

NWX-HHS ACF (US)

**Moderator: Sharon Newburg-Rinn
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1:00 pm CT**

Coordinator: Welcome, and thank you for standing by.

We do apologize for the technical difficulties that we've been experiencing this afternoon and appreciate your patience in joining today's call. Today's conference is being recorded. If anyone has any objections, you may disconnect at this time.

Also, during the question and answer session, you'll be asked to press star one to ask your question, and then you'll be prompted to state your name. So be sure your line is un-muted so that I can record your name and announce you before your question.

Now I would like to turn the call over to your host, (Sharon Newburg-Rinn). You may begin.

(Sharon Newburg-Rinn): Hi, everybody. Thank you very much for joining us. Really, my first order of business here is that I would just very much like to thank (Joe Bock) -- our head of the Children's Bureau -- now for joining us this afternoon. And he's going to just say a few words of welcome. Thank you.

(Joe Bock): Welcome to everyone who is on the line. We appreciate your interest and your willingness to weather our technical difficulties and participate in the webinar. We're very excited about it.

I think we all know from a child welfare perspective, that we deal with some of the most vulnerable people in our country, an even more vulnerable subset are those kids who come to our doorstep with developmental disabilities. We were very excited the CDC's been willing to partner with us and provide additional information to us and to our grantees because, you know, the expertise on disabilities doesn't sit here.

And I think the work that (Sharon) and (Rebecca) and (Jacquelyn) have done demonstrate that it really takes the dedicated career folks to get together to actually make collaboration and government work. And so I want to thank them for their time and their efforts. And I hope you find their presentation as interesting and as helpful as those of us from the Children's Bureau did when we heard it a couple few months ago.

But let me turn it back over to (Sharon).

(Sharon Newburg-Rinn): Okay, thank you Mr. (Bock).

All right. This is just a little agenda so you can see what's happening. We've already had Mr. (Bock) do our little welcome, and then I am next. And after that, there's going to be the main presentation, which is from our colleagues at the Centers for Disease Control and Prevention in Atlanta. You know, through the magic of technology, they're in Atlanta but we're in various other places. And that's (Rebecca Wolf), who's the team lead for Learn the Signs. Act

Early, and (Jacquelyn Bertrand), who is a behavioral scientist in the Fetal Alcohol Syndrome Prevention Program.

After that, we are going to ask for some comments and questions, and you'll be able to post those online. And then we're hoping that you will fill out the short evaluation form at the end of the webinar. And then we'll also talk with you about how you can access this later because -- as somebody mentioned earlier -- the whole thing is going to be recorded.

So, let me get on to the next part of it here. Okay, so it's my job to kind of explain why we care about this in the child welfare field, what's particularly important and salient about this topic. So that's the part of this that I'm going to be introducing. The early identification of developmental disabilities and what's the importance is in the child welfare field.

So, if you are in contact with children on a regular basis, or for many of you, it may be that you supervise someone who is, you already know about your (unintelligible) responsibility to be alert to possible signs that an additional evaluation would be desirable or advisable. And I want to emphasize strongly that you don't need to be an expert. That's not what this call is all about. We're not expecting you to be very, you know, high-level experts in testing the children and this sort of thing.

But by looking for certain things in what's happening in the normal process of child development, you would be able to detect whether or not children should be referred for more detailed evaluation. And that's what the CDC's program - - Learn the Signs. Act Early. -- is all about. It's for anybody who has contact with children.

And our CDC colleagues are going to give us more detail on what you need to know. They have some very helpful -- and I don't hesitate at all to add that they're free -- resources for you that you can download, you and your colleagues, or you can share them with community organizations, and also with families that you serve.

So, of course all developmental disabilities are important. And the CDC is going to go into a little bit more detail and explain what we mean by a developmental disability. And the Learn the Signs. Act Early materials can help you detect when something is not quite right, and not just the couple of types of disabilities that I am going to particularly focus on today.

So, the two that I am going to focus on more just so we can see what that child welfare connection is particularly our autism spectrum disorders and fetal alcohol spectrum disorders. And that is caused by prenatal alcohol exposure.

So, here's our little slide talking about autism spectrum disorders. Now autism spectrum disorders -- or ASDs -- are increasingly diagnosed in the general population. It's at 1 out of 88 children now. And there is really no reason to think that it's lower among the child welfare population. And actually, it's probably higher. And that's because we have studies that indicate that children entering foster care typically have higher rates of disabilities -- of all disabilities. So, we certainly would not expect this to be lower in our population.

We also know from the National Incidence Study of Child Abuse and Neglect -- nicknamed NIS-4 -- showed that children with confirmed disabilities had significantly higher rates of emotional neglect and serious injury or harm. So, it matters that they have any type of disability. And that, of course, would apply to autism spectrum disorders, too. So, we want to be careful when we

come into contact with these children that we are able to serve them properly and effectively and get them the services they need.

And the second one that I am particularly highlighting is fetal alcohol spectrum disorder. In that regard, alcohol abuse by the caregiver is a very well-established risk factor for child maltreatment. One study shows that's it about 10 percent of the cases, and it shows the listing there in case you want to look it up yourself. And another important source, again, is the National Incidence Study that I just cited a little while ago from 2010. And it also found that parental alcohol abuse was a factor in 14.7 percent of serious or fatal harm to children.

So, estimates of these things may vary somewhat depending on the study that you're looking at. But the findings do tend to imply that alcohol abuse by a biological parent would be a factor in the child's coming into contact with child protective services. So, therefore, if those parents are using alcohol, we need to be on the lookout -- all of us need to be on the lookout -- for the possibility that they will have disabilities and special needs because of that possibility of that prenatal alcohol exposure.

And now is where I'm actually going to ask you for something because we have quite a wonderful group of people on the line who are professionals in the field. And this is something I'm going to ask you to do later, but I'm going to mention it now, because we want your opinion. And this is going to be on the very last item when you do the evaluation at the end of those webinar.

And I just want to say that many of you are aware that we have a data system called Adoption and Foster Care Analysis and Reporting System. Naturally, this is the government, so we have to abbreviate everything and it's called AFCARS. But that data set doesn't really give us adequate information for us

to calculate actual rates of disabilities of children entering foster care. There is some information on it there. It's not necessarily very well populated. And not all of that information is entered in.

And also, we don't really have adequate information from that data set on parent alcohol abuse, and certainly nothing really even to distinguish between the mother and the father that would tell us whether or not the child might have been exposed to alcohol prenatally.

So, we are especially interested in having those of you on the line, when you're at the very end and you do your little evaluation -- it's a short evaluation -- but we especially hope you'll attend to the very last item. It will be item number six, where it's open-ended and we would like your views on what data, what other information would be important for you to know. What would help you? And I also just have my email address and so forth there. So, you can also send information to me maybe if you don't have time to do the evaluation at the end or whatever.

So, now that's it for me and I'm going to turn this over to our colleagues (Rebecca Wolf) and (Jacquelyn Bertrand). You want to go ahead?

(Rebecca Wolf): Sure, thank you, (Sharon). And thanks to both you and (Joe). I really appreciate the opportunity. I'm not sure. I haven't seen it pass over to me so you can see my screen yet.

(Sharon Newburg-Rinn): Yes, someone there is going to need to turn it over to you.

(Rebecca Wolf): Okay, but meanwhile, I'll go ahead and get started. So (Elisabeth), are you passing that over, or (Renee), are you passing the control over to my screen?

Woman: I'm sorry, who was that?

(Rebecca Wolf): This is (Becky Wolf).

Woman: Okay.

(Rebecca Wolf): So that we can show the slides.

Woman: (Sharon), yesterday in our run-through, there was also a relinquish button.

(Sharon Newburg-Rinn): There was a what?

(Rebecca Wolf): Yes, so (Sharon), if you'll click "okay"...

(Sharon Newburg-Rinn): All right.

(Rebecca Wolf): And I click "yes," and I hope you can now see the first slide that says, "Early identification of development disabilities."

Woman: I see it.

(Rebecca Wolf): Practical tools. Perfect, okay. Thank you so much. And thanks again, (Sharon) and (Joe) for sponsoring us today. My name is (Becky Wolf), I'm going to start out, and (Jackie) and I will be doing various slides together as we go through the talk today.

So first, I'm going to start with the take-home points for the webinar -- this presentation today. These are the main points I hope you'll really be able to take away when we're done. First off, is that developmental disabilities are really common, more common than most people expect or realize. And that

early identification of those developmental disabilities is really important because that's the key for children getting the services they need at the time they need them.

And you all have an important role and responsibility just like (Sharon) mentioned in developmental monitoring and early identification. And we can help you with that. We at CDC offer you free resources and tools and people. Those are what we call our ambassadors in the State to help you with that role.

So to begin with, let's define developmental disability. We use that term a lot, but I think it's helpful to remember what it really means. It's a chronic impairment, either mental or physical or both. It appears by definition -- developmental disability appears in early childhood, although the signs are very subtle, and that's one of the reasons for this talk today, is sometimes they can be very difficult to notice there's any developmental delays.

A developmental disability is likely to continue throughout a person's lifetime and results in substantial limitations in how children learn, how they can take care of themselves, how they can communicate, their behavior, their emotion and movement, and other areas.

And here you can see some common examples of developmental disability -- like (Sharon) mentioned -- autism spectrum disorder, fetal alcohol spectrum disorders. It also includes things like Down syndrome and ADHD. And children risk developmental disabilities are at -- no surprise -- increased risk for poor outcomes including poor school performance as well as poor overall health. So, it's important to catch these early to get the children the services they need.

So, developmental disabilities are actually shockingly common, 1 in 6 children in the United States, ages 3 to 17, have some kind of a developmental disability. One in 88 has an autism spectrum disorder, also quite high prevalence.

And next, (Jackie).

(Jacquelyn Bertrand): Well and we wanted to talk about why we were focusing on just autism spectrum disorders and fetal alcohol spectrum disorders, because in the general population, and then more concentratedly in the child welfare population, you're going to see all of the developmental disabilities.

Most likely ADHD is the most commonly diagnosed developmental disability, which was about 6.8 percent of the population, but autism and fetal alcohol spectrum disorders both have a lot of behavioral issues that come to light for parents that bring them to light to both clinicians and to caseworkers and things like that. And these two disorders have a lot of behavior disorders that overlap with early trauma.

And so there's a lot of issues about teasing apart what is what. And for clinicians and caseworkers on the frontline, that's an important issue in documentation, and teasing that apart, and then helping caregivers deal with it. That's an important issue. So, that's why we chose these two.

And these conditions can both be difficult for people, and parents, and caregivers who have fostered other children, raised their own children, cared for other children understand, what they're dealing with especially because very often in clinic I hear, "Well, I've raised so many children, and my parenting practices worked great, but with this child, they don't." And so

having to tease apart that particular comment -- which I think is a very familiar comment -- happens very often with these two disorders.

And both autism spectrum disorders and fetal alcohol spectrum disorders, caregivers very often come against is this child won't do this thing or can do this thing, whether it be a neurocognitive skill, whether it be a behavioral skill, whether it be an adaptive skill or something of that nature. So, there's a whole lot of overlap between these two disorders and some overlap with other disorders. But these are two that very often come to the forefront in many clinical situations. So, that's why we've focused on these two for this presentation.

And thank you, (Becky).

(Rebecca Wolf): So, just for convenience, I'm going to tell you about fetal alcohol spectrum disorders for the moment. And fetal alcohol syndrome was first described in 1973, so we're many decades on from there now. So, we've got a bit of an alphabet soup describing this.

But fetal alcohol spectrum disorders is an umbrella of disorders of other, more specific diagnosis, including fetal alcohol Syndrome, partial fetal alcohol syndrome, alcohol-related birth defect, alcohol-related neurodevelopmental disorder. A very old term is fetal alcohol effects. And a new term is neurodevelopmental disorder associated with prenatal alcohol exposure, which I'm going on to in a minute.

But if you look at how prevalent -- or how common this disorder is -- if you look at the most involved disorder, which is fetal alcohol syndrome, it's about 1 in 167 children. fetal alcohol syndrome is the most involved disorder within

the umbrella. It involves physical features, neurological disorder, and prenatal alcohol exposure.

Physically, it involves facial dysmorphia, which is small eye openings called how people (unintelligible), a smooth philtrum, which is the groove that's between your nose and your lip, and a small (unintelligible), which is the thin line at your upper lip. Those are the physical features, in addition with growth retardation. These all happen very early in gestation.

The brain aspects, which you can be accounted for in alcohol-related neurodevelopment disorder and neurodevelopmental disorder associated with prenatal alcohol exposure, are all things that can happen throughout pregnancy and across the either three trimesters. So, our 1 in 167 children estimate is for the full, most-involved diagnosis, but all the other diagnosis you would have to think of are greater than that. And as children get older and more of their cognitive and neurodevelopment happens, you would also again think the prevalence would be higher.

Also very concerning to us here at CDC is that across time since we've started to track this number, approximately 12 percent of women who are pregnant after recognition of pregnancy continue to drink. And so this is a very concerning number.

(Becky), can you go on to the next slide?

(Rebecca Wolf): Sure.

(Jacquelyn Bertrand): Okay. What I really want to talk to you about is neurodevelopmental disorder associated with prenatal alcohol exposure. This is a term and a diagnosis that was included in the most recent diagnostic and statistical

manual of the American Psychiatric Association, published this past May – DSM-5. I'm sure most of you have come across it, and you're coming to terms with that new manual.

NDPAE was included in the appendix of DSM-5, and that's part of the process for when it's in the appendix, it says we need some specific field trials about this diagnosis, but we really think it's going to be included in future editions of this manual.

So, NDPAE is really the diagnosis that's about the mental health and neurocognitive and neurodevelopmental aspect. And this is probably the diagnosis one, it's pretty can almost be interchanged with what we used to call AR&D. We're now calling it NDPAE. It's the mental health neurocognitive, neurodevelopmental aspect that are associated with prenatal alcohol exposure.

It needs more research because as you'll see, it has many components that overlap with other diagnoses, and we need to get some field trials to really specify this, but it's something that everybody -- clinicians, social workers, case workers, everybody -- they're just going to see more and more of it. And it's going to overtake this particular field.

And it has three components: neurocognitive deficits, behavior regulation problems, and adaptive dysfunction. However, as you'll see, it does overlap with other disorders. But when you drill down and you get down to the specifics of the neurocognitive, behavioral, or adaptive dysfunction, you find that they're different. So, there's a real reason to be aware of this diagnosis, and what the specifics are, and how it differentiates from other disorders, including ASD, ADHD, conduct disorders, and all the other things that are still included in DSM.

So neurocognitively, I'm just going to take memory and learning. Children with (unintelligible) SDs -- or NDPAE I'm going to say -- really have a memory and learning deficits like many other children do, but theirs have a different qualitative aspect in that they can learn things and they learn them really well, and they learn them to criteria, and they've got them, but very soon they lose them again.

For those of you who are familiar with autism, it sounds familiar, losing skills. But this one is very specific in that it's older children. It's not emerging skills like children with autism. It's older children -- the preschooler. It's learning your math skills, learning your addition skills one day and then losing it the next day and having to really start from scratch and relearn it over again, very serious visual motor skills, which we know cascade into things like math skills, greater than, less than, and things like that kind of thing.

The behavior regulation thing, we're going to see and this has a lot of overlap with early trauma -- behavior regulation. And but it's a little more specific in the impulse control and the situations that set it off. So, a child needs a really good behavior regulation evaluation to differentiate what's due to prenatal exposure and what's due to early trauma type of thing.

And adaptive, we know cuts across a lot of disabilities, but if you look at things like communication, it's not learning words, or learning syntax, or grammar, it's more when the child gets older and you're looking at they don't understand figurative language. They don't get the joke, teasing sets them off, and they don't know how to deal with it, and things like that.

So, I know as I'm saying all of these things, you think, "Well, I have all kinds of children that have that problem." For all of those children, prenatal alcohol exposure should be considered. And in the field, we think this is the diagnosis

that is going to come to predominate, and it eventually will have physical features or not physical features. But these are the behavioral things that bring children to light as needing an evaluation -- my computer just went out, sorry -- needing an evaluation or needing treatment and things like that.

So again, the reason we've chosen these two disabilities is that they have an awful lot of overlap. They are disorders that are very prevalent in an out-of-home care situation or child welfare situation. And they are the disabilities that have treatments that can be implemented kind of thing.

(Rebecca Wolf): (Jackie), can you see your slides?

(Jacquelyn Bertrand): I just typed in my...

(Rebecca Wolf): So, the next slide is the prevalence slide.

(Jacquelyn Bertrand): Well, and the thing I wanted to do here is I just showed you a slide that said, FAS is 1 in 167 children, if you look in very special populations, such as foster care, a study that was done out of the National Survey of Child and Adolescent Well-Being or international adoption kinds of things, or another place where we know alcohol is a problem, you'll see all of these special populations have much more prevalent rates of children with FAS. That's the full diagnosis of having the facial features, the growth problem, and the neurodevelopmental problem.

So, you all are on the frontline of encountering a whole lot of children who have this diagnosis or where this diagnosis should be considered, and referral for evaluation and treatment is appropriate.

(Sharon Newburg-Rinn): Could I just interrupt to ask you one thing here? So, you're saying that it wouldn't necessarily be the case that all of the kids who needed to be evaluated further would have all of these facial features, is that right?

(Jacquelyn Bertrand): Correct, and that's back to my iceberg (unintelligible) slide. The facial features is the smallest number of children. The most number of children have the neurodevelopmental problems, and that has to do with the fact that the brain develops throughout pregnancy, and so it's always vulnerable. It's vulnerable for the full 9 months. The face, and the facial features, and the growth are vulnerable either during the first trimester or the very end of the last trimester. So, the brain is always vulnerable and that's where we're going to see it.

(Rebecca Wolf): Okay, thank you, (Jackie). So, I hope you get your computer back on. And meanwhile, I will pick back up with the slides next.

So, we've talked about what developmental disabilities are, how common they are -- especially autism spectrum disorders and fetal alcohol spectrum disorders -- and next we want to talk about how early intervention can make a real difference. And this is why it's important to identify children with developmental disabilities, even subtle ones, early because these services can improve children's skills and outcomes, increase school readiness, and help families.

So, early intervention programs are funded by the Department of Education in every State. They're often referred to as IDEA Part C services or birth to 3 services. It's a little confusing because each State has their own name for their particular program. For example, in Georgia where we are, it's called Babies Can't Wait. But they are available at free or low cost in every State.

And as well, public early intervention services is not the only source of services for children with developmental disabilities. For example, many States have enacted legislation requiring private insurers to cover treatment services for autism spectrum disorder. So, there are other sources. But the birth to 3 programs are usually the first recourse for services for children.

So, birth to 3, but too many are identified late. Most children identified with an autism spectrum disorder had a concern noted in their file before they were 2 years old, but most children with autism spectrum disorder are not identified until after age 4, and often not until they get into kindergarten and enter the school system. And it's the same for children with fetal alcohol spectrum disorder. So, they completely miss the opportunity for early intervention services. And that's what we want to address.

So, early identification, and foster care, and child protective services, this goes back to what (Sharon) was talking about at the beginning, that there's a strong association between childhood disabilities and maltreatment, that children with disabilities are more likely to experience emotional neglect and serious injury or harm than their non-disabled peers. And that prevalence rate of some developmental disabilities -- as we just saw -- are higher in the children served in your program than in the general population.

So, that's why we wanted to talk with you all today because CDC offers resources, and tools, and information that can help you make a difference, that can help you get the children into the services and support they need by encouraging care providers to monitor each child's development and to act right away if there's a concern. And these are the two key things about improving early identification is monitoring every child's development and acting right away.

You and your caseworkers, and if you supervise caseworkers, you come in contact with so many children, that it's really likely that you're seeing some for whom you may already have a concern and not know what to do or not have resources readily available for dealing with that, or there may be other children with such subtle signs of developmental delay that it's hard to notice. But all of these children need your help.

And so the materials that we offer -- that I'm going to cover soon in the next slides -- can help increase families' awareness of early developmental milestones, which is the first step in knowing how to monitor development. You will be able to work with them to monitor their young children's development and encourage families to take action when they are concerned. And by the way, when I talk about parents and families, I mean the full gamut -- birth parents, foster parents, adoptive parents, guardians, and others who are primary care providers for young children.

So, why you? You know I think we may have covered some this already, but you work with these at-risk children and families. You work with the parents, or you supervise those who do, and you have a very influential role with those care providers. You're a trusted source of reliable information. And of course, as we all do, you want the best outcome for each child served by the child welfare system in your State or your region.

So, how exactly are developmental disabilities identified? Well, it's a four-step process that can be complicated or can be straightforward and it varies. But the very first step -- and the one we're going to focus on today -- is the developmental monitoring, and that is most commonly done using a checklist to track a child's developmental milestones. And that's done over time. It's an ongoing process.

Later in early identification, the next step is usually developmental screening. And that usually happens at the doctor's office or another health care provider's office. And standardized screening questionnaires are given at 9, 12, and 24, 30 months as recommended by the American Academy of Pediatrics, as well as autism-specific screening at 18 or 24 months.

And if the child doesn't pass that developmental screen, then usually the physician refers to a specialist for diagnosis, and that's where, unfortunately, the process can easily break down. Because in many communities -- and it maybe most communities -- there are not enough specialists to see all the children in need. And so the waiting periods can be long and very frustrating.

And that's why it's really important to know that you or parents -- again foster, adoptive, birth parents -- can call your local early intervention program and refer the child for an evaluation for services without a diagnosis, without a physician's referral. Any parent, any care provider, can pick up the phone and call their local program, and get the child evaluated.

Okay, so what is it we offer? Well, our whole mission of Learn the Signs. Act Early is to improve early identification like we're talking about. And the way we do this is through three different strategies, through a health education program -- and this is what we're going to be mostly talking about today, our materials and resources that will help you with that developmental monitoring and promoting it with families -- our Act Early initiatives -- which is another broader look at trying to improve communication and coordination among the programs and systems, and you know there are many at the State level that serve young children and care for children with disabilities. And finally, in order to make sure we're doing the best at these efforts that we can, we have research studies and evaluation on projects to support these strategies.

So, what we're trying to do with our health education program is exactly what we're doing right now today is work with programs -- Federal, State, and local partners -- that serve young children, especially low-resource families -- but not only low-resource families -- and to provide these tools and resources to help improve early identification and to ease your burden when you see children with unidentified, potential developmental concerns.

So, this slide is to inspire confidence that others have found the Learn the Signs. Act Early materials and resources useful and have integrated them into their program and are using them. You see here a wide variety, and especially a number of programs that also reach low resource families like (WIC) out of U.S. Department of Agriculture and others here. So, we have worked with a wide variety of these programs, and we are very pleased to be working with you all today.

So, what are these materials I keep talking about? They aid in developmental monitoring. They include developmental milestone checklists. And I'm going to pull those up online and show them to you so you can see exactly what we're talking about. They're tools for providers and parents to use as monitoring tools. They help encourage discussions about children's development between care providers and doctors and others. And they're useful for programs that serve young children.

So, before I show you the checklist, I want to define developmental milestones. Most of you, I'm sure, are very familiar with that term, but not everybody is used to thinking of developmental milestones as some of the more subtle social, emotional, or communication, or cognitive signs. So, things like taking a first step, or smiling for the first time, or waving bye-bye, are commonly understood developmental milestones, things most children can do by a certain age.

But for example, just on the last bullet here, pointing to something interesting, that's a really important developmental milestone, and it's easy to see whether a child has that skill or not, but it's not something that parents often think of as a developmental milestone to look for. And that's where we can help. So, children reach milestones not only in how they move or talk, but also in how they play and learn and act, and all children develop at their own pace, as we know. Most children reach developmental milestones at or about the same age.

So, our materials with developmental milestone checklists are based on research. In fact, the milestone checklists are based on the gold standard milestones from the American Academy of Pediatrics. They're written in plain language, very parent friendly.

They're all in the public domain, totally reproducible; you can make a million copies. There's no copyright. Everything is available in English and Spanish, and you can as soon as we're done, you can go online and print them off. We also offer free hard copies in limited quantities. And it is fair to say that these materials are really popular. So, here are what we're going to be talking about, and here are some quick pictures. And I'm going to go through each of these individually.

First of all, we're going to talk about the milestone checklist. And I know that this is hard to read. So, I'm going to see if this will work and see if I can pull this up online to show you instead the actual PDF. So, we're going to look at the 1-year milestone checklist. Try and make this a little bit easier to see on this screen here.

Okay, your child at 1 year, you see at the top, it has its place for the child's name and age and the date. And then it gives a little definition of developmental milestones and call to action for parents and care providers to check the milestones and then take this list to the doctor's office at every visit, and talk about your child's development, and what to expect next.

So, the idea is these are to be used for all children. They're especially helpful for children for whom you have a developmental concern, but they're useful for all children and should be used for all children. So, then you see on the left-hand column, and the beginning of the right-hand column, the actual milestones -- what most children do at 1 year old. And these are organized by domain: the social-emotional, the language, and the cognitive, and the movement.

So, I'm not going to read all of them, but I'll pull out just a few to show they aren't necessarily what you're used to thinking of as milestones, but they are things that a parent, or a care provider, or in other words a non-expert would easily be able to note, at least for the most part.

So, for example, hand you a book when he wants to hear a story. It's about in the middle of the list of the social-emotional. That's an important social milestone for children at 1 year. Plays games such as peek-a-boo, waves bye-bye, tries to say words you say. Or under cognitive, looks at the picture or the thing when it's named, looks at the right one, bangs two things together. That's a cognitive milestone.

Like I say, it's not what we're used to thinking. It's not like a first step, but it's still a very important developmental milestone. And then the ones we're more familiar with are the movement milestones, for example, you know -- keeping in mind this is for a 1-year-old -- sitting up without help, pulling up to

standing, improving, maybe taking a few steps without holding on, maybe standing alone.

You can see that these are pretty conservative milestones for a 1-year-old. And they're done that way on purpose. So, that's why we say most children by 1 year of age would be able to do these milestones. It may be that a lot of children are walking, but there are some who don't walk by 1 year. So, these are fairly conservative developmental milestones.

Then in the box, act early by talking to your child's doctor. These are red flags or warning signs. And the presence of any of the items in the box is cause for potential concern. So, if a 1-year-old doesn't crawl, doesn't stand up even when helped, doesn't search for things that she sees you hide, doesn't say any single word, doesn't wave or shake his or her head, doesn't point to anything, or loses skills he or she once had, those are warning signs.

And so, if you were using this milestone checklist on a child and you checked one or more of the things in this box, that would mean it's time to talk to the doctor about your child's development. It does warrant calling your State's early intervention program and ask for an evaluation. These are the more significant concerns.

The flip side, going back to the healthy developmental milestones in the other column, if one or two or three of those are missing for a 1-year-old, it's not really a cause for concern. It means you might want to look for them over the next few months and see if those milestones emerge. If a lot of them are missing, then it's worth a conversation with a doctor. But it's the ones in this box on the right that are really flags for concern.

Now I'm going to pull up, just to show you, another example of the 2-year-old milestone checklist, just so you can see them. And we have these available for all the ages of the recommended well-child visits from 2 months through 5 years. So again, you see the healthy developmental milestones on the left, the red flags or warning signs on the right, and here, for the 2-year-old, you see the American Academy of Pediatrics recommends that children be screened for general development and for autism at the 2-year-old visit.

So, that's a message in the monthly checklist as well, and now I'm going to go back to the slides.

So, we look at this online. We look at that. Here is just a little bit more information. These are useful for all children. And it is important to remember that they're not a formal standardized screening tool and they're available in English and Spanish.

And I'm keeping an eye on the time and seeing that we're running just a little bit late. I'm going to see if I can pick up the pace just a little bit.

This is the "Milestone Moments" booklet, and it's one booklet with all the checklists. It includes the full checklist, the warning signs, and red slides, referral information, as well as, parenting tips on development activities that parents and other care providers can use to encourage the development of their children.

So, this is a booklet. It's about 45 pages long. It can be used throughout the children's early - the child's early years.

A printable version is available online, and again, it's available in English and Spanish.

This is - this is kind of a fun growth chart. It's 3 - about 3 feet tall and 1 foot wide, and it has the regular measurements on the left and the milestones on the right.

And the reason I wanted to show you that is because that makes a fun tip for parents to hand out to parents. They - these can come packaged together. "Milestone Moments" booklets are available separately, but a parent kit includes this growth chart and the "Milestone Moments" booklet together, again available in English or Spanish.

The milestones brochure has a few important milestones ages 6 months to 4 years. It is really more for promoting development and monitoring and awareness and encouraging parents to think about tracking developmental milestones.

It does not have the full list of checklists. It can also, like all of these, be printed off the website.

This book is just a little bit different category, but I didn't want to miss the opportunity to mention it. It's called *Amazing Me*. It's written for 3-year-old children. And the main characters you can see on the front cover there is a kangaroo named Joey, who's 3, and he illustrates developmental milestones throughout the course of his day in this children's story.

And the person reading it, the adult reading it to the child, learns therefore, also about developmental milestones. These can be ordered for free. We do allow them in limited quantity.

We can also sell bulk orders if you're interested. So, that was about our materials. I know I went through that a little bit quickly, but they are easy to find and use yourself.

So, how to get them? You can download and print them today. You can order free copies, although we do have some bulk order limits, and you can customize them and take them to a printer yourself locally.

These are all available on our website at cdc.gov/actearly or the Spanish version cdc.gov/pronto. You can email us at actearly@cdc.gov also or call our 800 number.

So, many programs have appreciated being able to take our native electronic files and insert - and take out the CDC contact information and insert their own local community contact - or their own program's contact information and logos.

This is an example of the trifold brochure. You can see that Missouri First Steps and Parents as Teachers cobranding this. So, we provide the files. We can help you with this. You can plug in, or we can help you plug in your logo and phone number and website, then you would take the completed file to your local printer.

And we are more than happy to help you do this. And we have also seen a number of programs who have pooled small amounts of money in order - who work together and have pooled small amounts of money in order to get more advantageous printing prices, and that's pretty effective too.

So, we talked about what resources are available, but how would you actually use them? So, you can print them from - you can print the milestone

checklists, for example, from your computer and make photocopies in black and white would be fine or in color if you can and share them with foster and adoptive and birth parents or other care providers.

You can share any of these things. You can customize them and use them to monitor children's development over time.

Here's just some examples and this is just a, you know, just the barest tip of the iceberg and I'm sure you all will have some ideas yourselves about how to use these materials.

But for example, in California the Cooperative Extension agency is using "Milestone Moments" booklets in their parenting classes. And I think - I'm thinking that some of you may be involved in providing or developing or producing parenting classes, so that's something you could think about of using either the brochures or the booklets or the checklists when you do the - when you're training parents.

Florida Healthy Start gives *Amazing Me* to 3-year-olds in their home visitation programs. If you happen to be seeing 3-year-olds, you can order some of those books and have them handy for when you see those families.

In St. Louis, all the WIC clinics use the milestone checklists at every client visit, so the parent comes in for their WIC appointment, they complete a milestone checklist for the age of their child or their children while they're waiting just a few minutes to see the nutritionist.

The nutritionist goes over the checklist with them and makes an appropriate referral as necessary or appropriate.

And here in Georgia, Fulton County provides the milestones brochure in the waiting rooms. They just have stacks of them in the various health department waiting rooms.

So until now, I'm been talking about what you can do for all children, but suppose that you have in mind right now a child that you're concerned about developmentally and who has not received services or seen a specialist and what might be the best thing to do?

Well, we would suggest that you fill out a milestone checklist for that child. Use the younger age checklist, so if the child is between ages - so for example, if the child is 15 months old, use the 1-year checklist or if the child is - anyway you get - you know what I mean.

Use the younger age checklist if the child is between ages. Use that to - oh document prenatal exposures if you know that there was alcohol in the family or you suspect exposure, document that.

Encourage discussion over the checklist with the child's doctor, whether that's the parent or another - the foster-adoptive or birth parent or another care provider, or even if you have an opportunity to talk to a child's doctor.

Use that milestone checklist as the basis for the conversation. And then consider referring the child to early intervention or your birth to 3 year Part C program for evaluation for services.

And keep in mind a doctor's referral or medical diagnosis is not necessary before contacting your early intervention program or your public school for evaluation for services.

And (Jackie), do you want to talk about the practical suggestions for FASDs?

(Jacquelyn Bertrand): Yeah, and in addition to documenting all the milestones that (Becky) has talked about, we wanted to emphasize that opening a discussion with caregivers regarding prenatal exposure, whether they be foster care, pre-adoptive care, just children monitored by the CPS system kinship care, actually opening that discussion and providing an emphasis for how important that discussion is, is very helpful and that it helps document these exposures in the records.

And that's helpful to people in the system and caseworkers down the line, who are coming in contact with this family and what they need to know. It's also extremely helpful for clinicians and health-care providers as they try to interpret what's going on with the child and what may be appropriate and needed for the child.

And it's also helpful for us trying to document what exposures are going on, through some sort of surveillance system, some sort of system like (Sharon) was talking about early on, that alcohol is very exposed in this population and these children have a very high rate of exposure or alcohol is even involved just in the family situation and that come into play in all of the data systems that are going on.

And we would like to encourage you that if this kind of information and data about exposures is important, that again you talk about it in the exit survey that you'll get.

We'd also like to again, emphasis - just like I said, document those exposures or suspicions of those exposures, because again, it's extremely helpful.

Caseworkers in explaining to parents and caregivers in different situations about how children with this - these disabilities can have a *can't* versus a *won't* experience. Many children with these exposures or even autism spectrum disorders, it's a situation of can't versus they won't, and that's very difficult to tease apart.

And a caseworker or other specialists can be very helpful in explaining that difference in just that "aha" moment kind of thing.

And then, facilitating referrals very often, these are the professionals. They know the other professionals in the field, in the community, and they can facilitate referrals to either diagnostic systems or education systems or even mental health systems.

And (Becky), next slide. At CDC we have lots of information that's not only about - for families of affected children, but also primary prevention. It's always worth reiterating the message that drinking alcohol during pregnancy is not worth the risk and for many child welfare situations you're dealing with adolescents who are coming right up against this issue and letting them know the message of "There is no safe amount of alcohol. There is no safe time to drink alcohol," or "Should avoid other adverse prenatal exposures, such as illicit drugs, misused prescription drugs, and things like that."

So, avoiding prenatal exposure, these are all good things, and this is a - at CDC we have lots of information and materials available to address that.

And (Becky) the next slide.

I also wanted to let you know about some other very concrete resources that everyone could access. There is the National Organization on FAS, nofas.org.

This is an advocacy and information non-profit organization dealing with primary prevention and affected individuals.

They also have a very nice program for persons who - and adolescents in youths and young adults who are already affected and a very nice support group for them and also a support group for mothers.

There is a website for education materials, called "Do to Learn," and they have a specific toolbox for - which has educational materials for individuals affected by FASDs.

And most importantly, the FASD Center of Excellence at the - at samsa.gov. They have a Center of Excellence, and they have a very nice collection of grab-and-go single-page information sheets that deal with all aspects of prenatal exposures, including things about primary preventions, secondary preventions, treatment options, resource options, diagnostic things that parents may want to take to their primary care provider or others.

And then, again the support group for using young adults by SAMHSA is also co-supported by the ARC, and that's one of the - and then the Double ARC has a very nice education program kind of thing.

So, I think we're back to you, (Becky).

(Becky)?

(Rebecca Wolf): Oh, sorry. I've been talking away with my mute on. I apologize.

(Jacquelyn Bertrand): Back to you.

(Rebecca Wolf): Yes, thank you. So, along with all these resources that we've just been talking about, we have actual people who can help you, too. And these are called the ambassadors, the Act Early ambassadors.

And they are community champions who can serve as a State or territory point of contact for you all. And I think I'm going to again go to the real website to show you how you can find them.

So, if we're on the Learn the Signs homepage, we go to the bottom of this purple navigation box and click "About the Program," and we see the purple map and that's where we're going to click.

And the A's in the State means there's an ambassador. So, we can look in Oklahoma, and there's an ambassador, (Bonnie McBride), with her email address.

So, you can find ambassadors this way online and email them, and they can help you implement any of these - use any of these materials or implement this into your program, as we've been talking about.

And here's just the screenshot of that map. So, we've given you quite a bit of information, as you know, when the webinar is done, you're going to hang up and go back to the stack of things that you had to do.

So, what are the first steps that you could take helping families learn the signs and act early and try to improve early identification? So, we wanted to suggest just some simple steps to help move you forward along the line towards improving your late invitation.

And the first one, naturally, would be to go to the website and explore and look at the Immediately Available materials. Print out a sample milestone checklist or milestone brochure, and many of you, I know, are supervisors, share these with your colleagues or your teammates.

If can't - case managers, you might want to share them with your supervisors and talk amongst each other about how to integrate these materials into your work.

Check online, just as I just showed you, to find out if your State has an Act Early ambassador and email that person, if so.

Print and/or customize any of these materials, the checklist, the brochures or the "Milestone Moments" booklet and share them with parents, especially important, share them with foster parents, adoptive parents, and other caregivers.

No one needs to be a child development expert in order to use these materials. They are very parent friendly.

And anytime, email us at actearly@cdc.gov for more information, for access to our electronic files, for bulk orders, for answers, or any kind of help.

So, to wrap up, here are the take home points that we started out with. Developmental disabilities are really common. One in six children overall have a developmental disability. Early identification is super important, can enable these children to reach their full potential by getting the early treatment that they need.

And you have an important role and responsibility in developmental monitoring and early identification, and we here at CDC offer you free resources and tools and people to help.

So, I want to thank you for all your hard work in helping safeguard the healthy growth and development of our nation's children because that is absolutely what we care about, too, and we look forward to helping you.

And thank you for your attention on this webinar and here you see are (Jackie)'s and my email addresses, as well as, our Act Early mailbox.

And now, I think we're ready for questions.

Coordinator: Thank you. If you would like to ask a question, please press *1. At the prompt, please unmute your line and state your name so that I may announce you.

To withdraw your question, please press *2. Once again, if you would like to ask a question, please press *1.

One moment please.

(Tiffany Lewis) your line is open.

(Tiffany Lewis): Hello. My name is (Tiffany Lewis), and I'm calling from the Philadelphia Department of Human Services.

And I think my question may have been a little premature, but when you were talking about these facial features or to the dysfunctions of one that has fetal alcohol syndrome, I was wondering if there was any resource that we could

see something specific to know what to look for or what it would look like if we would come across that and basically investigations of child welfare?

So, if you're going out on an investigation and you don't know what to look for or you don't know what the predisposition of what a family is or you may have heard something, and you want to see it or you can have something to alert yourself.

What is that? What does that actually look like? Like is there something that lets us know what facial features or physical disabilities may look like in someone that has fetal alcohol syndrome?

(Rebecca Wolf): (Jackie)?

(Jacquelyn Bertrand): Yes. Okay, can I answer?

(Rebecca Wolf): Yeah, go ahead.

(Jacquelyn Bertrand): Okay, yes there are three cardinal features, facial features, their facial dysmorphic features that are associated with fetal alcohol syndrome. They're called short palprebal fissures which - that means the eye opening from left to right is small, so it gives the appearance of very wide-spaced eyes.

(Tiffany Lewis): Okay.

(Jacquelyn Bertrand): Also, well that's not the only thing that overlaps with a lot of other things, but also there is called the flat philtrum, that's that little ridge between your nose and your upper lip and you know, it all makes a little...

(Tiffany Lewis): Bridge.

(Jacquelyn Bertrand): Yeah, you - it's a little dip that we all have. Well, if that's very smooth and flat, that's also associated with it.

(Tiffany Lewis): Okay.

(Jacquelyn Bertrand): And you have a very thin upper lip or a very thin - there's something called the vermillion border, and it's hard to describe, but it's that little border between your lip and your upper lip. This is all I can say.

(Tiffany Lewis): Okay.

(Jacquelyn Bertrand): It's thin, and these are all called dysmorphic features, and they're best evaluated by clinical geneticist...

(Tiffany Lewis): Okay.

(Jacquelyn Bertrand): ...because there are lots of other minor anomalies of the face, head, neck, and body that are associated with other genetic disorders. So, you have to have what's called a differential diagnosis, but those are the - how people's smooth philtrum, thin upper lip or the vermillion border, those are the three cardinal features associated with prenatal alcohol exposure.

(Tiffany Lewis): Okay.

(Jacquelyn Bertrand): They're within the - within understanding that there are lots of dysmorphic features that can happen. There are things with the ears. There is the flat face that we all know goes with Down syndrome or epicanthal folds, all of these have to be evaluated together, just like you would want a complete neurodevelopment or neuropsychological...

(Tiffany Lewis): Evaluation. Great.

(Jacquelyn Bertrand): ...that you know. So, but if you see any one of these, yes, it's an absolute tell-tale sign that this child needs a further evaluation, and if you see any dysmorphic feature, what we call the funny-looking kid...

(Tiffany Lewis): Right.

(Jacquelyn Bertrand): ...so, of course, would want to refer that child on for a further evaluation either through a genetics' clinic, a developmental clinic, or whatever is available to your community.

(Tiffany Lewis): Okay.

(Jacquelyn Bertrand): A good question. Thank you very much.

(Tiffany Lewis): Thank you.

(Rebecca Wolf): And this is (Becky) again, just to add a little bit to that...

(Jacquelyn Bertrand): And I know what.

(Rebecca Wolf): As (Jackie) said earlier, not all children...

(Sharon Newburg-Rinn): Yeah, and then at the bottom...

(Jacquelyn Bertrand): Just fall.

(Sharon Newburg-Rinn): ...just say, yeah our total line count.

(Jacquelyn Bertrand): Our...

(Rebecca Wolf): (Sharon) I'm sorry. Just to say not all children who are effected by prenatal alcohol exposure have those obvious facial features, and for other developmental disabilities, you know, there may be nothing you can point to physically in a child and that's why it's important, you know, that's why we would still argue it's important to be checking developmental milestones for all children, because those signs may be subtle.

(Tiffany Lewis): Right.

(Rebecca Wolf): Behavior yes. Alcohol - we have through animal research and neuro-imaging, we know that's really - those facial features occur very early in pregnancy, first - very early in the first trimester, so and the brain is vulnerable throughout pregnancy.

So, you really want to be monitoring all of the behavioral and neurodevelopmental aspects.

(Tiffany Lewis): Okay.

(Rebecca Wolf): No one can see this morphology. You certainly want to refer that child on.

(Jacquelyn Bertrand): Thank you, (Tiffany).

(Tiffany Lewis): Thank you.

(Jacquelyn Bertrand): Good question.

Are there any more questions?

Coordinator: Yes, we have more questions. One moment, please.

(Kimberly Diamond Berry), your line is open.

(Kimberly Diamond Berry): Thank you very much. My name is (Kim Diamond Berry), and I'm from the Early Head Start National Resource Center in ZERO TO THREE.

And I just had a question of - I wondered if you could talk a little bit more about the differences between FASD and ASD, so that children are not continuing to be misdiagnosed because of not being able to differentiate between the two?

(Rebecca Wolf): Well that's - (Kim), that's a difficult question for us to answer, and maybe (Jackie) you might be able to find more information than I can, but what I would really like everybody to think about is just being able to pinpoint potential areas of developmental concern and leaving the differential diagnosis to the medical and psychological and psychiatric and neurologic experts.

(Jacquelyn Bertrand): (Becky), I totally agree. We're on the same page, and the frontline providers should really be focused on any milestone or abnormality. When they get to the clinic, the evaluation clinic, developmental clinic kind of things, yeah, they are going to look more specifically than anyone could ever do at home or do in a primary care setting or doing a child care monitoring system.

So, you're going to see an awful lot of overlap, as (Becky) says, in problems in developmental milestone checklists, in things, you know, that there is a problem.

When they get to the next stage, yes, you are going to see more problems at the secondary level. So at the milestone level, both children, children with ASD and children with FASDs are going to say, "These child - these children have social problems," but when they get to the secondary and the more evaluative clinician, they're going to look deeper and they're going to say, "Oh, the specific social problems they have are different," so children with an autism spectrum disorder, they're not interested in social contact.

Excuse me, I just had to cough. They're not interested, they're having eye-contact problems, they're avoiding social situations, versus children with an FASD, they're interested in the social contact situation, but they don't know how to do it, so they don't know how to slip into it great.

They say inappropriate things with their peers. They make pretty good eye contact, but they just say the wrong thing, once they have - once they've established that contact, versus a child like (Becky) was saying who wanted to bring somebody else's interests into their toy or what they were doing, a child with FASD can do that, but once they do it, they don't know where to go from there.

They have an awful lot of trouble with things like teasing, idioms, figurative speech, jokes, and things, but those kinds of things that develop later on, versus a child with an autism spectrum disorders, you see these kind of problems with establishing, drawing attention, and understanding what somebody else is thinking at a very young age.

So, they both have social problems, but when you get to a deeper level and something that needs more evaluation to tease apart, you do see differences, so I hope that helps.

(Kimberly Diamond Berry): Thank you.

(Rebecca Wolf): Thanks (Kim).

Other questions?

Coordinator: I believe it's (Wendy). Your line is open. There's only one other party in queue. I've opened your line. Please check your mute button and state your name.

(Lynelle): Hi there, can you hear me?

Coordinator: Yes, we can hear you now.

(Lynelle): My name is (Lynelle), and I'm calling from child protective services in New Hampshire.

And my question is, if children are presenting with behavioral difficulties, due to early trauma exposure, would this be treated and addressed differently if the behavior was due to a developmental disability?

(Rebecca Wolf): So when a child enters an early intervention program, they do an evaluation for services, and they address the symptoms.

(Lynelle): Okay.

(Rebecca Wolf): So because - and that happens, until a child gets an actual diagnosis from a specialist. So, what happens first is in treatment the child's symptoms will be addressed, and I guess, they - I guess the etiology of those symptoms isn't taken into account until there is a diagnosis.

(Jacquelyn Bertrand): But once there is a diagnosis, just to build on what (Becky) has just said, once there is a diagnosis, then the treatment plan and planning out in the future will be or should be modified in accordance.

So a child with early trauma -- abuse, neglect, or other early trauma -- is going to have a different trajectory of treatment from a child who has just a prenatal exposure...

(Lynelle): Okay.

(Jacquelyn Bertrand): ...but the same behavior problems which is also different than a child who has both and that's...

(Lynelle): Right.

(Jacquelyn Bertrand): ...a huge amount of child...

(Lynelle): Right.

(Jacquelyn Bertrand): ...such a children that come into care. But, that child who has both, is different even than the child that just had early trauma, so is - there is a cumulative effect going on and that factors into the treatment plan and things like that.

So, knowing the child's prenatal exposure is very important for treatment planning and for diagnosis, and that's why we emphasize documentation.

(Lynelle): Thank you.

(Jacquelyn Bertrand): Thank you.

Coordinator: I'm showing - oh excuse me, one more question just came up. One moment.

(Rick Fuller) your line is open.

(Rick Fuller): This is (Rick Fuller). I'm with the CASA program in Fairfax, Virginia. Can you tell me where this presentation will be posted?

(Rebecca Wolf): (Sharon), are you on the line? It's going to be posted the Children's Bureau site, so I'm talking from CDC, so (Jackie), and I can't answer that, so (Sharon), are you on the line?

If you're speaking, we can't hear you. You're probably on mute.

Sorry, I guess we don't have the answer for that right now.

(Jacquelyn Bertrand): Okay, well we post it on Child Welfare Information Gateway as far as we know, but we can certainly have an email sent out to all the participants that tells them where it will be posted.

And there are...

(Rick Fuller): That would be appreciated. Thanks very much.

(Jacquelyn Bertrand): And we'll take my understanding it takes a couple a weeks, but it will be there.

(Rick Fuller): Okay, thanks.

(Rebecca Wolf): You're welcome.

Coordinator: Excuse me. (Sharon)'s line is open now.

(Sharon Newburg-Rinn): Oh, okay. So, you people can hear me now?

(Rebecca Wolf): Now we can.

(Sharon Newburg-Rinn): Okay, good. I was wondering 'cause I unmuted it, and it didn't seem to do anything. It's my understanding that our ICF colleagues, you know, our contractor is going to make - everybody who registered will be notified when this is posted and that it would available on the Child Welfare Information Gateway, which is run by the Children's Bureau or by a contractor for the Children's Bureau.

But if - I think my name is listed here on the first presentation, and I guess, everybody has a copy of that too and on the last page of that, there is my email address, which is ([Sharon.Newburg-Rinn](mailto:Sharon.Newburg-Rinn@acf.hhs.gov))@acf.hhs.gov.

And so, if anybody is having trouble getting onto that or finding it or you know, and so forth, you can let me know.

And maybe I should get - if I could have control over the screen again, I can put that back up there, so my name will be - my email address will be posted on there.

Could you techy folks give me back control of the screen?

(Rebecca Wolf): I just did. Do you have it?

(Sharon Newburg-Rinn): Yeah.

(Rebecca Wolf): Okay. Good.

(Sharon Newburg-Rinn): Okay. So now hold on. Whoops. Everybody gets to see my entire computer screen.

(Rebecca Wolf): Do you have a lot of files (Sharon)?

(Sharon Newburg-Rinn): Yes, I do. All right. This is what I want to get. Okay. So, that one does not have my email address, but here it is.

That is my email address, and the webinar is going to be posted online and I think, but I'm not sure that if you registered, that you will receive the URL, so that you can review it.

But, if I am wrong, if that doesn't happen, now you know where to find me, and you can harass me about it, and I'll make sure that you get the information that you need.

Coordinator: (Courtney), your line is open.

(Courtney): Hi, I just wanted to know how do we get continuing education units for social workers and substance abuse counselors?

(Sharon Newburg-Rinn): Wow, I don't know. Do we have somebody from ICF on the line about that? (Renee) do you know anything about that?

(Renee): Unfortunately, I do not, but we can find out for you.

(Sharon Newburg-Rinn): Okay, so again, my email address is up there and because we don't know the answer right now, we will, you know, you can email me and tell me you need to know that and I'll see what I can find out.

(Courtney): Thank you.

Coordinator: I'm showing no further questions at this time, ma'am.

(Sharon Newburg-Rinn): Okay, well that's good. Well, let me just back up to this - wait a minute - let me...

(Renee): (Sharon), I have several online, if you'd like...

(Sharon Newburg-Rinn): Oh, you do. Okay. Well, all right, go ahead then.

(Renee): There are a few people that have signed off, so I will try to pick the ones that are still online.

Okay. Can you talk more about the differences between FASD and ASD so children are not misdiagnosed?

(Sharon Newburg-Rinn): Okay, that is going to be something for our CDC colleagues to address.

(Rebecca Wolf): Yeah, and think that's - that (Jackie) did a pretty good job of addressing that. (Jackie) was there anything else you wanted to add?

(Jacquelyn Bertrand): I - the only thing I would add, is that autism-specific spectrum disorders is entirely a mental health disorder. It's entirely described through the American Psychiatric Association, versus FASDs which has a medical component, which has these facial features and growth features and very occasionally, some more organ maldevelopment things, like kidney issues and what not.

But so, I think those are the two big differences that FASDs include these dysmorphic minor facial - just more view, which is minor physical feature anomalies, mostly centered in the face and can - were originally used to describe the disorder by Ken Jones in 1937 versus autism spectrum disorders, which is entirely described by behavior.

That being said, most developmental disorders, because they are developmental and just because of the nature of children, there is a huge overlap that we see in the behaviors at the upper level, the grand - you know, the grand overarching level, we see an over - an awful lot of overlap of behavior disord - behavior prob - of behavior issues at this overarching level.

So, we see social issues. We see adaptive issues. We see neurocognitive problems. We see attention problems over thing - across things like, intellectual disabilities, formerly called mental retardation, autism spectrum disorders, ADHD, and fetal alcohol spectrum disorders at a very general level.

We see an awful lot of overlap. As we get better and better about our neuropsychology or neurocognition or just behavior in general, we're starting to split these things apart behaviorally and neurodevelopmentally, so at a very specific level, we are starting to see differences and those are reflected in the

DSM-5 in lots of criteria that are coming out and will be coming out through the American Academy of Pediatrics, the American Psychiatric Association, the American Psychological - oh I forget their name.

(Rebecca Wolf): Yeah, we know.

(Jacquelyn Bertrand): Another APA, you know, and all of these organizations, so we're getting better and better at defining behavior in neuro-development and more specific levels and as we go forward, we will have better and better answers for you.

(Rebecca Wolf): And I would just like to add onto that, that all that is true. However, no one expects you all, unless you are clinical specialists on the line, but I was not expecting that audience, so no one expects you all to be able to make a diagnosis.

That's the role of specialists. So, in fact, it's probably not even a good idea if you have a develop - a concern about a child's development to speculate about what the diagnosis might be, except in certain rare exceptions, because that's really the realm and the domain of the specialists who are trained to do that.

And parents, including foster parents and adoptive parents, yeah, I mean, it's hard enough to have a conversation that you're concerned about development. Parents may not be receptive in the same conversation to hear someone say, "Well, I think your child has autism," they may or may not, but that can make the conversation that was already difficult, be extremely difficult or end.

So, I would just caution you, I mean, I think it is important to have an awareness of what developmental disabilities are and what some of the symptoms might be, but I think it's important to remember, that the job of diagnosis is really done by the medical and clinical specialists.

(Sharon Newburg-Rinn): And wouldn't say that that's the point of looking at the milestones...

(Rebecca Wolf): Exactly.

(Sharon Newburg-Rinn): 'cause it doesn't tell you really what's wrong, but it gives you a hint that there should be some further evaluation done.

(Rebecca Wolf): Right, and so many children are missed, so that's, I think that's where it's important to put your energies and effort into tracking the development of each child that you - that's in your care and you come in contact with or for those who do that you supervise.

(Jacquelyn Bertrand): And we would agree from the alcohol prospective, talking about alcohol use during pregnancy, talking about other illicit drugs or prescription drug use during pregnancy, that's not the job of the frontline provider, that's the job for someone else, but if you have a suspicion, document it and refer on, saying, "We have reason that this child may need a further evaluation," because asking some of those really, really tough questions, usually takes more time than a frontline worker has time for.

Are we there?

(Rebecca Wolf): All right. Are there any other questions?

(Renee): Yes, there is. I know you say learn the signs early, but is it ever too late if we are dealing with older children, say 10 to 12 years old?

(Rebecca Wolf): No, it is never too late. We don't have, you know, I'm sorry to say, we don't have milestone checklists past age 5, but it is never too late to get a child, no matter what age, services.

Treatment services can help at any age. I mean, we hope that all children would be identified early, but we know that's not the case.

(Jacquelyn Bertrand): And beyond that, we would agree from the prenatal exposure side, identifying a child and documenting that in their record and then getting them into - and having that knowledge, that can sometimes lead to extended education, vocational training.

It may come into play unfortunately, if you're talking about the criminal justice system, all of that is never too late to document, diagnose, or use that information in planning for services or future eventualities.

So, it's never - no, never too late.

(Rebecca Wolf): Never too late.

(Jacquelyn Bertrand): Yeah, and very worthwhile.

(Rebecca Wolf): Other questions?

(Renee): We do have a few more, but the people are not online anymore, so I can send them off to the presenters if I could and maybe get back to them or send them to me and I'll get the answers to them?

(Rebecca Wolf): Sure, because I think we are going a little over time, and I hate to keep people on when they...

Coordinator: You do, excuse me ma'am, you do have one more question in the queue.

(Rebecca Wolf): Okay.

(Jacquelyn Bertrand): Okay.

Coordinator: (Reese), your line is open.

(Angel Reese): Oh actually – hi, my name is (Angel Reese). I'm calling from Children and Family Services.

You actually did touch on part of it, but I was just wondering, is CDC planning on coming out with a milestone checklist for children over the age 5?

(Rebecca Wolf): No, we don't have any immediate plans to do that, and I understand the need, and we wish we could, but we are really trying to heavily push using the Milestone Checklist for starting at the earliest ages.

(Angel Reese): Right. Right.

(Rebecca Wolf): So that's - you know, that's our MO. That's where we are right now.

(Angel Reese): Okay. Okay. Thank you.

(Rebecca Wolf): Thanks, (Angel).

Coordinator: We have no further questions, ma'am.

(Rebecca Wolf): All right. Well, thank you very much. I appreciate and thank you. (Sharon), if you want to wrap up?

(Sharon Newburg-Rinn): Okay, yeah. I think we're finished here. I just want to again really encourage people to do their survey that will pop up at the end, and I especially draw your attention to that last item, number six, that asks if you have any additional comments or suggestions.

And we're especially interested to know if you have ideas for kinds of data or information that you wish you had, that would help you as you work for - with children who have developmental disabilities, and especially fetal alcohol spectrum disorder or ASD or autism spectrum disorder.

So, and it's a very short - the survey that we would like to ask you to fill out. But thank to you everybody and again, I think my email address is still up there. Everybody's free to contact me.

I think I may need to take - clear out a few old emails, so I have some room there to accept new ones.

But, thank you very much to everybody.

Coordinator: Thank you for your participation. Your call has concluded. You may disconnect at this time.

END