

Identifying and Working with Children with Fetal Alcohol Spectrum Disorders

Steve Shuman: It's now my pleasure to introduce my friend and colleague Candace Shelton.

Candace Shelton: Thank you, Steve, and thanks for all the housekeeping that you did to let everyone know we all know how important it is to get our certificates. Before we begin, I want to share a reading with you to start our webinar in a good way. This is a reading from Don Coyhis' "Meditation with Native American Elders."

"Dissimilar things were fitted together to make something beautiful and whole." – Nippawanock, Arapahoe.

"Sometimes we look at something close up and it appears to be ugly, but then we drop back and look at the whole and it is beautiful. If we look at an insect close up it may be ugly, but if we drop back and look at the whole insect it becomes beautiful. When we drop back even more and observe what its role and purpose is, the insect becomes even more beautiful. For example, if we look at a whole insect nation, we will see a great order. Each insect, though it may look ugly, is participating. It's fitting together and making something beautiful and whole."

"How are we looking at ourselves? Are we focused on something ugly about ourselves or are we dropping back and looking at ourselves as a whole? We all have a purpose, and we are all beautiful. Creator, today let me see the beauty of the whole."

I like this reading because it's important both personally and for our children. When a child has difficult behavior that may be troubling or that we have a hard time dealing with, we must drop back and look at the whole. When working with children that have a disability, we must drop back and see the child is more than their disability, to see the beauty of the child. As the reading said, we all have a purpose, and we are all beautiful.

I'd like to introduce myself, I'm Candace Shelton. I am a member of the Osage Nation, I come from the Gray Horse district. In Arizona I'm a licensed substance abuse counselor, and I maintain a psychotherapy practice. For 12 years, I was the senior Native American specialist for the Substance Abuse and Mental Health Services, SAMHSA, Fetal Alcohol Spectrum Disorder Center for Excellence.

I traveled and did training and technical assistance throughout Indian Country working with staff, individuals, and families. Currently, I am the subject area expert for the American Indian/Alaskan Native population for the National Center of Health, Behavioral Health, and Safety. I am honored to be here today and to share this information with you, and I am joined by my esteemed colleague Dr. Jennifer Fung. Jenn, would you like to introduce yourself?

Jennifer Fung: Yes. Thank you, Candace. Thank you for the introduction and for that beautiful reading. I think that really sets the tone just perfectly. Thank you for inviting me to join you

today. As Candace mentioned, my name is Jenn Fung. You can call me Jenn. I am the inclusion lead for the National Center on Early Childhood Development, Teaching, and Learning, or DTL. I actually just joined DTL about six, seven months ago. I come from an early intervention and early childhood special education background.

I have been an infant toddler teacher and early intervention specialist, family resources coordinator, a parent coach in my early career, and then most recently I've been a professional development and training specialist providing PDE and ongoing support to help Part C and 619 and early care and education agencies, really focus on including young children with disabilities in all types of program options. I'm happy to bring that perspective to the Head Start world, and I thank everyone for welcoming me so warmly, and I'm looking forward to sharing this information with you today.

Candace: Thanks, Jennifer, and I'm so glad you're here and we're both very honored to be here to share this information with you today. You've gotten some information about us, now we would like to get some information about you. We have two polls that we're asking you to fill out. Our first poll is about who is here today? You can answer these and please do so that we know who our audience is, whether you're a director, health services staff, family engagement staff, education staff, home visitor, or other.

I see that they're filling out the poll, and we are ... Wow everyone's doing a good job. It's helpful for us to know who is here and who attends our webinars. Thank you for filling out the poll. Have we finished? No, we're still going. If you would please respond to the poll so that we can evaluate and see who's here. Looks like right now other is winning.

Jennifer: Candace, I'm seeing in the chat it looks like lots of the other might be disabilities managers or disabilities coordinators joining us today.

Candace: Oh great. Thanks Jenn for checking that out. I'm not looking at mental health consultants. Great. Well that's really wonderful. And life coach, home educator, I'm a disability coordinator, great, mental health. All right thank you. Let us move other winds, and yes we've identified what are all the others. So thank you for sharing that poll.

Our second pole is asking who ... If you attended the poll that we did ... the webinar, excuse me, that we did in April. We want to know that because this is really a two-part series. Our first webinar was about prevention, so we wanted to know how many of you attended that first one and second. It looks like we have more people that were not on the April webinar. Great.

Well thank you for that, that's helpful. I think the noes have it. Well thank you very much for spending the time to do that, the polls. As I said, our first webinar, which was in April, the topic of that poll was the title was "Preventing Fetal Alcohol Spectrum Disorder." Our focus was really on pregnant women and working with expectant families around knowledge, around fetal alcohol, and I just want to review a little bit about what we talked about in our first webinar.

Some of the prevention strategies that we talked about was how important it was to provide information to our expectant families and to pregnant women so that they know and have information about prenatal exposure to alcohol. The second was to ask expectant families, what do they know about substance use during pregnancy? Sometimes some families know a lot and some families don't. It's very important to get that information and talk to expectant families about what they know.

Then it's important for us as providers to offer nonjudgmental support for pregnant people to be abstinent during pregnancy with the focus ... and again the focus on our first webinar was about having a healthy baby. That's what's most important. Then the last was ... it was important to know the resources in your community if an expectant family needs additional support. What are your treatment programs? Where might there be intensive outpatient? Where might they get some support if they find that it is difficult for someone to stop drinking during pregnancy?

We also had a list of resources for you, and we put up some of the basics that we have. There were many, and this resource will be in your handout. Also, one of the other things that as Steve said and I've said, this is the second of our two presentations about fetal alcohol spectrum disorder. The first one is not up yet but will be on the ECLKC website, along with this one. They will soon be posted there. So if you didn't get the first one, you can go back and see it. Or if someone doesn't come to this one and went to the first one, they can come and see this one.

Those are some prevention strategies. What are we going to learn in this webinar? First we're going to define fetal alcohol spectrum disorder. We're going to identify the causes, and we're going to explain the criteria for the diagnosis, which is the diagnosis is fetal alcohol syndrome or FAS. Then we're going to talk about the characteristics of children that have an FASD and describe the strategies that work with these children to improve outcomes and to help be more successful in working with these children.

When we look at, what is FASD? FASD is an umbrella term that has been used to explain the range of disorders that occur when a woman drinks alcohol during pregnancy. FASD is not the diagnosis. FAS is the diagnosis. We'll talk about FAS just in a little bit. The problems that come from the prenatal exposure to alcohol can be physical, mental, behavioral, and they have a range depending on the amount of alcohol consumed during pregnancy from mild cognitive deficits to severe which can wind up in fetal death.

The term, FASD is a fairly recent term for some of you that maybe have been in the field for a long time. We used to talk about FAS – which was fetal alcohol syndrome – which is the diagnosis. Then they talked about everything else was fetal alcohol effects. Well no one really knew what that was. Yet they were seeing different effects, and they decided that it was important to start identifying those effects that were happening instead of just saying it's not FAS, it's something else.

There are five types of FASD, and you may see these. But to know what they are, again, Fetal Alcohol Syndrome, which was first termed, which was first coined by Dr. Smith and Dr. Jones at the University of Washington in 1973, was when they first started using that term. Another term is Partial Fetal Alcohol Syndrome, PFAS, which may be that not all of the characteristics of the diagnostic criteria are there but there are still obviously disability. Then Alcohol-Related Birth Defects, ARBD, described the physical birth defects that are caused by the prenatal exposure.

Then Alcohol-Related Neurodevelopment Disorder, ARND, describes the brain damage in the neurodevelopment on disorders. Then we have Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure, ND-PAE, which also describes again the neurobehavioral development disorders. When we talk about a continuum, which is important to understand as I said earlier, on this continuum is all of our ... the ARND, DB, and fetal alcohol. One end of the continuum is mild cognitive deficits, at the other end of the continuum is fetal death that the fetus was unable to survive because of the alcohol exposure.

Let's talk about some FASD facts. This first one for me has always been the most important and has driven me to do this work, which is FASD is 100% preventable. If no woman in this country drank alcohol when she was pregnant, we would never have another birth of an individual who had an FASD. Now other birth defects are not preventable because they have a genetic component. When we talk about Down syndrome, sickle cell, spina bifida, cystic fibrosis, cerebral palsy, those all have a genetic component and will remain in the gene pool in the population. FASD does not.

It is the leading known cause of preventable intellectual disability. Again the word here is preventable. It's not caused on purpose. When I was working in treatment at a woman's treatment center where they were able to bring their children to treatment, I met many women, and I never met a woman who ever wanted to harm her baby. What I did meet was several women who could not stop drinking, who were addicted.

We have to look at this as when we come across a pregnant woman who's drinking, what kind of support do we need to give her? Is it information to tell her that she needs to stop drinking while she's pregnant? Or is it that we have to have more intervention with her to maybe help get her some treatment because maybe she is addicted and not able to stop on her own? FASD can occur any time during pregnancy even before a pregnant person knows they are pregnant. What's important to know? Fifty percent of pregnancies are unplanned. Many women get pregnant and don't even know they're pregnant.

What is important if someone is drinking alcohol and they are not wanting to stop drinking alcohol, what is important then is that person needs to be on birth control so that their consumption of alcohol, if they were to get pregnant, does not impact the baby. I always have worked with expectant families that, if you're trying to get pregnant and you've gotten off your birth control pills, it is really important that you not be consuming alcohol because when do you know you're pregnant? How many of you knew you were pregnant immediately? Sometimes people don't know they're pregnant for two to three months.

The question I get a lot, is this caused by biological father's use? Of course the answer to that is, no. But what they are finding is that there have been some modifications in DNA from the chronic alcohol use of a dad, and you know especially with some of the epigenetic research that's going on right now. This is not a new disorder. There are observations from Aristotle and quotes in the Bible about the effects of women drinking alcohol during pregnancy and the results of the child being born with some disability.

We look at the cause of FASD. The sole cause of FASD is women drinking alcohol beverages during pregnancy. We have to be careful of women who are, you have to look at the alcohol content of anything. We have these hard seltzers, these hard coolers. We have alcohol pops. We have wine spritzers. It's zero amount of alcohol to drink when a woman is pregnant because alcohol is a teratogen, which means it causes a malformation in the developing fetus. Of all the substance of abuse, including cocaine, heroin, and marijuana, alcohol by far produces the most serious neurodevelopmental effects in the fetus. That is because alcohol crosses the blood brain barrier in the brain much quicker and to more extensive level than cocaine, heroin, and marijuana.

FASD and the brain. If I was going to give anything for you to remember that we are talking about brain damage. The effects of FASD last a lifetime. For many people who have used cocaine, heroin, or marijuana, the child may have some effects of that. But once the child has time without those substances in their system, there is no lasting effects of that. FASD is different because it affects the brain. What's important to remember and Jenn's going to talk about this, that with support and recognition that you're dealing with brain damage that people with an FASD can grow, improve, and function well in life with proper support. That's very important to remember.

This is a picture of the brain. On the left side is the brain of a normal baby who died of other causes, 6-week-old brain. The brain on the right side is a brain of a baby who died from failure to thrive from their prenatal exposure to alcohol. You can see the brain on the left is a normal looking brain, and the brain on the right was unable to sustain life due to the prenatal exposure to alcohol. These are pretty graphic pictures, but it shows what happens. This is not genetic. This is all about a pregnant woman drinking alcohol during pregnancy.

In the next slide, we are looking at FASD and the brain. I wanted to show these slides because it shows what happens in the brain. These are MRIs. The first slide, slide A, is of a 14-year-old that has a normal corpus callosum. We're not going to go into brain structures here. There's no test here at the end of this presentation. But I want you to know that the corpus callosum is an important brain structure that helps us use both sides of our brain. To have abstract reasoning, to think things through, we have to use both sides of our brain. It is imperative that that be a functioning part of our brain.

In slide B, what we see, what alcohol appears to do in the brain is it affects the corpus callosum. It is one of the major reasons in the brain that it has an impact. In slide B, you see that this is a 12-year-old that has a diagnosis of FAS. That corpus callosum is thinner, and it's misshaped.

In slide C is a 14-year-old with FAS. In this slide, this individual has agenesis of the corpus callosum, which means it's not there. It never developed. This individual would have a really hard time thinking things through, having abstract reasoning because they don't even have a corpus callosum.

In the next slide, these are two images of the brain of a 9-year-old girl with FAS. The first is a side view. Again, you see the smallness of her brain. She also has no corpus callosum, and other brain structures are malformed. They asked her to turn her head sideways, and they took another MRI. What you see is this large hole in the back of her brain near her cerebellum. What alcohol does to developing brain cells is it causes them to go to wrong places in the brain.

If an eye cell has been affected by alcohol, it may migrate to the ear. Well, it's going to die in the ear because it's not an ear cell. This MRI of this brain shows this huge hole where all of those cerebellum cells never developed and died before they were able to form in the brain. You would not have expected this 9-year-old girl to act in any kind of an average way as she doesn't have all of her brain cells. I show these brains because I think it's important to realize that when you're dealing with kids that are having difficulty, sometimes it's about their brain. It's not being resistant or not compliant. It's really about the effects on their brain.

Our next slide, we're going to talk about the diagnosis of FAS. There are four criteria of FAS. Actually the CDC has said this top criteria which was known prenatal maternal alcohol use. The CDC is now saying, we don't have to know if mom drank because, if she has the other three criteria, she has either consumed alcohol. There is one other substance that can cause these same abnormalities, and it is called toluene. Toluene is a substance in cleaning solution. If somehow a woman ingested or was somehow exposed to toluene, she may have these three main criteria for diagnosis. Otherwise, it's prenatal exposure with alcohol.

The first is growth deficiency, which is two standard deviations of a deficient growth of physical size and/or brain size. The second is the central nervous system abnormalities, which I have just shown you with the damage to the brain. The third are the dysmorphic features, which is the face of FAS. For some of you who knew, there used to be a lot of criteria that they did was looking at the face. They have changed that primarily due to different facial features from different groups that may have a flat mid face, for example, that just may be part of their natural heritage. They change that, and they've gone to three.

The first one is the short palpebral fissures, which is your eye opening. Your eye opening, the space across your nose and your other eye are supposed to all be equal. Actually, our face forms about the 19th to 21st day of gestation. If there is alcohol exposure, then what they see is that the eye openings get smaller. We used to say that the kids with FASD had big eyes, and it's really not that they had big eyes. It's that their eye openings were smaller.

The next two I'm going to talk about together, and one is the indistinct philtrum, which is the ridge above your lip, and the third one is a thin upper lip. If we look at the pictures on the right, number three would be average, an average philtrum and average upper lip. If we move up to number four we see that the philtrum is a little smoother, the upper lip is a little smoother.

Then if we move up to number five we see that the philtrum is smooth and the upper lip is very, very small.

These criteria are part of the four-digit code that Dr. Susan Ashley of the University of Washington has published about to help to look at the different levels. Her four-digit code has, obviously, number five would be an FAS diagnosis. Number four maybe some exposure but not as far as the facial features are concerned. Don't know how much of the central nervous system abnormalities of the growth deficiency are. She can make a diagnosis, and it may be one of the five that we talked about earlier and not the full-blown FAS diagnosis.

The other thing I want to bring up very shortly is that getting a diagnosis is difficult. It requires a team. And there are diagnostic teams, but they are far and few between. Actually, the University of Washington, where Jenn is, there is a great diagnostic team there. There are diagnostic teams in Alaska, Ohio, Minnesota, but it takes a team to make this diagnosis. Part of what I bring this up and what we're really talking about today is that you don't have to have a diagnosis to understand that these children may have difficulties. For you as providers look and say, and I always use this criteria, this kid doesn't get it.

If you have done, and Jenn's going to give you a lot of different ways to look at ... to help these children, but if they still don't get it, you may go and start saying maybe there's something else going on here besides maybe being resistant or just having a difficult time. Maybe this child actually has a physical disability. At this point, I'm going to turn this over to Jenn and let her give you and to discuss some of the characteristics of these children.

Jennifer: Perfect. Thanks, Candace. Yeah like Candace said, we will start by talking about some common learning and behavioral characteristics because we think those can really help being aware of what some of these common characteristics are and what some of these common impairments and difficulties with learning are can help inform the interventions and support strategies that we use for children. Just to stress what Candace said, we know that this is a spectrum disorder. While there are some common learning and behavioral characteristics, these really do arise in unique combinations and to varying degrees across individuals. As Candace mentioned, this has to do a lot with how much exposure there was prenatally.

We also know that there is a really great interaction between the individual child's characteristics and their environment that can really impact how they develop and learn and how these characteristics, how these different learning and behavioral characteristics, appear and manifest each child. This is when we talk about nature and nurture interacting. This is really the case here. We know that risk and protective factors can really impact development, and we'll talk a little bit about that in a moment.

All that being said about the spectrum and that individuals with FASD are unique in how they individually present with their learning strengths and needs and behavioral characteristics, we do know that because of the issues with brain development that Candace was talking about there are some common impacts on learning, behavior, and adaptive functioning. As I

mentioned, being aware of these can really help shape how we intervene and what types of support we provide.

The first characteristic that I wanted to mention is talking about cognitive impairment. Steve if you could go back a slide, that would be great. Thinking about cognitive impairment. We wanted to mention this first, because this really does ... We know that in early years and in early development it's difficult to separate development between the different domains. Cognitive development impact speech development impacts social functioning and development. We know that with those underlying differences in brain structure and functioning, there are some impacts on cognitive development that do impact other areas of functioning.

One thing I wanted to mention is that in terms of intellectual disability, IQ scores, some children, thinking about this range, some children may have a lower IQ, but actually many children, individuals with FASD, have what's considered normal IQ functioning. However, even when children have normal cognitive functioning and normal IQ, many children still have issues with memory and attention which you see is that second bullet. These issues with memory and attention really can impact many different areas of participation and functioning in their environments. It can make learning slower and more difficult and can contribute to a number of different challenges with learning and adaptive functioning.

One challenge that's mentioned a lot, and I know Candace has a lot to share around this, is what's called sporadic mastery. This variance or inconsistency in learning and performance and behavior from day to day. It might look like a child has learned something, has mastered a skill, has used it, and then the next day they're not able to recall it. They're not able to perform that skill. As Candace just mentioned, without understanding what's happening in the brain that might look like resistance or defiance, but this variability is a common characteristic, a common neurocognitive characteristic. Those on-and-off days are something that we do see often with young children who have been prenatally exposed.

Another cognitive characteristic that I wanted to mention is difficulty, Candace mentioned this as well, but difficulty with abstract and symbolic thinking and symbolic reasoning. This can really impact what types of teaching strategies we choose and use. Then a couple other things I wanted to mention, one is an issue with generalization. This idea about learning a skill in one environment at school or at home or with one person even and the ability to use that skill across settings, across people. Generalization we know is often a challenge for individuals with FASD.

Then the last thing I wanted to point out was issues with flexibility, so difficulty shifting attention, difficulties changing between tasks. For some children, this is a big issue. Again how this looks, many children may appear irritable. They might appear stubborn. Some might use repetitive speech or behavior when they're having difficulty shifting attention, which again you know behaviorally may appear quite different than what's actually happening. Next slide, please.

We also see some issues and impairments around speech and language. Again, knowing that it's really different from individual to individual. Some individuals, some children may have in terms of their expressive language, what they can say and what they can communicate, they might have a smaller vocabulary. Their expressive language may be delayed, while other children may say as many words as you would expect the same-age peer to say. However, what we often see is challenges with what we call pragmatic use of language, so that's social use of language. I can say words but how do we use those words with other people to get my needs met, to form relationships, to interact, right?

Then another thing we often see is this inconsistent or kind of uneven development between expressive language and receptive language. Receptive language is what children process and what they understand. While they might appear to have fairly normal expressive language, while they have a vocabulary that again matches their same-age peers, their receptive language may actually be quite delayed. Again, that really comes back to, especially when we think about language processing and understanding and being able to follow directions when we're talking about more complex or abstract language being used, it makes it more difficult to process and understand that language. Next slide, please.

Thinking about social-emotional impairments, this is an area where there is a lot of focus around interventions. Again, we talked about that impairment with a pragmatics of expressive language, but learning and using social skills can be very difficult. Well, I would argue can be difficult for many young children and many individuals. But oftentimes for individuals with FASD or who may have been prenatally exposed, learning these social skills that are not concrete, that are quite abstract, learning how to use those and then in what situations do I use those can be really, really difficult.

Then thinking about emotional regulation. This ability to recognize emotions both in yourself and in another person and then control impulses, manage big feelings, we often refer to them in early childhood. But when you become dysregulated, being able to recognize that and use strategies to get yourself back to calm and regulated can be often quite difficult and is, like I said, an area of focus for intervention for many young children.

When we think about motor delays we often see issues with gross motor development, and young children are often described as clumsy or maybe having poor coordination. Then we also see a lot of issues often with sensory processing. Someone's body, the way that their body responds to external sensory stimuli, whether that sound, what they hear it's auditory, visual, response to touch. Again, knowing that this is a spectrum, there's not a common sensory profile, but we might see people being under-reactive or over-reactive to that sensory stimuli especially touch and auditory input. Then this issue of proprioception, so awareness of where your body is in space again, that idea of being uncoordinated or clumsy.

Then the last learning and behavioral characteristic that I wanted to talk about are adaptive skills and adaptive behavior. When we think about adaptive skills, we often see issues or challenges with children's independence, their ability to play and kind of entertain themselves on their own, and issues with caring through self-care routines, whether that's hand-washing,

toothbrushing, toileting. Again, thinking back to those cognitive deficits, many of those are multistep, and that ability to kind of sequence directions can be a challenge.

Then behavior, we know that there are some common behavioral difficulties. One, as I mentioned earlier, attention to tasks. We often see children having shorter attention spans. Many children are actually often diagnosed inaccurately with ADHD. Then another challenge that we see frequently in a focus of intervention is impulse control and really being able to control those impulses and regulate when your body gets dysregulated.

Candace: Again, one thing I wanted to say about for providers what's really important when you're talking about these behaviors is one direction at a time. Multiple directions get lost, and that has to do with your memory issues. So for providers, just take for one direction then another, then another. A lot of times those kids will follow what you do, but if you give them multiple directions they're probably not.

Jennifer: Absolutely. Yeah, thank you. That actually sets up the next section quite nicely. When we're thinking about early support and early intervention, just really briefly before we get into talking about specific strategies and approaches that we can use, I'll talk about intervention broadly for just a minute. Because of what I mentioned earlier, that interaction between the individual's characteristics, their biology, their brain, and their environment, because of the effect that interaction has on development, intervention focuses broadly. The most effective interventions focus broadly on increasing protective factors, some of which you see here on the screen. Really thinking about reducing risk factors, increasing protective factors that can really help put that child on a more adaptive developmental trajectory.

We know that interventions are likely to be most successful and effective when they include intervention that's provided directly to the child and support that's provided directly to the child but also looking at those environmental factors, especially thinking about providing parents support and really thinking about interventions for parents that focus on helping them understand and respond to their child's behavior and using some of the strategies that we'll describe in the next slides.

When we think about strategies and what type of support do we do, what type of teaching practices do we use, again, this is a spectrum and there is no one-size-fits-all approach. There is no one curriculum. The most important thing that we want to consider when we're planning for instruction and support is matching the strategy that we might use to the child's individual needs and really their learning characteristics, their functioning within their environment, and their behavioral characteristics.

Because of what we know about brain development and those associated impacts on development and learning that we just discussed, there are a few key strategies, actually one of which Candace just mentioned, that we hear really frequently. One is to be concrete and be specific. We have to say, say what you want to see. We use a lot of without even really thinking about it. Think about what you're doing, look where you're going. Right? What does that mean? What do we want to see the child do?

Another really common effective approach is using consistency, routine, and providing structure. And that's in the environment, that's in our expectations for children even down to the language that we use for instruction and support. When kids know what to expect, it helps support their learning and they're functioning in their environments.

Then the last thing I wanted to mention before we move into some of these specific strategies is repetition. We cannot repeat that enough. We know that these ongoing issues with short-term memory really make it difficult for some children to recall information even, as I mentioned, if it's been learned and retained for a period of time. We know that repeating instruction, reteaching skills can help with long-term memory. And there are other supports, like you see here on the slide, that we can use to help children learn but also help participation, help functioning in the environment. What you see here on the screen are the strategies that we'll talk about today. On your resource list, I wanted to mention that there are links to many different resources that describe these strategies that can help people learn about them and use them in different learning environments.

The first strategy that I wanted to talk about is this idea of setting up, planning, intentionally planning, or modifying an environment to really help support the learning and behavior and functioning of children. When we think about the environment, we think about a few different features, the physical environment, the social environment, and what we call the temporal environment. Today I'm going to focus on the physical environment and the temporal environment.

Examples of modifications to the physical environment, one big one for these children is really thinking about changing or intentionally arranging the environment to support the sensory needs. We want to be aware of different environmental factors that might be overstimulating for the child if we have an individual who's over-reactive to sensory stimuli. That might be harsh lighting, loud background noises, and make those changes as needed.

Then another thing that is really important when we think about the physical environment and how we're setting that up is thinking about using our physical environment to provide cues to the child for what we expect in terms of their participation and their behavior. We spend a lot of time, as Candace mentioned, giving directions, giving reminders, setting things up and for children who have issues with language processing, issues with memory and recall, issues with sequencing information, that is in one ear and out the other for many children. But when we add, and we'll talk in a moment about adding visual information to the environment.

But when we think about having our environment help us cue children really thinking about letting the environment do the talking, we're thinking about the number and type of materials that are in the environment, how boundaries are kind of defined physically and visually in the environment. Then as I mentioned, what we'll talk about on the next slide, is adding visual information to the environment to really think about letting the child know what's expected of them and what they should be doing. Next slide.

When we think about adding visual information, this is a really, what we like to call high-leverage strategy, this is a really powerful strategy for young children because of many of those learning and behavioral issues that we've discussed. Visual information can be added to help communicate expectations to the child. What are you supposed to be doing now? What are you not supposed to be doing now? Help with regulation. Here are some specific behaviors, some specific steps I can engage in if I'm starting to feel overstimulated. If something is too loud, this is what I can ask for, and thinking about ways to help manage play.

We talked about independent play, leisure skills as an area of challenge for many children. We can also add visual information to help let children know this is how you might play or this is how you might engage with this material or during this activity. A great thing about visual information and adding visual supports to the environment is that they can really be matched to the child's developmental level and how they learn best. This information is static. It doesn't go anywhere. It doesn't rely on memory to help a child know where to be, what to be doing.

Then the last aspect of the environment that I wanted to mention that we often use a lot of support strategies and where we focus some of our intervention is the temporal environment. Again, when we're thinking about issues with attention and challenges to sequence activities, whether that's across the day, first we do arrival, then we do play, then we do hand-washing or even whether that's in an activity, we see many young children have difficulties as I mentioned with multistep routines whether that's hand-washing. First I turn on the water, then I get soap, then I make bubbles, then I rinse, then I turn it off. That's a lot in one simple activity. There are many different supports that we can use to help children manage how much time they spend, how activities are sequenced, what type of support we provide to interact even like I said within an activity or within a routine.

The next area of intervention and support that I wanted to mention is, as I mentioned earlier, this is a really big area of focus for many young children with FASD, explicit instruction on social skills. When we think about social skills, it's important. We use them every day. There are many different social skills, but they're really abstract. These are not concrete easy-to-understand behaviors, right?

They rely on observation and imitation. They rely on attention to subtle cues. They rely on recall. They rely on the ability to generalize. One skill I learned I can use in a different situation and with a different person. For many children, they need to be explicitly taught what these social skills and behaviors are. When we think about key social skills, we think about friendship skills, we think about emotional regulation skills, and we think about problem-solving skills.

What you see here on the screen are some examples, a very few. There are many different examples of friendship skills. What a child needs to focus on is really going to be variable depending on their own individual development, their needs, and strengths, but we think about initiating play, sharing and taking turns, sustaining conversation, or staying on topic. You see an example here in the screen. The middle picture is giving compliments, right? One part of being a friend is giving compliments. But when we think about even that that's a social skill of giving a compliment, what does that mean? Right? We might even need to provide explicit instruction

on what a compliment is and how you do it. It's something you like about somebody. It's something that's true. Some kids might need to be taught some specific words or sentence starters. "I like how you ... You're good at ..." Right? That's what we mean when we think about, let's take this big skill, let's break it down, and let's provide some really explicit and repeated teaching with this type of visual support.

Next slide focuses on emotional regulation. Again, we know that this is a really, really important skill. If children aren't taught explicitly to use the skill and maintain it, it can be a real challenge for children, but also for the adults in learning environments. When we think about emotional regulation, you know I mentioned earlier, identifying emotions, even knowing what an emotion is, what a feeling is in your body or someone else's body, and the ability to use words to describe that, all the way up to being able to identify that I have a big feeling that I need to regulate and what are strategies that I can use to do so.

Then the last thing that I wanted to point out in terms of explicit social skills is problem-solving and that ability to solve problems both problems that occur, you know, I can't reach this, I can't get this, I can't use my communication behavior to get my needs met, but also problems with other people, other children in your environment. When we think about explicit instruction on problem-solving skills, first what is a problem? What's a problem and what do I do when a problem comes up? Right? And we talked about these problem-solving stuff.

Identifying that there's a problem, identifying possible solutions, trying out different solutions, and then kind of evaluating how did that go. Was that the right solution? I'm giving kind of these big examples with skills on a long and broad developmental continuum that this is what I'm talking about when we're thinking about, OK, let's break this big idea of emotional regulation down into these different steps and figure out where this child is on that continuum of learning and what do we need to do to help them learn and retain and use that information. Again, thinking about oftentimes that relies on those external supports that structured environment, that repetition which I'll talk about on the next slide, and that use of consistent expectations and visual support.

Steve: Jenn?

Jennifer: Yeah?

Steve: Jenn, this is Steve. We're almost at the top of the hour, and the chat seems to indicate people are really engaged, they're really liking this. If people need to get off there will be a recording sent over the next few days, so you'll hear the entire thing. We will try to get to as many of the 20-odd questions, not odd, but 20-plus questions that we have at the end. I just wanted to give people a heads up. I think this is all too valuable to just stop at the top of the hour. OK?

Jennifer: Perfect. Thanks Steve, and I'm actually almost wrapped up so this is great timing. The last thing I wanted to mention is this idea of repetition. Not only do children need intentional instruction and explicit feedback – this is what we wanted you to do, this is what a compliment

was, I saw you give that compliment – and so that intentional instruction and that explicit feedback on what the child did and when they use that skill, what we want to see them do more of. But we also know again because some of these deficits in memory and attention and that ability to retain and generalize skills, most children need that repeated instruction and what we call sufficient opportunity.

If we wait for a teachable moment to arise and then kind of teach and scaffold and address a new skill, like we do with many young children kind of as a foundational practice, that's probably not going to be enough in terms of the amount of instruction that these young children need to learn and retain and use these skills.

Also, when we're thinking about repetition and planning for instruction throughout the day, this also can help address generalization. We're not just teaching social skills at recess or at outdoor play, we're teaching social skills during free play, we're teaching social skills during mealtimes. That can really – when we're teaching the same skill in many different contexts – that can help children learn that generalization and learn to use that skill across many different settings.

As I mentioned on the resource list, there are many different resources that we can use to help plan to embed instruction throughout the day, from breaking skills down, like I just mentioned, and then really thinking about tools that can help us plan and organize those planned opportunities for learning across the day. Make sure that you check out that resource list to look. Again, I provided resources across these different strategies that I hope that people can go to, check out, learn more about the strategy, and hopefully use it right away.

Then the last thing that I wanted to mention in terms of intervention and support, again coming back to that idea that we just talked about some direct intervention and support strategies and approaches for young children, but what we know about, again, that interaction between individual characteristics and the environment and the impact that that has on development and what we know about the most effective intervention and focusing broadly on the child, but also their social contexts, their environmental contexts, that this really is a coordinated approach to intervention and support for young children and their families in order to have the most positive outcomes.

When we think about that coordinated approach and we think about helping families fully access your program's comprehensive services to really result in the most positive outcomes, this is going to take really strong coordination of your team. Thinking about identifying the strengths and needs and resources of the child and family and help matching supports to those needs and to those strengths but also helping families identify what potential barriers might be to accessing whether those are the services within your program or community resources and services that you might want to help families access. Thinking about what those barriers might be and helping to eliminate some of those barriers so families are able to fully access like I said those comprehensive services.

Candace: Thanks, Jenn. Thanks for all that information and it's so important. I have one statement that I use in my training with staff, and this is to remember that every day can be a new day for an individual that has an FASD. That can be hard, but if you remember that then it just helps you I think in your work with these individuals.

Jenn talked about a coordinated approach, and it's not a new concept. Here is a statement from this elder who said, "Let us put our minds together and see what life we can create for our children." That is so true in a coordinated approach, especially for those children that may have a disability.

We have a list now of resources, and we have some wonderful resources on this first one for resources around FASD. SAMHSA has a Treatment Improvement Protocol 58 addressing fetal alcohol. The Centers for Disease Control, NIAAA, and the National Organization for Fetal Alcohol Syndrome have wonderful resources and many connections to other resources. I invite you to look at these resources. They'll all be part of your handout. I think Jenn has some that she wants to highlight too.

Jennifer: Yeah. This first slide just had some general information, but I added some. On the next slide, as I mentioned, I organized them by the strategies, those kind of broad strategies. So thinking about environmental modifications and visual supports, there are different resources to help like I said help education staff and families learn about these strategies. But then also the visual supports I've included a couple of links to ready-made freely available visual support so that people can download and use immediately.

Then a couple more that I wanted to point out on the next slide, some strategies and resources to help teaching behavioral expectations and helping to establish and communicate and teach children what the routines are and how to participate in those routines. Then the next slide has some links to resources to help with that organization. These are some social stories and strategies which are really, really useful. Then some resources to help, as I mentioned, think about organizing learning throughout the day and providing that repetition and that sufficient number of teaching opportunities.

Steve: Wow. Amazing, amazing, amazing. You are quite the team. Like before we started, I said they were a power couple with lots of great information. My takeaway is that this is really about individualizing for that child with FASD or FAS. You're going to have to individualize every single day and that so many of these strategies could be used with children with other impairments as well, other deficits – so really wonderful practical strategies. We have so many questions. Olivia, please keep putting the evaluation link in so people who are leaving make sure that they get the evaluation.

I'm going to just start these questions. Some I think I know who to direct them to. If not, please jump in. Candace, the first question was about the DSM-10. Has it been updated to include FASD? Do you know?

Candace: I think the one that I gave you the NP, I'm not looking right at my ... but they don't. It's been a struggle. We have tried so hard to get FASD into the DSM. It is not part of that, but there is a criteria for that to be – I forget what the section was. But there is one there that they can use if they need to get a code.

Steve: OK. The next question, understanding that FASD is not genetic, but is a mother's alcohol used genetic?

Candace: Well, that's a good question. They do, they certainly have found the alleles and things that make predisposition to how you metabolize and how you use alcohol. If you have one parent, the percentage is 50%. If you have two parents that are alcoholic, the percentage goes up. They have not identified the specific gene, but they have looked at the predisposition if you grow up or have parents who are both alcoholic.

Steve: Thank you. This particular staff person recognizes that we have a lot of foster and adoptive children in Head Start, and their current families don't know whether they've been exposed to alcohol in utero or not. Is there a way to diagnose when you don't know if there has been an exposure? And I know you talked to Candace about the CDC not putting a lot of emphasis on mother's use when there are other characteristics.

Candace: And they've done that Steve just for that reason because there are many we don't know. Before it used to be they had to know about maternal use. Now they don't need to know that. The best time to diagnose a child is between as around 6 years old because of the facial features come in more strongly in the behavior, manifestations are more identified as being problematic and not just a delay or whatever.

It is a problem. It is not knowing, and that's the sad thing is that many children get put into their foster care because of these substance use of mom or the parents. The best time is around 6 and again just to look at the behavioral manifestations are going to have more information and as I said, it's difficult to get the full diagnosis. But I understand that is an issue, and that's why they dropped off, that's why the CDC did drop off the knowledge of current use.

Steve: So a mom who may have consumed alcohol before she knew she was pregnant but stopped immediately when she found out, what are the chances that the baby might be affected?

Candace: Well, yay for that mom, and that is really important. Any time any woman knows she's pregnant, stop drinking. You know Steve I can't answer that because again you have the different dispositions of the developing fetus. We have birth moms that have given birth to a child that has FASD, and she didn't know she was pregnant for a month, and she stopped then. She still had a child born with an FASD. We've had moms that didn't know they were pregnant, didn't stop drinking until month four. We have moms that drank all the way through pregnancy and don't have children that have an FASD.

They may be down on the lower spectrum, having some difficulties with some of those abstract things like math and reading and that kind of thing. It really has to do with the – this is the problem with this issue. There's no dose-related information that I could say, if you drink this much here, you're going to have this much deficit.

Steve: Thank you. Can FAS be detected before the baby is born?

Candace: Not to my knowledge. I don't think they do MRIs to developing fetuses brain that I know of. So no, it's not like finding out if you have another birth defect. By looking at the embryonic fluid you can tell about other things, but you cannot do that with FASD.

Steve: Thank you. How about any manifestation of the mother's face while she's pregnant. If she's drinking does her face change as well?

Candace: No.

Steve: Yep.

Candace: No.

Steve: Thank you. Next one, oh goodness. I got ... sorry I lost my questions here for a second. Sorry. This has to do with your first webinar. I'm going to recommend that anyone that's asking about the amount of exposure and all of that, there's a lot in the first webinar about that. But do most children diagnosed with, I'm going to mispronounce this, agenesis ...

Candace: Agenesis ...

Steve: Agenesis of the corpus also have FAS? In other words, are there other reasons for the agenesis?

Candace: I believe there are Steve. There could be some sort of brain abnormality that may not be associated with alcohol. It's just that alcohol in the developing fetus, that part of the brain is mostly impacted in the corpus callosum. The agenesis of the corpus callosum is one of the criteria that we see when they do evaluations.

Jennifer: Yeah. They can ... agenesis of the corpus callosum can occur with other issues with development as well.

Steve: Thank you, Jenn. I'm glad you got to have a word in edgewise. This is an interesting question, and I think Jenn you may be a good one to start with this. I've heard that FASD can be misdiagnosed as attention deficit disorder or attention deficit hyperactivity disorder. In your experience, have you seen this as well or have any thoughts about this misdiagnosis issue?

Jennifer: Yeah. I think that's pretty common, and I see Candace nodding her head. A number of misdiagnoses is actually. ADHD, maybe not a number, but ADHD for sure I think is a really common misdiagnosis. And then some of the learning and behavioral characteristics that we

described are learning and behavioral characteristics that we often see in young children on the autism spectrum.

I think that that is a challenge. But I think that when we focus and organize our approach to support an intervention on the child's individual characteristics and how those learning and behavioral characteristics are impacting their adaptive functioning and their learning, then it doesn't necessarily matter what their diagnosis is. The important thing is, like you said, individualizing and matching the strategies and the intervention practices that we're using to the child's learning and behavioral characteristics.

Steve: Thanks. This is a classic question that always comes up when we talk about FASD in the past. A glass of wine once in a while was considered OK. Is that no longer true?

Candace: You know Steve, the CDC, SAMHSA, and NIAAA, most people are saying zero amount of alcohol is best during pregnancy. I was doing a presentation one time, and I had a doctor stand up and say, "You can't tell me that one glass of wine will cause an FASD." And I said, "You're right, but you can't tell me it won't."

Sometimes it really has to do with timing of the drinking especially early, early, early on, but I can't tell you for sure that one drink – and we still have doctors that are saying it's OK to drink during pregnancy. That is not the recommendation of SAMHSA, CDC, NIAAA, NOFAS, anyone. They're saying no amount of alcohol during pregnancy just to be safe.

Steve: Thank you, and I think that's all the questions we have time for. It's past a quarter after the hour. Olivia has put our email address health@ecetta.info into the chat if you have more questions or questions that were not answered. She's also put this link to the evaluation, and the evaluation we'll bring you to the certificate. You will all get the same link in the email that comes out in a few days that will also have the recording and the handouts.

We encourage you to subscribe to our mailing lists. Olivia has put that link in the chat a number of times, and it will also be in your email that comes up. You can always reach us, the National Center on Health, Behavioral Health, and Safety at this address, this phone number, and find our resources on the ECLKC.

I want to thank Candace and Jenn for just an incredibly rich and yeoman's work there for going past the hour of getting all that really practical, helpful information. It can be a confusing morass because there are so many reasons that children may display a disability or delay, and to focus in on FASD today was just really, really valuable, so thank you for that.

I want to thank Kate and Olivia for handling things backstage. But mostly I want to thank this incredibly engaged audience, over 800 of you asking questions, responding, talking in the chat, and mostly I hope learning. Thank you, thank you, thank you. The compliments are very much appreciated, and we will be sure that Jenn and Candace see them.

Candace: Thank you, Steve, for your hard work and the back room.

Steve: You're welcome.

Candace: The back room, thank you.

Steve: And the back of the house here. OK, I'm so glad. And the webinar is going to come down, and there should be a final link to the evaluation coming up.

Jennifer: Thanks, everyone.

Candace: Thank you, bye-bye.

Jennifer: Have a great afternoon.