Transcription

Media File Name: Introduction to FASD Screening _ Diagnosis.mp3
Media File ID: 2570134
Media Duration: 59:14
Order Number: 1900283
Date Ordered: 2017-05-25

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Megan: Hello, everyone, and welcome to this Ask the Expert Webinar, Introduction to Fetal Alcohol Spectrum Disorder Screening and Diagnosis. I'm Megan Hiltner with the Healthy Start EPIC Center. And on behalf of the EPIC Center and the Division of Healthy Start and Perinatal Services, we welcome you to this event. We have approximately 60 minutes set aside. The webinar is being recorded and the recording, along with the transcript and slides, will be posted to the EPIC Center's website following the event. Before I turn it over to your speakers for today, I have a couple more housekeeping announcements. We do want your participation throughout the webinar. So, if at any point you have a question or comment, please chat them in to the bottom left corner of your screen. We will be taking questions via the chat box at the end of the webinar today, and we do want your feedback on the webinar. So, please take a moment following the event to complete a survey that will pop up on your screen right after it's closed. We hope you did take a moment prior to the webinar to take a pre-test, and at the end of the webinar, you will be asked to complete a post-test survey as well, and that is combined with that feedback survey that will pop up on your screen right after. So, please take a moment and fill that out with any of your questions, comments, and what you've hopefully learned by the end of the event. With that, I'm going to turn it over to Ms. Dawn Levinson, Behavioral Health Advisor to the Division of Healthy Start and Perinatal Services, for a brief welcome and introduction to the webinar. Dawn?

Dawn: Thank you, Megan. Good afternoon, everyone. This is Dawn Levinson, and I am very pleased to welcome you all today to today's webinar. Today's webinar on FASD is part of the bureau's three-year initiative to integrate fetal alcohol spectrum disorder's prevention into the existing training and technical assistance services provided by Healthy Start EPIC Center. The FASD project focuses on increasing knowledge and skills among Healthy Start and Federal Home Visiting grantees with a special emphasis on Native American communities. We place this initiative in the context of Healthy Start's larger umbrella focus on a strategic plan for behavioral health or mental health and substance use issues, and we seek grantee input and feedback on this plan through pulse check questions, discussion groups, advisory groups. And I just thought I'd mention, I'm always happy to take any questions from grantees at any time. So, please consider me a resource for you on all things behavioral health. And without further ado, I will introduce our two speakers, the Health Start EPIC Center's own Janet Van Ness and Hannabah Blue, my partners.

Janet Van Ness is a consultant to JSI and the manager of the Healthy Start EPIC Center's FASD initiative that I just mentioned. As a community health educator, she has devoted much of her career working in the areas of reproductive and maternal and child heath, along with substance use to sort of prevention and treatment. And Hannabah Blue, also a consultant with JSI and a member of the Healthy Start EPIC Center team working on the FASD initiative, she is Navajo or Diné originally from Kirtland, New Mexico and has a breadth of experience working on health and racial justice issues, particularly those affecting native and indigenous communities, LGBTQ populations, and youth. And now I'll turn it over to Hannabah. Thank you.

Hannabah: Thank you so much, Megan and Dawn, and hello, everyone. Again, this is Hannabah Blue, and I am so excited to be here with you today. So, we will be talking about fetal alcohol spectrum disorder screening and diagnosis, but we will also give you some context for this information, and we'll reference information that we shared in the first two webinars that we've done on FASD. These two webinars were on information about FASD 101, as well as screening, recent additional referral to treatment or expert. These are available via our website, but we will also toss them out to you through the course of the webinar. And so to that end, we will be talking about the effects of alcohol on the developing embryo and fetus. We will explain the diagnostic framework for fetal alcohol syndrome and describe the considerations involved in making an appropriate referral for an FAS diagnostic assessment.

And so we first wanna start with why fetal alcohol spectrum disorder, why is this an issue, why are we focusing on this, and how is it an issue. Well, specific to Healthy Start and addressing infant mortality, the risk factors for FASD are drinking alcohol during pregnancy, and so you have to have alcohol and you have to have pregnancy. And so, again, in terms of infant mortality in the United States, as I'm sure all of us know, these are the top five causes of infant mortality in the United States, birth defects, preterm birth, maternal complications, SIDS, and injury. And which of these are affected or can be affected by alcohol use? All of them, right? And so this is really important to the work that we're doing, you know, not just in caring for women, for pregnant women, and for children, but also this specific project where we're focusing on addressing infant mortality.

And one example of where we see this directly is this recent study that came out in 2013 that showed that children of women who were diagnosed with an alcohol disorder during pregnancy or within a year of

giving birth have three times higher risk of dying from SIDS. And so, again, alcohol use can affect all of those leading causes of infant mortality indirectly as well as they're starting to do research in terms of showing it directly, and here's one example in terms of sudden infant death syndrome. And in addition to contributing to infant mortality, prenatal alcohol use also affects children who are born with these effects, and these effects are a range of serious and lifelong problems, including physical, cognitive, behavioral, and social deficits. And we will actually talk about it and reference these throughout this webinar.

And so what is the message that we can give to women about alcohol use? As I said before, there are two components needed for alcohol and for pregnancy, one is alcohol and then the next is a pregnancy. And so prevention rests on reducing alcohol use and reducing unintended pregnancies, which we know is something that's happening in a lot of programs through Healthy Start. And so what the CDC says about this and the message that they'd like to provide people is that there's no...and because there's no known amount of alcohol that is safe for women to use during pregnancy, their official message is that women who are pregnant or who could become pregnant should not consume alcohol. But it's not that easy, right?

And so in terms of the effects of alcohol, alcohol use can affect a lot of different things. It can affect the unintentional injuries, it can affect violence, but also risky sexual behavior such as unprotected sex, sex with multiple partners, and sexual assault. And so that specifically for teens, too, the reducing unintended pregnancies. Healthy Start does a great...all programs do a really great job of working with women to create reproductive life plans, but alcohol use can cause those plans to be thrown out of the window. And so it's important to focus on both of those areas in conjunction, alcohol use as well as working on addressing unintended pregnancies.

And the problem is common, alcohol use during pregnancy. About 50% of non-pregnant women within childbearing ages use alcohol with about 10% of pregnant women reporting use. And a recent study, the same statistics, found that the most common profile of a woman who is using alcohol during pregnancy was the woman who was college-educated, who was employed, and was in her late 30s. And so it really touches so many different aspects and so many different women across spectrums, across life spans, and it just is a common problem that we really need to work on continuing to address.

And so once you have alcohol during pregnancy, once we know that women are using alcohol during pregnancy, how then does it affect the embryo and the developing fetus? Alcohol is a nearly universal solvent, which means that it can readily cross the placenta. There's a common misperception or idea that the placenta can act as a barrier or as a safe cocoon for the baby, but it doesn't. And after it crosses the barrier, fetal liver and organs are unable to fully metabolize or expend or expel the alcohol, and the embryo or fetus is exposed to the same blood alcohol content levels as the mother. Kind of one good opportunity is we know that the exposure of alcohol is also affected by timing, and we'll talk about each of these.

We'll talk about the timing of when women are using alcohol during their pregnancy, the dose in terms of how much they're using, and there's also these other fetal maternal factors. We know a lot of things go into this, a lot of things go into this. Things that are still being studied, things that are still, you know, we're finding out what these effects are. And so, yes, we're still finding out what these effects are, but in terms of the timing, the dose, there's really opportunity there for prevention. Because it's possible that fetal growth and development may be regained if drinking stops at any time during pregnancy as well as it is decreased during pregnancy. And so there's a camp fair [SP] in terms of our program to really work with women as well to stop during pregnancy if they are currently drinking or to reduce their use if they're drinking.

Again, so timing of exposure of alcohol during pregnancy matters. And so there are different periods, as we know, the trimesters within the pregnancy that alcohol use during these different trimesters can have different effects on the fetus or the embryo. And what's interesting, and I'll show you in the next slide, this chart that we have is that alcohol is unique. This chart is a chart that shows the critical periods of human development. So, across the top, you have the age of the embryo, the fetus in weeks, and then from top to bottom, you have the different systems and body parts and body systems of a developing fetus. Alcohol is unique as a teratogen, which is basically something that can affect embryo or fetus during pregnancy, in that it can cause problems through exposure throughout the entire pregnancy. But, again, these different types of effects are different depending on when alcohol is used within these different weeks.

And so, starting on the left... I'm gonna get my little green clicker guy here. There he is. So, starting from the left, and you see these are the weeks that go through from the top, so two weeks, in this period, after

conception, alcohol use can lead to the loss of the embryo, but it is unlikely that prenatal exposure at that time, during the two-week period, would lead to the birth of a child with birth defects and delays from FASD. But after two weeks, you really start seeing alcohol use potentially able to affect all of these different systems moving forward. So, you said about when women typically find out that they're pregnant, and so one of these numbers that they've come out with is between four and five weeks. So, at this point, you can still, between four and five weeks, if women are drinking before they actually find out that they're pregnant, they still may be affecting these different areas, the central nervous system, the heart, the upper limbs, the eyes, the lower limbs, and then the ears. And then as the pregnancy continues, you start having effects on the teeth, the palate, and the external genitalia.

And so, during the 1st trimester, which is the 3rd week to the 9th week after conception, is the time when exposure can lead to significant congenital abnormalities, including brain, heart, eyes, palate, and limbs. And then exposures during the 2nd and 3rd trimesters are less likely to lead to congenital structural anomalies but can lead to effects on the brain. So, brain development continues to be susceptible during this time and remains vulnerable to the effects of alcohol exposure. And the way that these effects on the brain manifest themselves is through growth impairment and those cognitive and behavioral issues that will be...

All right, and so what is the critical period for alcohol exposure? Pregnancy, the whole thing, that's the critical period. Studies have shown that prenatal alcohol exposure can affect the development of the fetus at any point during gestation.

[00:15:25]

[Silence]

[00:15:40]

Okay. And so many times you also hear people say that they do not drink that much or too much during pregnancy. I know that personally. That's something that I heard. I saw it within my family. It's a common statement out there. But how much is too much? I stated before there is no known safe level of alcohol use during pregnancy, and the amount has a dose response rate, which means that the amount of alcohol that a woman uses during pregnancy mattered, in that the more she uses,

the more severe the effects can be, the less she uses, the less it potentially can be, but we know that no use means no effects. And so the higher the blood alcohol content level and the longer the exposure, the greater the alcohol risks in the developing fetus.

So, in terms of prevention, it's important to also address alcohol use to our women of childbearing age, not just because, you know, women may find out late in the pregnancy that they're actually pregnant, but also because one study found that among women who were heavier drinkers during pregnancy or, sorry, before pregnancy, so they were heavier drinkers before pregnancy, they had a harder time stopping once they became pregnant. And so, again, in terms of prevention, working with women who are of childbearing age to stop or reduce the amount of alcohol that they're drinking.

And so babies that are born with the manifestations or the effects of prenatal alcohol exposure, you see these effects, premature birth, birth weight is often reduced, and then limited growth in childhood, but adolescence and adulthood, it's really interesting, sees an increase in obesity, but I think it's that regulation of body mass and those types of effects that develop later on in life. But also a physical malformation as well, such as the facial features that we'll go into a little bit later, but also heart defects and physical anomalies in the ears, liver, eyes. Microcephaly, that we also see in Zika, is the small head size, which can also mean small parts of the brain, which also, again, leads to those cognitive and behavioral problems.

And so all of that, before we even get into the definition of fetal alcohol spectrum disorder, because we wanna give you that context, give you that background and just kind of set the stage for what we're talking about here. And so fetal alcohol spectrum disorder or FASD disorder is actually an umbrella term that describes the range of effects that can result from prenatal alcohol exposure, but it's not a diagnosis, it's not a diagnostic term. FAS, which is fetal alcohol syndrome, is a medical diagnosis, and it falls along the spectrum where you're talking about in terms of the range of effects.

And so here's something of a spectrum that kind of shows the different range of effects. So, on the top, you have FAS, the fetal alcohol syndrome, which is the most common as well as the most severe of the FASDs or the fetal alcohol spectrum disorders. And you can see that if this is on one end of the spectrum with the severity being largest, because it has effects on growth, facial features, and the brain. And then

going down this specific chart, you can see that there are these other diagnoses that have less effects. And so FASD, again, is an umbrella term, it's a spectrum, and then these are the specific diagnoses that include a range of different effects in terms of their severity and what they affect in terms of birth outcome. Also, to put this in context of other birth defects, again, why are we focusing on FASDs, is that here are some, again, some common birth defects. FASD, as you can see in this rate, blows all of these out of the water. It's very common, including FAS, which is less common than autism but more common than these other birth defects that we see. But because of this, FASDs are the largest preventable cause of birth defects and developmental disabilities, because it's 100% preventable, 100% preventable, and this is, again, why we need to focus on this.

And so who within our population is it affecting? The exact numbers of FASD are hard to pin down, and especially for various races and ethnicity. The amounts or the numbers that we have are all estimates from the CDC, and as an estimate, it's also hard to identify sub-populations that are affected, but we know that there are differences between the races and ethnicity, including disparities that we see among minority communities, and in particular, in comparison to population side among American Indians. And so I mentioned this is why we have a specific focus on working with American Indians and tribal communities. But another recent study that came out showed that there's also differences and disparities, children in child welfare. As you can see, really high rates among FAS for children in child welfare as well as all FASDs.

All right. So, again, to give you this background, this context of what we're talking about, we wanted to kind of set you up with this information, and now we'll pass it over to my colleague, Janet, who will give you more information in terms of the diagnostic framework presentation.

Janet: Thanks, Hannabah. Hi, everybody. The first two webinars that we did this year on FASD, following them, we asked people who attended to let us know what additional information would be helpful to them, and besides wanting to know more about the effects of alcohol on the developing embryo and fetus that Hannabah just covered, there was also interest in learning more about how FASDs are diagnosed. My goal today is to give you a little bit of a window on what happens when a referral to a specialist is made for a possible diagnosis for fetal alcohol spectrum disorder, specifically FASD. So, first, I'd like to turn our

attention to the diagnostic framework for fetal alcohol syndrome, and then later I'd like to have us discuss the concerns, and challenges, and other issues that come into play when considering making a referral for an evaluation for FASD.

So, first of all, the impetus as a Healthy Start provider for considering making a referral for diagnosis depends very much on the individual context, but this may include concerns about physical or facial abnormalities, concerns about growth delay, developmental concerns, behavioral concerns, and certainly prenatal alcohol exposure. And there are a lot of points of initiation within our programs, could be a clinician who is concerned, it could be a parent or a foster care provider who raises concerns, it could be a social services provider or educator who also has an insight into possibly spotting a concern. It really is important to have a knowledge of the physical and the neurodevelopmental domains that are critical for an appropriate referral, which is why Hannabah has talked so much about what we see in terms of the effects of alcohol on pregnancy. And also I'm gonna be talking again about the diagnostic process that I think will be helpful to you as providers in Healthy Start to see where diagnosis will lead.

So, there's no one test to diagnose FAS or FASD, and many other disorders can have similar symptoms. And deciding if a child has FAS takes several steps. And evaluation includes a comprehensive history, and that would include exposure history, exposure to alcohol, birth records, growth records, medical records, documentation of birth defects. Clinical interviews certainly would include asking about maternal drinking behavior during clinical interviews, obviously assessing the issues of concern that brought the patient there, and physical assessment. Diagnosis is a medical diagnosis, so diagnosis can only be made by a physician optimally as a member of an interdisciplinary team, pediatric geneticist, a dysmorphologist. There are, you know, physicians who can make this diagnosis but certainly is enhanced when the input and an evaluation by other clinical providers is taken into account.

The Centers for Disease Control has worked with a group of experts and organizations to review their research on FAS and FASD and to develop guidelines for diagnosis. The guidelines were developed for FAS only, so that as I go forward, I'm really gonna be for the most part talking about diagnosing FAS. CDC and its partners are presently working to put together diagnostic criteria for other FASDs, and a lot of progress is being made in this area. And Hannabah made note of alcohol-related

neurodevelopmental disorders and other conditions that are related. So, the clinical and the scientific research on these conditions is going on now.

So, I wanted to just move now to talking about diagnosis of really FAS, what are the diagnostic criteria for FAS. First of all, I'd like to start talking about the physical features, Hannabah has mentioned some of these, but I wanna give a little bit more detail on this. And I actually just skipped a slide, so I wanna go back, sorry about that. And so the three cardinal facial abnormalities that are associated with fetal alcohol syndrome are these. First, the short palpebral fissures, and that's not a term that most of us use, but it's basically the horizontal measurement of the opening of the eyelids. These are smaller, 24 millimeters in an infant is perfectly normal, smaller than that would obviously be an issue. The smooth philtrum, and the philtrum is the vertical groove between the base of the nose and the border of the upper lip. And, you know, if you're sitting at your desk right now and you're gonna just take your index finger and check out your own philtrum, you could feel the vertical groove between the base of the nose and the border of the upper lip. This tends to be flat as a sign. And then a thin upper lip, most clinicians determine this feature subjectively. The height of the upper lip varies among ethnic groups, and it's called the vermilion. And it should be compared to a population of the same ethnic background, but you can see on that image that the upper lip is very, very thin.

So, moving on from the specific facial anomalies, growth deficits. Basically, pre and/or postnatal growth retardation can be an issue, and that would be height and/or weight at or below the 10th percentile. Typically, weight gain remains poor, but it can, as Hannabah mentioned, increase in adolescence and adulthood, and as she also mentioned, obesity is now more common with adolescents with FASDs than in the general population. And the height or weight at below the 10th percentile, it's really at any age, so it's at birth, at any age, and that would be considered a sign unless it can accounted for by an intercurrent illness. Short stature is also part of this, and that typically persists but not always. There are occasional findings. Hannabah went through this list, and I just wanted to put this up there as a reminder. These are occasionally seen in a patient who has FAS, abnormalities of the eye, cleft palate, heart defects, vertebrae scoliosis is often an issue, problems with the kidneys, and neural tube defects, and also issues with limbs, in particular you can often see fusing of the radius and the ulna in the arms, and also the last digits of the fingers can be shorter, and that can be observed.

I don't know why I keep flipping this so rapidly, I apologize. So, again, thinking about physical impact, central nervous system structural abnormalities are also an important sign and thing to be looking for. Hannabah mentioned microcephaly. The central nervous system is made up of the brain and the spinal cord, and so that, when something goes wrong with it, you know, the impact can be enormous. Structural issues, microcephaly, obviously smaller than normal head size for the person's overall height and weight, and, again, that's usually the standards that have been promulgated are at or below the 10th percentile. And also significant changes in the structure of the brain can be observed in brain scans such as MRIs or CAT scans.

Did I once again skip a slide? I apologize. I'm having a little bit of a technical problem here. Okay. That's sort of a rundown on the physical features that we see with an FAS. Then central nervous system abnormalities. I talked already about the structural, literally the structural changes and effects of alcohol. There are also global and functional deficits. So globally the evaluator will be looking for performance below that expected for an individual, age, schooling, or circumstances. This might include developmental delays and in terms of functional delays, cognitive or developmental deficits, motor functioning delays, problems with the nervous system that can't be linked to another cause. They might include poor coordination, poor muscle control, and problems with sucking as a baby. Also delays in walking, gross motor skills, difficulty writing or drawing, fine motor skills, clumsiness, balance problems, tremors, difficulty coordinating hands and fingers, and again poor sucking. Depending on how old the patient is, problems with attention or hyperactivity, and even older issues with executive functioning deficits, poor social skills, language problems, memory deficits. These are just some of the central nervous system abnormalities that can be seen and that are looked for with the diagnosis.

So, the other area obviously for an FAS is we want to evaluate maternal alcohol exposure. Now, confirmed use of alcohol during pregnancy can strengthen the case for FAS diagnosis, but it is not required to make a diagnosis of FAS. It does become more important when considering diagnosing FASDs because of the nuance nature of the symptoms and the facts that many, many symptoms can be related to other conditions. But for FAS diagnosis, it's not one of the essentials for making that diagnosis. So, in terms of reporting exposure to maternal alcohol exposure, a provider would be thinking about confirmed prenatal alcohol exposure or unknown maternal alcohol exposure. In terms of confirming

alcohol exposure, this could be by clinical observation, and positive blood alcohol levels, a self-report, reports by a reliable informant, a history of alcohol treatment, legal or medical problems associated with alcohol use or abuse. And unknown maternal alcohol exposure could be confirmed or can be explained by adoption where there are no prenatal records available, a birth mother who may have an alcohol use disorder but confirmed evidence is lacking, or there may be conflicting reports between reliable informants. Sorry, Megan.

So, as I mentioned, the diagnosis of FASD is it has to be sort of a differential diagnosis assessing physical features, central nervous system abnormalities, and maternal exposure. No single feature of FAS is unique to prenatal alcohol exposure, but what is required for diagnosis of FAS is that all three of the facial features that I mentioned, the eyes, the philtrum, the lip, those do need to be present for a diagnosis of FAS. Growth deficits also have to be documented, and central nervous system problems need to be documented. A person could meet the central nervous system criteria for FAS diagnosis if there's a problem with the brain structure, even if there are no signs of functional problems. But since typically there can be a lot of ambiguity in terms of presenting symptoms and evaluation, and so given the fact that there are a number of other conditions that could present in similar ways, there are environmental factors, there are other syndromes that have similar signs and symptoms, and so a typical case summary has suspicious but often an unconfirmed history of exposure, it can be a bit of a moving target to zero in on this, and that's where the work that's being done right now in terms of better nailing down the features of other FASDs beyond FAS is so important.

Hannabah shared this table which sort of shows this FAS and partial FAS. Those two conditions don't require documentation of maternal alcohol exposure, but the others do. Again, it's because of that ambiguity. No two people with an FASD are exactly alike. They can include physical or intellectual disabilities as well as problems with behavior and learning. The symptoms, as you could see, just even as Hannabah was describing the process prenatally, these symptoms can range from mild to severe, and treatment services for people with FASDs are going to be different for each person depending on those symptoms.

So, I wanna talk for a little bit about providing feedback for families in the face of a diagnosis, and there is no cure for FASDs, but research shows that early intervention treatment services can definitely improve a child's

development, and these services help children from birth to three years of age. Obviously, a lot of these kids are within our population at Healthy Start, so the services include therapy in terms of helping a child to talk, walk, interact with others, and, therefore, the early diagnosis really is the key here. So, in terms of reporting this to a family, in providing emotional support, this can be a devastating diagnosis. It can be, for many, a very fearful diagnosis, and the feedback really needs to move, you know, from outlining what the report is, the results of the evaluation, but also moving on to educating the family about FASDs and on navigating the educational and social services systems that are in place and that are hopefully part of your own referral networks in order to develop a treatment plan for the child.

I did wanna mention here, I don't really have a slide, but there are a number of protective factors that we need to be aware of as we're thinking about this. And first, you know, it's sort of sounding like a broken record, but early diagnosis, a child who's diagnosed at a young age can be placed in appropriate classes, get the social services needed to help early diagnose, help families later, help school staff to understand why the child might act or react differently from other children. Involvement in special education and social services is another protective factor. Children with FASDs have a wide range of behaviors and challenges that might need to be addressed and may need to be addressed in an FASD-informed manner. Loving, nurturing, and stable home environments are also protective, they're protective for everyone, but children with FASDs can be more sensitive than other children to disruptions, to changes in lifestyle or routines, and to harmful relationships. So, having a stable, loving, home life is very important for a child with an FASD. In addition, community and family support can help prevent the secondary conditions such as criminal behavior, unemployment, incomplete education. And absence of violence is another protective factor. People with FASD who live in stable non-abusive households don't become involved in youth violence. They're much less likely to develop secondary conditions than children who have been exposed to violence in their lives.

So, I'm gonna go full circle now. It may seem a little backwards, but when considering a referral for an FASD diagnosis, lack of information about maternal alcohol exposure and difficulty asking questions can often get in the way of early diagnosis. And every single one of these bullets has the tagline, as I go through this, of "Get in the way of early diagnosis." So, I just realized ahead of time that that's where I'm coming from on this, the earlier that an FASD can be diagnosed, the better. But

lack of information about alcohol exposure, difficulty asking, this issue relates to often asking difficult questions is difficult and can be problematic for staff who really feel that they don't necessarily know how to ask the question or may feel that, especially when a participant reminds or says that you're being nosy asking those questions about alcohol.

Fortunately, the screening tools, I think, are a tremendous asset here. There are substance use-related questions in the screening tools and positive results on that mapped to other more in-depth opportunities to screen, and I think this is tremendous advantage within the Healthy Start program that these screening tools are being used. I think to support use of the screening tools, we have on our tentative work plan, because participants in our discussions have asked for more information on assistance of asking those difficult questions, opening up that conversation. Another area for often concern is potential stigma and also potential criminalization. It varies from state to state as to what the reporting requirements are for healthcare providers who are working with an individual who is using alcohol during pregnancy. There's a lot of concern and confusion. This is an area that we are also gonna be addressing in the coming year to help our grantees to better understand that landscape.

The other challenge can be lack of information about where to refer, and this is something that we've learned as we've been talking to grantees. And depending on where you are, there are very often not a lot of resources to make a referral for an assessment. Often, those resources can be miles and miles away from where your participant lives. It definitely is an issue. Particularly, it seems to be an issue in rural areas, but it's definitely of concern. In some cases, referral resources don't seem to be readily available at all. And finally, and I said this is a general point of consideration, and I think one of the things about Healthy Start is that part of what you do is you make connections with community partners. And so the lack of information about services available as a child or an individual receives the diagnosis, I know this is something that grantees are working on constantly, and it's also another area, again, where, going forward with our initiative, we are going to be focusing on helping grantees possibly through community training to create some of those referral linkages with community partners. And we see that as a real positive with the initiative that we're working with right now. Hannabah?

Hannabah: All right, thank you so much, Janet. I'd also thank you all for

your interest in this topic area and your work. Since the start of this initiative, which was the fall of this past year, we've been developing an approach to this topic. We've been engaging with grantees in different ways in really finding out the best way to approach this along with Dawn Levinson, who's on this call, on looking at the behavioral health as a whole. And so we also just wanted to give you some updates about how we can continue this conversation, continue the work in this area, and just some things to look out for as we're all continuing to work on this. And so one of the first things that we wanted to say thank you to the folks who have participated in discussion groups around this topic as well as behavioral health topics. We had discussion groups from March to May where we talked to grantees for tribal, urban, tribal plus native, and those who also work in native communities, urban, rural, border grantees in community health centers.

We had fruitful discussions about the work that's going on in these communities, the issues that are going on, strengths that communities bring, and then as well the differences and commonalities between grantees in addressing this issue. And so we had great fruitful sessions, and you may have seen some emails about continuing these discussions. Many of the discussion groups decided to continue discussing this. It's been an area of interest, and we really appreciate folks and your time and your willingness to do that. And also, again, we've been hearing about the work that people are doing in this area, and we really want to not just find out what the needs are but also highlight what people are doing and be able to do that through also these discussions.

As we noted during these discussion groups, what we also wanna tell you all at this point is that these discussion groups as well as...I'm sure many of you saw the opioid post-chat query that Dawn Levinson sent out to you and then went personally through the project officers to really find out what's going on also with opioid use and meet within your communities. And so, along with that, the discussion groups, we've been pulling together this information to figure out what is gonna be most helpful in terms of our training and technical assistance offering. And so we're at the point where we're pulling those together for these upcoming months and this upcoming great year, and we just ask you to keep an eye out for those topics and those offerings that we'll have in the next few weeks, the next few months that we're excited to roll out to you, again, that are responsive to the feedback that folks gave us about what they're needing, what they're wanting, about different strengths that they also bring from their communities. And so we're excited to bring that to

you, so just keep an eye out for that as it comes through.

Also, just recently, this past week, there was a release, the opioid and behavioral health resources quick start list. It's a new resource that's available to really give a good gamut of information that really is able to address opioid substance use and behavioral health, resources that are available for your programs, and Megan just chatted out the quick start list. So, if you wanna take a look at that, if you haven't seen it yet, please feel free to use it, pass it along as well. If there's anything missing or anything that you think should be added, you know, please let us know. We're always looking to also get more information on new resources to apply to our work as well.

And then finally we are developing an advisory group around these topics who will continue to help inform our work, and our concentration, our approach of these areas. And so if you are interested in serving in an advisory committee capacity, please let us know. We'd love to chat with you. Again, we heard so much great stuff about what people need but also what people are doing in these areas, and we really wanna bring that up as a strength and as things that can be shared across the grantees.

And one last thought, we really appreciate the folks who were able to complete the pre-test. And so we're actually gonna be sending out a post-test after we finish up here. And so if you'll please complete the post-test as well, it would really greatly help us as we are looking at this presentation as well as other presentations that we give and to improve them so that we're meeting our objective for our work and for our knowledge sharing here. All right, so I will pass it back to Megan. Thank you again so much.

Megan: Yeah, great. So, everyone, if you have any questions, or comments, or concerns, the resources that you would be willing to share, please chat them into the chat box in the lower left corner of your screen. We do have about 10 more minutes left for Q&A, so we do hope you would chat any questions or comments in. One question I had for you Hannabah and Janet is, if folks wanna join your advisory groups, how would they sign up?

Hannabah: Please do reach out to myself, Hannabah Blue or Janet Van Ness, and let us know your interest in joining the advisory group, and we will then be in contact with you about the next steps for that. We'd really greatly appreciate your support on that.

Megan: Great. So, if you wanna chat in maybe your email address and Janet's email address into the chat box. And that way, folks, if you wanna be for that advisory group, you can sign up.

Janet: So, this is Janet. I also wanted to add that an advisory group with nothing to do is really boring, so we've got some very exciting initiatives that we are wanting to get the expertise and the input of grantees in a couple of really important ways. One of the things that we will be doing soon starting over the spring and summer is developing an online program, a two-module program on FASD and behavioral health. That will be both a standalone resource for all Healthy Start and Home Visiting programs on this subject, but also we'll provide some supplemental information and support to the community health worker course that I know many of you are familiar with. It was recently launched over the last few months on the Healthy Start website. So, we're very excited about that, and I have personally seen us looking at the development of the community health worker course, how important the input of Healthy Start grantees in making that a tremendous resource, and we are embarking on this new initiative to offer online resources in this area. And so I hope that if any of you are interested in helping us in providing input on that that you will contact Hannabah or myself.

Megan: Thank you, Janet. Just chat it in the link. For those of you that haven't checked out that community health worker course, I just put the general link for the website in the chat box, but you'll be able to just go to the drop-down menu. I'm pretty certain you'll be able to find it there. So, another question that just came in is, can you share some of the themes or other topics that came up in your discussion groups with some of the grantees?

Hannabah: Absolutely. So, we had very fruitful discussions amongst grantees across all levels, and we heard some great things that came out. And so one thing that came out is while alcohol use, you know, may be a problem in communities, right now various groups of grantees in communities are looking also at other substances, I think, big issues in their communities. Opioid use including prescription pills, meth use, marijuana had come up as a big area of interest and need. And so we definitely are taking that into consideration and looking at ways that we can provide information also across substances, you know, how are other substances and what are some emerging things that are coming out about how different substances are affecting pregnancy outcomes.

Another thing that we heard also is root causes of substance use has been a big area that people are interested in, you know, not just at the point where we're seeing that women are using during pregnancy, but also how can we get behind that and what is affecting them, what can we do to affect the things that are affecting them. And we heard that it's a big topic of area, including things like domestic violence, trauma, historical trauma, generational trauma, and just different topics like that and how they kind of fit into each other and what we can do about it.

Another area that we heard about, another big, big area is criminalization consideration of substance use during pregnancy, not just, you know, in terms of fetal alcohol or alcohol use during pregnancy but other substances as well, and the considerations of that, as it may affect women who are afraid to partake in prenatal care, partaking in the program, because they don't want to run the risk of losing children, of being arrested. And, you know, we're hearing that those might be concerns amongst communities in terms of what are the laws in different states, what are the implications, and how is that affecting program participation for a lot of communities. Those are some of the big things I thought of. Janet, anything you'd like to add?

Janet: Yeah, I definitely wanted to just mention high levels of depression, stress, and anxiety, which obviously are factors with substance use, are definitely raised as a challenge in our discussion groups voiced by the folks who've participated in it. Also, you mentioned trauma, but intimate partner violence is certainly an issue. I think that the messaging that's needed around the effects of alcohol use during pregnancy, one of the things that we've been trying to do with these three webinars, and I know you saw it, is to weave in messaging that we think will be helpful to you as Healthy Start grantees. And I think we, in terms of our initiative and in terms of our search for appropriate resources, really need to be thinking a lot more about messaging. And also provider training on this. It's not unusual for, and I would wonder whether any of you had this experience, to hear about providers who when asked by a woman who's pregnant whether a glass of wine every day or a glass of wine a few times a week is "okay" to be reassured that it is. So, we have some provider education to do also.

Hannabah: And one more thing I wanna mention, and this is something, you know, we are being very intentional and really wanna always bring out, is strengths that we see and things that people can also provide to each other in a peer basis and share with each other. So, some of the

strengths we heard are some really great models and referral systems for behavioral health services. There's been some great models that people have shared, some great strategies that people have shared that they've said have worked well in different instances, different cases that we definitely wanna highlight those. Another one that we heard from the native and tribal discussion group was spirituality and culture as a protective factor is something that has been shown to be effective and helpful in promoting health amongst women and children. And so, again, we definitely wanna highlight some of those strengths that we're hearing in different communities and make sure we're keeping those at the forefront, just much as the needs and the challenges.

Megan: Well, that sounds like a great foundation and a point to build so many wonderful training and technical assistance opportunities off of. So, folks, I'm just gonna wrap up now with some really tiny font on this screen for some resources. But all these slides, and the transcript, and the recording of this webinar will be available to everyone. But I wanted to highlight a few resources in the Healthy Start evidence-based practice inventory that's also on the EPIC Center's website that are related to the content shared today. First, there is the American Academy of Pediatrics FASD toolkit. There's a link to that. To your point, Janet, of what you were just mentioning about providers, there's ACOG's FASD prevention program resource listing here as well. There's also an evidence-based practice inventory tip 58, addressing FASD, which advances treatment, invention, and improvement protocol, that's also in the library there. For screening questions, evidence-based screening questions, the TWEAK scale for screening is listed there in the library as well. The two webinars prior to this are both archived. So, if you haven't had a chance and would like to listen or check out the slides from those, I put the links there as well.

And mark your calendars, we do have two webinars scheduled in June. The first is with members of the Healthy Start grantee community. There are gonna be four grantee programs that are gonna share information about six months into the Healthy Start screening tool implementation. They're gonna share best practices, barriers, and resolutions to administering the Healthy Start screening tool. That's June 6th from 3:00 to 4:30 Eastern. And then on June 22nd from 3:00 to 4:30 Eastern is the kickoff for the Healthy Living series. So, mark your calendar for that as well. All these webinars, you can get registered for through the training that goes on the list there, or you can go to the website in the training calendar there. We have a couple minutes, I guess. Are there any closing remarks from any of our presenters, Hannabah, or Janet, or

Dawn, that you would like to share?

Hannabah: This is Hannabah. Again, I just wanna say thank you. We're so excited to bring you this information, but we're here on this initiative as it affects our participants of the programs and just to encourage you to reach out to us and engage with us on these topics as we continue to roll out the different training and technical assistance offerings with any resources that you have, with any questions that you have, and just to just keep us in mind for that. So, again, thank you so much.

Janet: I'm gonna second Hannabah, what she said, and realized we would love to hear from you if you are able to help us as an advisory panel member. But also we really would very much appreciate hearing from you with your ideas and your comments, and any resources that you think might be helpful to your fellow Healthy Start grantees would be enormously helpful. We've already gotten a lot, and we know that there's a lot more out there.

Megan: Great. All right. Well, with that, everyone, thanks again for your participation. This concludes the webinar. Please complete the feedback survey and the post-test. Thanks again.