

REALTIME FILE

AUCD
RESOURCES FOR BUILDING AND STRENGTHENING FASD INITIATIVES

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>> ANNA COSTALAS: Hello and welcome to resources for building and strengthening FASD Initiatives. My name is Anna Costalas, and I'm the resources manager here at AUCD. I'd like to thank you all for joining us today. Before we begin, I'd like to address a few logistical details. First, I'll provide an introduction of our speakers, then there will be time for questions. Because a number of participants are audio lines are muted throughout the webinar. However, you can submit questions at any point during the presentation on your webinar console and the end when we're doing question and answers you can also unmute yourself to ask a question. This entire webinar is being recorded and will be available on AUCD's library, and there will also be a short evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar and also provide suggestions for future topics. I will now pass the microphone to David Deere.

>> DAVID DEERE: Thank you and good afternoon, or good morning, depending on your time zone.

I am David Deere. I've recently retired from the UCEDD and the LEND programs in Arkansas. I'm currently chairing the FASD SIG. I want to welcome you to the first meeting of the SIG, where we hope to serve as a connector for UCEDDs and LENDs to strengthen or to build your programs on FASD. Our dream is forest to become the nation's leader for FASD clinical services, and to be recognized as a significant source for awareness, education, intervention, supports.

I can think of no other group better positioned to fill those roles.

Joining me today in the presentation I have several members of our committee.

I have Elizabeth Cleveland, who is with the Arkansas regional LEND, on the faculty at the University of central Arkansas.

I have Leah Davies, with the Texas center for disabilities studies at the University of Texas.

I have June Malachowski, who is with the Michigan Developmental Disabilities Institute at Wayne State.

I'll mention we have two other members of the steering committee who are not presenting today, and that's Lewis Brasard (phonetic) with the New Hampshire, Maine LEND, and also the Chair of the FASD New Hampshire.

You may be hearing more from Louise in the future. She's getting the affiliates in our states and the UCEDDs and LENDs connected so we can share expertise and resources.

Then the final member, lost but not least, Wendy parent Johnson, the director of the UCEDD at the University of Arizona.

I'll mention this group came together a couple of years ago to put together proposals for the UCEDD annual meeting.

We don't hold ourselves to be the experts in the field, and we've recognized that some of the most accomplished people in the country are at our UCEDDs and in some cases on the webinar today.

We simply want to serve as a catalyst or a broker to connect expertise with those who need it.

We realize most of you have little or no funding dedicated to FASD, which is also true for most of the steering committee.

There are just too few resources available for FASD. It's been disturbing to me to see the decline in funding in federal agencies over the last several years, even as we have increased awareness, just how prevalent this condition is.

But the purpose of the webinar today is to give you some tools to integrate FASD into your existing programming.

We hope that we have things that some of which you can direct people to, some you can plug into what you're doing, or you can get information and build your own expertise at your local level.

We'll have an opportunity to suggest other resources through the chat box and during the discussion period, following the presentation from the steering committee. We're intending to take about the first half hour of the session today.

Then take the last half hour for us to talk about needs that you have in your programs or resources that you may want to share with others. So, Anna, if you would move to the next slide.

I should also mention that you should have received from Jordan a set of handouts.

One of those handouts is the one we're going to go over today.

That's the one that's titled "resources for building and strengthening FASD Initiatives."

The second handout is just something extra for you to have. It actually was developed by the national organization on fetal alcohol syndrome. We went through that and checked all the links to make sure they're still working. If the link wasn't working and we couldn't find one for that resource or organization, we took it off. We did not also check out the telephone numbers and email addresses. I can't vouch for those. But the others should be good. It goes into a lot more detail, but we felt like it would be good to pull out some of the key resources for different areas and different topics of interest within FASD.

That's what we'll be going over today, with the resource titled "resources for building and strengthening FASD Initiatives."

I want to begin by talking about the one document that is still available on the website. They used to have a very robust website with all sorts of resources listed.

They ended their program a few years ago and took everything else off the website.

Tip 58, the treatment and protocol 58 is very comprehensive about building programs and services around FASD.

You should have the link to reach that, if that's an interest you have.

We have some other ways to get general information, if you're wanting to get up to speed.

Several years ago, a few of us put together one of the central LEND neuro developmental disability curriculum resources on FASD.

If you're not familiar with that or part of the LEND, you may not be familiar with it. Check with the LEND program in your state if you want access to it. They have resources on 50 or 60 different topics. One of them is FASD. That is not a pull-the shelf module that you can use with trainees, but it is a collection of resources that you can use to put together a presentation or training materials on FASD.

If you can't find that through your LEND program, you can get in touch with me, and I will make that available to you.

The next thing I want to highlight is fantastic opportunity from the University of Washington where they've trained lots and lots of diagnostic teams. The focus there tends to be on teams that are being trained. They have both online training that is available for relatively little cost, and then they also provide an in-person option. I'm not sure if that's going on right now, although we do have Susan Hemmingway on the webinar today. When we get to the discussion period, if you have questions about that, Susan can help with that. She's the person that's put that together and oversees that. But the option they have in-person, you go to Seattle and participate in their clinic for one or two days.

My understanding of that, they don't charge for that. Of course, there would be the travel cost that would be associated with that.

If I got some of that wrong, Susan can certainly correct me when we get to the discussion period today.

The centers for disease control and prevention have five modules that they have developed.

Those are online training. They're all roughly about an hour or so in length.

They are also free for training and free continuing education for those.

They have one that is sort of an introduction to FASD. It's called the FASD -- for healthcare professionals.

They have one that's a diagnostic overview. There's one implementing screening and brief intervention.

One on preventing alcoholic exposed pregnancies. One on interprofessional collaboration and practice.

Then the last one I want to resource for general training, I want to highlight the University of Missouri who has a set of online modules available. The thing they have that's a little different from the CDC, the CDC's are sort of content-focused.

The University of Missouri has several -- like, there's one for parents, there's one for speech therapists, one for social workers, one for occupational therapists. They cover a number of different health professions that would be working in the arena of FASD., as

well as one on interprofessional care. Their training is also free. If you want continuing education, there is a nominal fee for that, with the Missouri website. Those are some things that sort of getting orientation, getting started, or delving into more deeply into one particular area. There are a lot of other resources that are out there. These are some that we felt like were worth highlighting to you. Hope they might be useful for some of you that are on the webinar today.

Anna, if you would advance to the next slide?

Now we're going to talk a little bit about resources for individuals with FASD and their families.

Again, the University of Missouri, I just mentioned their online training. One of their modules is titled "loving and caring for a person with FASD." Most of the ones they have are geared toward health professionals. That one is geared toward families.

There is also an option for a support group. There are a number of states and local areas that have support groups, but nationally, one that we would recommend to you is from the double arch that's part of the program called a renewed mind, the parent organization for that. They have a national online support group that meets two different times each month. There's two different time options for people there. Fisher coordinates that group. She has worked in the FASD field for couple of decades.

She was very much involved in developing the triumph training materials.

I think Elizabeth is going to mention triumph in just a moment when she goes over her set of resources for educators.

They also have resources for families. That's another place that family members can look.

One other thing that's not on this list, it is on the separate handout we've given you. I'd like for you to be aware of.

The circle of hope. That is a group for birth mothers of children with FASD that is run out of NOFAS. Kathy Mitchell, the vice president there, is the coordinator of that group. She herself is a birth mother and provides some really good supports for that group through the circle of hope. If you go to the NOFAS website, we have links to a number of different programs on their front page. One of those is circle of hope. I'm going to pass it now to Leah to talk about prevention of FASD.

>> LEAH DAVIES: Thank you. Hello everyone. I wanted to echo what David said to start, which is I believe that true experts on the persons with lived experience who have FASD and their family members, several of who I see on the call today. I wanted to give you a shout out. That's part of the SIG. We're excited on a professional level to raise awareness and take on FASD if they aren't already. I want to really strongly encourage all of you who represent either a part of the UCEDD or a LEND to explore working with the families and individuals who might have an FASD themselves in your state, as they are the true knowledge brokers, the best knowledge brokers here. Regarding the prevention of FASD, we have excellent tools available for you, and I encourage you to check them out. First on the list is the CDC. David mentioned them. You can find them easily online, but I particularly want you all to be aware of a couple of modules they have. One is regarding the implementation of alcohol screening and brief intervention, which is one of the evidence-based practices to reduce likelihood that someone would be prenatally to alcohol. Great module, completely free, and free continuing education for health professionals. The second module I want to highlight is

also called preventing alcoholic pregnancies which you'll hear referred to as AEPs. Truck-full of good information. CMEs also for medical providers if that is of interest. We also wanted to draw your attention to the University of Missouri online training around the implementation of alcohol screening and brief intervention, which is targeted also for healthcare approaches. It's great because the training is free. There is however a small charge for continuing education credits, but the module itself is high-quality, dynamic, easy to access, and it would be a good place for you all to think about getting a little initial knowledge around how to potentially provide -- when people -- information they need in order to have healthy pregnancies. The next on the list is the choices model. Choices is actually featured in the national registry of evidence-based practices, the NREP. Specifically targeting the reduction of likelihood of alcoholic pregnancy would occur. Interviewing based model that targets the reduction of alcohol use as well as more consistent use of effective birth control. It's kind of a dual focused, dual prong approach to providing people with options to reduce the likelihood there would be alcohol exposure during pregnancies. Choices is funded by the CDC, so that's relatively easy to access online. The last two bullets on this particular slide are targeting young people. The K-12 FASD education and prevention curriculum was developed by the entity David mentioned earlier, the national organization on fetal alcohol spectrum disorders, NOFAS. It's successful around classrooms around the United States. It's fun, easy, online, four modules, relatively quick access. There is a cost to that one though, just a heads up. A small cost, I believe \$75 for the entire curriculum. The final bullet on this prevention slide is regarding the better safe than sorry curriculum, developed by the national institute on alcohol abuse. It's targeting students but written in a way that is intended to be used across a myriad of ages. It's relatively adaptable, and it's a really good tool. So, that is the message we wanted to give you around prevention. I would encourage everybody in this network conscientious. If a family member has a loved one with an FASD, continuing to give them messages about how to reduce exposure of future or additional pregnancies are amongst people they know is a really great approach to -- in my opinion, it's a human justice approach. Okay. I'll pass this slideshow on to Elizabeth, and we'll talk about things later as well.

>> ELIZABETH CLEVELAND: Thanks, Leah. I'm Elizabeth Cleveland. Speech pathologist by background. Everything else on this presentation is a social worker, so I'm the lone wolf in the speech pathology realm. I'm bringing ray sources today for educators. One of the most common places and most common time periods these kids are being identified is during school. A lot of times, it's in elementary school, sometimes middle school. Of course, there's sometimes identified in high school as well.

We often have parents and caregivers who have a child who has been diagnosed with an FASD say to us, what do we do about it? What's the next step? How do we get the schools to go along with the treatment or the intervention? These are great resources for that. The first one on here, the eight magic keys DVD, found on the NOFAS website. It's about 21 minutes long, and it's about \$20 to purchase. It has eight key strategies that it focuses on, and it's got a little main character in there, Mario, who goes into these scenarios that might happen to a child with an FASD in the elementary or secondary school ages. He literally goes through and finds each of the eight keys, and it gives great perspective for how to approach each scenario to help the child with an FASD be successful. I also would like to say that although each of these are really

great for children and educators of children are FASDs, they can be used in every realm. These are not -- they don't have to be specific to kids with FASDs. They would be beneficial for every realm.

The second bullet here, the triumph educating students with an FAS is what David was mentioning earlier. It's through the double arch. If you go to the double arch's website, which is doublearch.org, and then you can do back slash, triumph/today. You can find this link to this unit. It's a 16-segment online training, and it's for educators and parents.

It gives the tools and techniques that a caregiver or an educator might need to understand FASD and to help provide those important supports for the people who have FASDs. You can purchase all of it. You can purchase all 16 segments, or you can buy each one individually. It's a great resource as well.

The third bullet, students with FASD, simple strategies for behavioral and academic success.

This can be found through the NOFAS website. It's about an hour-long webinar, presented by Deb Evanson (phonetic).

She has been an advocate for people with FASDs for a long time. This would be a really easy video that could be shared with a teacher or a principal or school counselor, something like that. Just to give an overview of some strategies that would be helpful for a child who does have an FASD. This fourth bullet here, do 2 learn, teacher's tool box, can be found on the do 2 learn website, which is the word "do," the number 2, then learn.com.

From a speech language pathologist, this is a fantastic resource. There are thousands of free pages that target various skills, social skills, cognition. There's lots of stuff. There's games on there. Songs.

They have a specific link for some information about FASDs. They have a long list of characteristics, and then a long list of supports that can be implemented for people with FASDs. When I found out about this, I got really happy because we're always looking for new creative things to bring into therapy sessions or to hand out to teachers. You can print these off and hand them to an educator or a parent or caregiver or whomever works or lives with the child with an FASD, and it can be a really fun way to implement strategies that can help them. Finally, this fifth bullet, reach to teach, educating elementary and middle school children with FASD. This is also a great easy to read fun resource for teachers and parents. It's got some great information on it.

It focuses on two different characters. You have Shawna, elementary school aged, and Jesse, middle school aged.

It goes through the scenarios that a child who is of those ages who has an FASD might come across and what the environment around these people can do to help the person be successful.

It's a free resource. I think -- I believe all five of these links are in the handout you were given.

Anyway, that's it for resources for educators. I know there's a ton more out there. These are just five that are quick to get to and easy to use and pretty user-friendly. I think I'm passing it back to Leah now.

>> LEAH DAVIES: Yes. Moving on. Thank you, first of all, Elizabeth. We'll talk about resources for social service providers. As a social worker myself, I can tell you

the information out there that could be relevant or is appropriate for social service providers is wide and deep. There's so much available, but not as much that's targeting social service providers as such. However, I wanted to give you two strong resources on the slide now. You're looking at the names of two research briefs, both -- excuse me. Called issue briefs from the Canada fetal alcohol disorder. The first one called fetal alcohol spectrum disorder and welfare and looking in detail at the experience of persons who have engagement with the child welfare system and have an FASD. You may all already have this information, but I wanted to point out to you that the incidence of FASD estimated to be existing within the child welfare system is significantly higher than in the general population, both for children within the system and also for their caregivers and parents who may have been FASD themselves. It's certainly part of the social sciences that we should be conscientious about and paying attention to. The second bullet available for you, specifically as a resource, is called creating intersections, a staple I can and person-centered harmonizing framework for housing individuals with fetal alcohol spectrum disorder. I will say the services in that part of the world are -- by their nature, more comprehensive when it comes to FASD at this point. I joined David hoping we can become a better resource and a better set of knowledgeable persons for people who have an FASD in their families in the United States as well. But that specific Canada network listed here is specifically focusing on approaches to supportive housing that can work for individuals who have an FASD with the idea that we need to be very intentional about reducing homelessness for this group and increase opportunities for people's wellness as a whole. The other thing I wanted to mention talking about social services and FASD, the fall association of social work, NASW, has quite a few issue briefs themselves, targeted around social welfare in the United States, including child welfare, homelessness, and prevention. That is another set of tools that you all should be aware of.

Pass it back to June to talk about the next section. Not back to June. To June. (Laughter).

>> JUNE MALACHOWSKI: Hi, everyone. Thank you for joining and thank you for having me. I am a social worker by trade as well.

I'm going to talk to you. Criminal justice is really important for a person with FASD in the legal system because there's predisposed involvement, in all types of course, probate, adult, juvenile, perpetrator. The FASD alters the brain function.

Approximately half of the people with FASD will face some legal trouble at some point.

The prison population for the adults has a much higher rate of FASD than the general population.

Children with an FASD are 19 times more likely to be incarcerated than children without it.

By predisposed, I meant they have contributing factors like difficulty for taking consequence of their action and impulse. Easily persuaded by someone. They find it hard to understand the rules. They may not be able to understand the Miranda rights. They may not recognize dangerous people or situations, or not recognize nonverbal cues, or over-react to minor incidents.

For the judicial system, there's no universal screening and assessment tool available at this time.

Which leaves the initial identification in the hands of the judges, the attorneys, the case workers. If they're unaware of the signs, then they don't get a fair chance. However, the American bar association released guidelines that state Courts should be considering FASD disability as a factor in mitigation with juvenile and adult offenders during sentencing. Particularly, when the dealt penalty is an option. They're pushing for anyone facing the death penalty to have an FASD screening.

So, I did want to point out some things that you can do right now for keeping in mind, working with a person who has an FASD.

Use simple and concise short literal terms. Be attentive to nonverbal cues.

Convey to the judicial and larger community for the need for screening and diagnosis and treatment.

There's a couple resources I'm going to point out that I think you have -- they should be in your packet.

The journal of psychology and law, that's an article that discusses how attorneys and judges should respond to fetal alcohol spectrum disorders. That link, I don't know if it was active. I did want to point that out to my panel. (Laughter).

And then the fetal alcohol spectrum disorder injustice is based out of Canada and it's devoted to all aspects of the justice system. They also provide a wide range of services including ways to protect rights of a person with an FASD.

Then the first one is pretty self-explanatory. I'm being mindful of time trying to rush through it.

I'm going to pass it over to the next person.

>> ELIZABETH CLEVELAND: Thanks, June. I think it's me. (Laughter). Yes. I'll do the same thing June just said. I'm not going to go into a lot of detail about any of these professional associations because there's a lot of similarities between them.

Again, the links in the handout should help. I will talk about the importance of professional associations.

You can see here there's four bullets, the American academy of pediatrics, the American college of gynecologists, American academy of family physicians, and midwives. Professional associations. Each of their websites, even if you just Google their websites, you can find information, journal articles related to each of these associations. Many of these associations were created as initiatives to train physicians and other practitioners on prevention and therapy and intervention for people who have FASDs, and of course prevention of FASDs.

I will talk about the American academy of pediatrics because there's an FASD toolkit on their website, specifically. It was created to do just that, to raise awareness and promote surveillance and screening. That is something that is not done regularly in Arkansas. David and I are both from Arkansas. We hope to be able to educate people of all backgrounds and all professions so we can better identify and prevent FASDs, and better help people with FASDs continue to be successful in their lives.

So, these are just four associations. I'd love to come back in a year from now and see other professional associations have FASD programs as well. Who knows where the next year -- if our work continues the way it's going, who knows where the next year will lead us. David? No. You, June? After this? Okay.

>> JUNE MALACHOWSKI: The slides shifted, so I'm not sure --
(No audio)

>> JUNE MALACHOWSKI: So, when supporting someone with an FASD, it's helpful to have the go-to resources.

These websites can be used for your work, for personal use, or those who can benefit. I know the CDC and the NOFAS have gotten many plugs throughout, but it doesn't hurt to hear about it again. The websites on the slide are like a hub of an abundant amount of information in one spot. All offer information I'll discuss. I encourage you to navigate these websites because they may have something more of which you're looking for that I haven't mentioned.

For instance, the CDC, I think this web page is tech logically friendly. It was easy to navigate for me.

It contains things such as the data, statistics, fact sheets, videos, training, education, as mentioned before.

Research articles, so much more. NOFAS, which I'm sure you're heard in this presentation --

Rightfully so. They have a wealth of information within. In addition to what's been mentioned, it includes readily resources from the state. There's local NOFAS affiliates or other resources particularly for your state. It has a resource directly nationally. They have information on living with an FASD, diagnosis information, and treatment and support.

The FAS community resource center, it provides more of a suggestions if a child is suspended from school, or how to deal with it when the person with an FAS says it's not fair, or the parent says it's not fair, why do I have to deal with it. There's suggestions for how to deal with that. There's also a developmental timeline for FASD on this website.

Then there's finally suggestions on how to explain behaviors to other people who do not understand what an FAS behavior would look like. I'll pass the slide to the next person.

>> ANNA COSTALAS: That was the last slide.

>> DAVID DEERE: I muted myself. That is the last slide.

>> JUNE MALACHOWSKI: Oh, okay.

>> DAVID DEERE: Just to wrap up, I hope that this has been useful.

We just hit the high points on several resources. We've left quite a bit out that could have been included.

In fact, I'll give a nod to South Dakota.

We had on the web page for education resources your guide that you have.

I took that off because we were trying to limit the number we were covering today.

Sometimes more is not better. You just get lost in a tidal wave of options.

We took it off because our next webinar is going to be on August 5th, and the topic is supporting student success for students with FASD. Marty Johnson from South Dakota is going to be our presenter for that.

We also will have another webinar scheduled on October 14th.

We have decided not to come up with a topic yet. We wanted to have some conversation today and see what's the greatest need of the SIG.

We have several ideas of things we can plug in, but we want to hear from you.

I'm not sure about how the annual meeting will take place this year, since it's virtual.

Our plan had been to meet at the annual meeting. I'm not sure if the SIGs will have that same option this year.

If they do, we'll meet at that time as well. The webinars we're doing initially at least will sort of follow this format.

We'll begin with some content, then move into a more general discussion.

The last thing I'd like to say before we do open the mic for everyone else is that.

We certainly welcome anyone to be a part of this, including people that are not part of a UCEDD that may not be affiliated with a UCEDD or LEND. As long as their values are in alignment with us.

For instance, we wouldn't really want people part of the SIG who are promoting the message that it's okay to drink when you're pregnant. As long as their values are generally in line with values we find at our UCEDDs, we welcome anyone to be part of the SIG.

And I'll also say, if you're not part of the SIG and you just joined the webinar today, we were glad to have you part of it.

You're welcome to stay on for the discussion. If it's not relevant to you, we also recognize that you may want to jump off the webinar at any time, and you're welcome to do that.

I mentioned the training at the University of Washington. Let me just ask Susan if there's anything you wanted to add to what I said or to correct what I said. (Laughter).

>> Thank you. Actually, you did an excellent job of accurately presenting it.

The FASD Dakota online still exists.

An important component of that online course was, I think, perhaps one of the most meaningful components is typically a team would take that course, complete it, and then sign up to come visit us in clinic. That's something you can't really capture in a video. Team members would join us literally all day and watch two diagnostic evaluations take place, now that they understood how the four-digit code works. COVID days, our clinic was closed down since March. Not being able to do direct contact with patients. I'm proud to say last Friday we did our first ever fully remote diagnosis of a boy on the other side of Washington State, received a partial FAS diagnosis with nobody ever touching anybody. It's not my first preference for how to do it, but as many of you might know, you know, sometimes these kiddos have had a lot of tests, seen by pediatricians. We could accurately render a diagnosis for them. Again, still strong preference for the benefits of a direct evaluation, but we will continue doing this. On June 26, we will reopen clinic for the first time and conduct a partial remote, but in-person evaluation for FASD diagnosis.

All the clinicians instead of being all in one room at one time will each be in separate rooms with laptops and Zoom.

Only the clinicians that need to directly assess the child will have direct contact with the patient, and all the COVID PPE issues and things like that. We're anxious to see how that goes, but I fully expect we will reopen clinic with those two mechanisms for diagnosis.

As David mentioned, some of you have visited the clinic. At any particular clinic, we typically have up to 10 community professional students who are joining us, watching the whole process. That probably will not get reinstated directly for quite some time. We're completely over this COVID outbreak. But I am going to be reopening that via Zoom. Since all of our team members have to Zoom with one another anyway, and Zoom with the family, might as well just let up to 10 community professionals Zoom with

us and watch the whole process. Yeah, we're moving our way towards getting all of this up and going for the future of COVID.

>> DAVID DEERE: Thanks, Susan. We have -- well, for a couple of months I guess we've conducted our assessments through Zoom.

We're discussing that may be an option going forward for the people in the four corners of the state where it's not feasible to make a 9:00 appointment in the central part of the state. When you find out you can do things, you realize you have other options. Like you, it's not ideal, but it's --

>> Better than nothing.

>> DAVID DEERE: Better than nothing. We don't want the perfect to be the enemy of the good.

>> Yeah.

>> DAVID DEERE: Well, great. Let me -- I have some things we can talk about, but what I'd really like to do now is just open the mic for any questions, comments.

Anything anyone has for the group?

>> ELIZABETH CLEVELAND: I want to make a comment about the chat box we're seeing right now. We have gotten some great resources posted on there. Anna, I think you said we could get a copy of the chat after this? Will we be able to download that?

>> ANNA COSTALAS: That is correct. We can go ahead and grab the resources that are in the chat box and add them as a separate document for folks who would like them. There will also be a transcript of the event available on the event page as well for folks.

>> ELIZABETH CLEVELAND: Great. Thank you.

>> DAVID DEERE: Thanks for the awesome support that you give us autos. Shout-out to Jordan and Adrian, staff liaisons for our SIG. They've put a lot of work in. I'll also mention Jordan has just gotten our list up and running. Anyone that wants to join the SIG can do that by going to the list and joining through that mechanism, or they can email me, which is what I've asked people to do until now.

>> One thing I'd like to bring up is throughout this talk, you've mentioned a number of bulleted resources.

I missed the part where -- are all of these posted somewhere on the AUCD site or something like that?

Is there a way for some of us to contribute to it? Over the 30 years we've been doing diagnostic clinic, we have a notebook of over 1,000 different recommendations. They're specific to different age groups and issues with patients that come in, but still, I think a lot of folks might find those resources to be of interest. I must say, you have resources here I haven't seen. (Laughter). You know? That's always the case. We're all reinventing the wheel or inventing it individually. In the absence of the center of excellent, that was a go-to website. It might be interesting if all of these resources could be parked in one place like in AUCD website.

>> DAVID DEERE: Yeah. A web page for the SIG. We can put all of these things there. In the meantime, we can add those to the document we distributed today, and we did have question in the chat box about that. Anna had posted the URL where people -- if they haven't already received the -- we just have the titles up here on the PowerPoint.

We do have a document that had links to each of these that we talked about today.

Then we have the third document, which is the NOFAS document titled "resources for education," but there were a lot of things that applied to both education and to other groups as well that are a part of that. So, those are already available, but yes, we'd love to add anything. Susan, I love your suggestion of tapping into your rich experience that you've done and the things you've collected.

But I think ultimately -- and if there's somebody with expertise in developing websites, we could work with you, but it would be great if somebody offered to step up and offered to make a website for the SIG. This is your group. The people that are presenting today are some of the ones that have done some initial planning, but it's to help all of you to help one another.

>> LEAH DAVIES: In that vein, I wanted to say one more time. For those of you in your respective states are interested in getting something around FASD, I highly encourage you to reach out to try to identify if there are already family groups doing work on FASD. I think we can learn much more from them than they can from us. I see parents on the call I'm familiar with from north Texas FASD group. Generally, it's a good way to start, I think, to get the lived experience at the table. I would also say that there are NOFAS affiliates in every state in the country, and those affiliate entities, if you're not familiar with them, would be good places to initiate contact in your state for some initial stage planning and looking at what's already out there.

>> DAVID DEERE: I'm not sure that every state has an affiliate. Most do, but I think there may be some where there is not an affiliate. But I could be wrong.

>> LEAH DAVIES: You're right. There's a few that probably don't. I'm sorry.

>> JUNE MALACHOWSKI: They can always check the NOFAS website and see if their state pulls up.

>> DAVID DEERE: If there's not one, you can certainly consult with us and with NOFAS about how to get one organized.

>> ELIZABETH CLEVELAND: David, there's also great international affiliates with NOFAS too, and other fetal alcohol spectrum disorder related groups. Leah, you mentioned FAS, but there's NOFAS UK, AU. There's neat things going on in the world. I'm so excited to be a part of this SIG and to see where the states can take this information and learn from each other and be helpful in so many ways.

>> DAVID DEERE: I want to say one other thing about how I feel like whether you know the first thing about FASD, you know disabilities and a lot of resources for disabilities that probably your NOFAS affiliate may not know about. They may have FASD knowledge you don't have, but you have something to bring to the table with them, and they have things they can use to enrich your program. I think there's a lot of value in making those links with one another.

Also, I want to mention that on our steering committee, one of the people that didn't present today, Louise, is a parent of a young man is -- a young adult with an FASD.

Also, I want to give a shout-out to Elizabeth and June, both working on their PhDs and their dissertation has to do with FASD. Elizabeth is looking at FASD and working memory, and June is looking at the criminal justice aspect of FASD.

Did I get those right? Did I get them --

>> ELIZABETH CLEVELAND: Yup. Right for me.

>> DAVID DEERE: So, we're glad to have more people adding to the knowledge base and expanding their skill set.

The people on the call, we've all talked to one another, the people in the steering committee.

What would be helpful to you in a future webinar?

>> Questions I often get from community professionals is they would love to have access to scripts or even videos of how to broach the issue of alcohol use across a whole spectrum of women, from the women who are really struggling with the addictions of alcohol, to the woman who, like most of us, maybe has a glass of wine on occasion and didn't know she was pregnant and drank. How to bring up the topic, much like in the brief interventions that we talk about.

I actually participated, I think it was with the American academy of pediatrics in a small group of people many years ago and created a bit of a webinar with really excellent text that helped -- scripts that helped people know how to respond to the pushback they're going to get, especially when dealing with alcohol is not their area of expertise. I learned the other day that's been lost, the website is gone. Of course, that happens. Does anybody know of any place, a resource for scripts of how to broach the topic of alcohol use and reduction of it during pregnancy for the whole spectrum of women that one might encounter?

>> LEAH DAVIES: Several of the CDC modules have scripts, part of the evidence-based screening models. They don't all include videos, but there are videos out there that I think we could reasonably as a SIG pull together, and I think that's a really smart addition. I'm seeing in the chat box people referencing scripting for how to talk with people who may be receiving an FASD diagnosis. I think that's another topic that makes a lot of sense, and we should give thought to how to support.

>> ELIZABETH CLEVELAND: I also had a thought.

If you're a user of social media, which I am, there are lots of Facebook groups and different various support groups out there.

A lot of them are international. That might be a place we can get more resources or we can send parents and self-advocates, if they need a safe place to have that support. But there's a lot of them. Lots of them are really big too.

I know Arkansas has its own. I know several states have their own. Usually, they're associated with the NOFAS affiliates, but there's some that are just huge in great resources.

>> DAVID DEERE: Great ideas. Anything else anyone has?

Let me just say we do want to continue hearing from you.

As we said, we want this to be your group.

I'm thrilled that you have been part of this today.

One thing I didn't mention when I talked about recruiting membership and reaching out to people, even outside the AUCD network.

I've contacted the center directors and LEND directors who did not have someone that was on the SIG already.

I sent that out yesterday. I've heard from a number of them already.

I don't want to give the impression there's only one SIG member per UCEDD or per LEND.

You can have 10 if you have people that are interested. There's no limit.

We're hoping to have at least one from each program. That's sort of a dream or a goal we have.

So, I'd like to remind you that -- again, on August 5th, we will have our next webinar. That will be on supporting student success.

Marty Johnson Martin from South Dakota.

With that, I think we've come to the top of the hour. If anyone else has anything we need to hear before we adjourn --

>> David, this is Michael. Hey. This is Mike Thornton from Arkansas. My Zoom decided to crash.

>> DAVID DEERE: (Laughter). That happens.

>> The thing I'd like to see -- the topic I'd like to see is how self-advocates can help in forming bonds in the FASD community.

You know, I've attended some of the FASD clinics. I'm learning I can always learn more.

>> DAVID DEERE: Yeah. Mike is a member of the LEND program, faculty member of the LEND program here in Arkansas. He's our family advocacy faculty person.

>> ELIZABETH CLEVELAND: Self-advocacy.

>> DAVID DEERE: I'm sorry, yes. My brain and mouth often disconnect. Thank you for the correction.

He's been a valuable part of the LEND program for several years. That's a great suggestion, Mike.

>> Thank you.

>> JUNE MALACHOWSKI: The two really good ideas for another webinar -- they're in the chat box.

I don't want them to go unnoticed. The FASD prevention interventions in American/Indian populations. I think that's a great one. FASD suicide prevention and intervention strategies.

>> DAVID DEERE: Thanks for calling those to our attention. We will review everything in the chat box more closely, and we'll certainly consider all that's there. Welcome hearing more from you in the future.

Anything else we need to hear from Anna or Jordan?

>> ANNA COSTALAS: This is Anna. Thank you all for presenting. Thank you all for attending. This webinar has been recorded. It will be archived and ready on AUCD's event webinar library. I'm putting the link in the chat box. Also, if you can take a few minutes to complete our survey. That's a good place to put future webinar topics. (Laughter).

So, I hope you all have a great rest of the week. Please be safe. We look forward to seeing you soon.

Take care.

>> DAVID DEERE: Goodbye everyone.