something and take an action that may be healthier or may be more supportive in the moment of what they are really needing.

And again, we kind of -- we have done this with an emotion recognition scale and I'll just touch briefly to say that especially for somebody that we have worked with, who COVID pandemic has been just terrifying. And she already has a lot of expressions of suicidality when she's had a hard day and so working on emotion recognition scale, allowed us to help her find some of that nuance in between.

So when she was feeling anxious, she would jump to a ten and say that she felt suicidal. But using the scale that she created with one of our coaches, we were able to help her identify what she was physically feeling and emotionally feeling, and find some places where okay, maybe I'm not a ten today, maybe I'm actually down at a four, and here's where what I'd like to do about it. I'll hand it to Alyse. Next slide, please, thanks.

>>SPEAKER: Okay. So I'm Alyse, and Maggie, thank you for that introduction to adapted DBT. So the book that's on the screen that I have a copy of is called the emotion regulation skills system, for cognitively challenged clients by Julie brown. A set of skills that are built from DBT concepts and adaptations of the standard DBT curriculum, it's adapted to be successful with the IDD population. And anyone that's trained or familiar with DBT may realize that there are familiar DBT terms that are not within the skills, but you will notice how certain DBT skills are deconstruct and repackaged, the meet the needs of vulnerable learners. That is why it's repackaged in this way, we want to make sure that it meets the needs of our IDD population.

What I love about this curriculum is that it is set up in 12 week sessions. So it is something that you can do over time. But there's also stand alone practices as well that you can pull out. The skill system breaks the DBT informed approach into two categories. The all the time skills, which are skills that can be used at any time, regardless of what's going on.

And calm only skills.

It's important only to use these -- not use these skills in the midst of the crisis, but when the individual is calm. They separate out these skills so that it's when the individual, when the learner is able to actually build up their skills, and when they should be using them. So in learning something new, is not always possible when they're already very highly anxious or in crisis.

Next slide, please.

So to start, the first -- all the time skill that I want to introduce is called clear picture. Clear picture is a skill that helps the

individual notice what's going on for them both inside and outside right in that moment. Within the skills system, clear picture has several worksheets to break down the process that can be utilized with the individual. One of the parts of this skill is noticing my breath. This helps the individual focus on their breath, the air going in and out

as it is without trying to change it. Focusing on their breath 100% in the moment, which has them to be present. Checking the surroundings, this focuses on the individual using all of their senses to observe what's going on around them.

Even if they don't like what's happening.

Their goal is to simply observe. Rather than focus on what they would want instead, it assists them to be present in the moment.

A body check is an opportunity for the individual to notice their bodily sensations, this allows them to be mindful in how their thoughts and emotions are making them feel.

Labeling and rating feelings, helps the individual note that they may be feeling more than one thing at a time. And be able to rate the importance or the impact. This allows an and assess the individual to experience the emotion and not react and the rating of the importance may not be as high as they thought.

Noticing my thoughts. This provides an opportunity for the individual to examine their thoughts, automatic thoughts and self-talk, which thoughts might be helpful and which might not be. It's also important that the activity is meant to notice the thoughts. Urges are what can call impulsivity and actions, like their thoughts and feelings, urges come and go, and actions are not necessary. A lot of these aspects of clear picture, are things that you'll recognize that were talked about earlier by Denise, Maggie, as different practices that are helpful to stay more mindful and in the moment. And this curriculum kind of pulls it all together within this one skill. Next slide, please.

So safety plan is the next all the time skill. So safety plans help the individual have a plan for when they're less likely to be able to think through their actions, or as Maggie talked about earlier, the executive functioning is more impacted. This safety plan within the curriculum assists the individual to notice their inside risks, so risks and triggers that are internal, the thoughts, urges, feelings and fantasies.

As well as outside risks, so people, places or things.

The curriculum talks the individual through three types of safety plans. The thinking safety plan is one that is used for only low risk situations. And it's not something that's written down, they talk through, a process, think through, how they might handle a situation, actions that they can take.

Really planning out how to react in different situations. To prepare themselves for increased anxiety or crisis. A talking safety plan

is using medium or high risk situations. This is where they tell somebody about their risks, they talk it through with another person. They talk about their thoughts, their urges, and any actions that they might want to take. And they gain that assistance from that caregiver to develop a plan of what actions they would want to take. That might be more appropriate.

And a written safety plan is used for more high risk situations, or if the individual does better with things written down, sometimes that visual is better for them.

This is discussed as a possibility risk, dangers, urges, it's all written down, and it plans to address these areas and be well documented. The safety plans help to give them something to go back to. So if they do develop this and they're calmer or at low risk, something physical and visual that they can look back to that they developed themselves with support to be able to get through those moments. And a lot of the other skills that have been talked about during this webinar and are things that may go in the safety plan are reactions that they want to take instead of the original urge that they have. Next slide, please.

So the new me activity. So this curriculum outlines three skills in the safety plan. One of these is the new me activity. This activity focuses on the individual focusing their attention on what they're doing, rather than being distracted by the risk. So only paying attention to the risk, to ensure that they are safe. This activity should be used in low risk situations, by focusing on what they need to do. They can stay on track and keep their feelings from increasing.

The thought is, when they overfocus on the risk, they may become more unsafe and emotional. So focusing on this activity allows them to think more clearly. It has several focuses within if new me activity, so there's focus activities, feel good activities, distracted activities and of course, fun activities.

And again, all of these things can be used as stand-alones, and be applied in other aspects within the safety plan and within schedules, which I'll talk about in a little bit as well. Next slide. Okay. So moving on to one of the skills that the curriculum describes as a calm only skill is expressing myself, so the expressing myself skill focuses on the individual sharing what's on their mind and in their heart.

It outlines multiple methods of expression that can be used and connects to skills using the new me activities in ways that the individuals can express themselves. The goal is to assist the individual in utilizing expression to feel better, to problem solve, to think through their actions, and reactions, and build stronger relationships.

The skill also teaches the individual when it might be necessary to wait to express yourself, if it won't make the situation better.

They're too upset or maybe the other person is too upset. These activities have multiple method in teaching the skills, including express myself plan, which is really great because everyone has different expressive and receptive language skills, so we want to make sure that all of the -- make sure that all of the activities are able to be adapted based on their abilities which they are. Next slide, please.

Okay. So some additional strategies, the adapted DBT methods that I talked about are very helpful in addressing anxiety and managing emotions but they're also helpful, methods to support individual. So some social stories. So this is really important during this time. There's a lot of change, I can't imagine not understanding what's going on right now being isolated in place, potentially quarantined, everyone is wearing masks, everyone looks different. So social stories is an opportunity to assist the individual and understanding the why.

So it's not just this is just how it is. Why do people have to wear a mask, why do I have to wash my hands and use hand sanitizer, why can't I hug my aunt? We're providing the full picture. Having the individual understand what's going to come next as best we can within a pandemic is really helpful to decrease the anxiety that they might be feeling. You, thinking about our individuals, whether it be going to school or day programs, I know within our program, there's a lot of anxiety

of when those activities are going to open up, when can I see my friends, when can my family come visit me? So helping them understand those future expectations as well.

Social stories can be used proactively. Such in a situation that you anticipate a concern. Or reactively to explain something to them more completely. In response to COVID, there are several social stories to explain the need to wear masks, maintaining social distancing, and importance of washing hands and cleanliness. Explain the need for social isolation, school and day program closures, and reopening plans, changes to routine

one resource that I have seen and there's a lot out there, a quick Google search, autism little learners.com. They have a whole COVID-19 page on their website, they even go through getting a hair cut while wearing a mask. They go through riding the bus with social distancing in place. And wearing a mask.

And why does my doctor look different? Why does my therapist look different and have to wear a mask? There was like 20 of them that I saw last I looked.

So that's a really great resource and that was autism little learners.com.

With any intervention that you use, in order to limit anxiety and provide support, care givers should ensure that they're providing routine structure. It's incredible important during these

uncertain times to provide consistency, predictability, very direct and concrete as possible. The routine that the individuals are normally used to, has changed. So it's really important to provide them with a new routine to follow and support them in adapting. Next slide, please.

Okay. So I know that this came up and I saw this the chat that there's a lot of questions and people reaching out for the YouTube channel, so one of my colleagues, I know, posted it as well. In the chat. But I want to talk about easy access to tools and resources, there are many places that you can find resources on line, Google is a wonderful thing. But I wanted to highlight a resource that is public that my New York START region has developed. 25 videos covering topics such as self-care for the caregiver, anxiety and depression during these times, mindfulness, meditation, yoga practice, breathing exercises and many, many, many. The videos can be used over and over as a part of the routine structure you have for individuals. There's a morning video for each day of the week to get each day started on the right foot. This is a resource that can be find by searching NY START region 5 on YouTube. Next slide, please.

>>SPEAKER: Thank you, Alyse, Denise and Maggie. This is Jill. Karen introduced me at the beginning. I work with the center for START services, my job is to quickly summarize what we have talked about, you've had a lot of -- heard a lot of good information and we hope that it will kind of spur you to investigate more and to pull more resources together.

But just a summary of what we have talked about, you can see just in categories here, that describes some of the things that you heard. But I want to emphasize that in this time of COVID, and people being really anxious, we have a primary goal of being able to address these immediate stressors and help somebody through this situation or this particular day or this particular thing that's happened. Which is critically important. And what we're doing alleges is building resilience.

Karen talked at the beginning about learned helpfulness. So when people are feeling like they don't have the skills, when things have changed, when they're very stressed. They can become very helpless. And so what we're trying to do is build resilience. Next slide, please.

So I just want to end on thinking about the things that contribute to resilience. And if you take a look at these, you'll see that some -- that the strategies that were described earlier really fit into these. So for example, things that contribute to resiliency, biology, you know, all of us are born with a certain temperament and things that contribute to our resilience. You think about people with IDD, they often come into the world with some vulnerabilities, so you've heard

through this presentation, ways that we address those vulnerabilities of IDD and think about a person's level of executive functioning, and try to -- by providing structure in the situation. With psychosocial skills, paying attention to the environment, helping people themselves to identify their emotions and feelings. And remembering that people live within a context of other people. So you heard a lot about also providing strategies, mindfulness for caregivers and people in that person's environment. Self-regulation is something that a lot of folks with IDD can struggle with, especially during a stressful situation or stressful times. So again, you heard lots of things about soles of the feet, grounding techniques, the importance of exercise, and contributing to increase self-regulation. Another part of resiliency is mental agility or being able to adapt or to anticipate things that are going to change, and how you adapt to them. And you just heard from Alyse, the description of social stories. And social stories can really help with this and helping somebody understand the whys and be able to face something that may change in their environment or in their life. Optimism, we all -- with all of these strategies in the work that particularly the START teams do, we're providing hope to the system. So there's something that we can do. People are feeling stressed. Feeling anxious. There are things that we can do and provide that ability for people to feel hope. With self-efficacy, that's believing in your own ability to execute some course of action to address things. And again, you heard about strategies for creating structure and routines and giving people kind of adding to their executive functioning so that they do feel they have choices that they have the ability to an effect how they're feeling and what's happening in their life. Connection, I think we talked about, Maggie talked about attachment. And really, seeing what we sometimes we don't like the word attention seeking often, but that is connection seeking, and the importance of attachment and relationships in a person's life are critical to being able to build resilience and be able to handle things that come up in your environment. And then the eighth one is positive systems. So having people around you that are focused on the positives, focused on strengths, and we talk about strength spotting and recognizing people's strengths and not just focusing on their vulnerabilities and how do we use those strengths to then build resilience? So this was just to kind of bring this all together into really emphasize the point that we want to people help right now. And we also want to create strategies that build resilience in someone, so that later down the road, they'll have more ability to deal with stressful situations that come up. So it's more than just the immediate concern, it's also looking towards the future and helping people with IDD to build some of these things that do contribute to resilience

for all of us. So that is our wrap-up.

I know we are a few minutes over, but if there are any questions, that come up, we could take a couple, I think?

>>SPEAKER: Yes, thank you very much to our presenters. If you have questions, please put them in the chat box and I will read them aloud to our presenters. I'm not seeing any questions, just a lot of thank you to our presenters, and thank you all once again for attending this webinar. This webinar has been recorded and will be archived on the AUCD website. Please feel free to take a couple of moments to complete our survey that was sent earlier. There's a question. How important is family support?

How important is family support?

>>DR. WEIGLE: I'll jump in. Actually, it's absolutely critical when we are -- when we're helping anybody in a family, we really need to make sure that we're helping everybody. So that caregivers have the ability to provide care. Right? Especially right now. I think everybody is feeling the stress. And any time we work with people, with developmental disabilities and otherwise, I will say, I include family members. Because that is the person's central support network and if we get everybody on board we're much, much more likely to be successful.

>>SPEAKER: Thanks, and I see another question. What can a START team supporting an individual in the group home to implement the kind of things that you discussed today?

>>DR. WEIGLE: We would teach the direct support staff how to use these strategies. And what we find is that when we do engage everybody in the system for instance, like direct support staff and as well as house managers and etcetera, family members, is that everybody feels better. Everybody feels more effective at their job. And the DSPs that we have worked with are really much more effective and actually their days are better and their work is better, they've also reported things like they feel like their work is more meaningful when they have these types of strategies and supports in place.

>>DR. HINTON: Right now with COVID-19, I think that it's also acknowledging that all of us are being impacted by -- we talk about psychosocial vulnerability, we've all been impacted by COVID and I think that recognizing, too, that within a residential setting, that the staff also is experiencing anxiety and uncertainty, so those strategies like you said, are kind of universal for all of us to be able to do that and as Denise mentioned, anxiety can be contagious and calming can be contagious if we can get everybody to feel less anxious, it makes everybody feel better.

>>SPEAKER: The videos on the YouTube channel have been helpful. We share that with not just family systems but our group home systems and it takes the pressure off of the DSPs and they can just play the

video and do it with the individuals, so that's something that can also help for START teams to support a group home, as well, is help them build a team, and help with the videos, the morning video is great.

Our resource center director filmed all 7 of those, and literally tells you when to pause to have a conversation about what she described, it takes all of the work out for them. So I think that making it that easy is something that has helped as well. So feel free to use those.

>>SPEAKER: I saw the question about people having maybe meltdowns, since programming and supports are lost during this time. And again, you know, Alyse referencing the videos on the YouTube channel, we really try to create the ability to create a virtual therapeutic -- by using those videos, so that hopefully they can provide some structure and implement some of those things that were taking place at the day programs.

>>SPEAKER: Great, thank you, everyone. So seeing no other questions, once again, this webinar will be archived and available on our AUCD website and we'll be sure to make sure that that link gets out to everyone. And please take a few moments to complete our survey. Thank you all so much.

>>SPEAKER: Thank you.

>>SPEAKER: Thank you.

>>DR. HINTON: Thanks.

>>SPEAKER: Thanks.