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Early Identification of Developmental Disabilities in Child Welfare - Practical Tools

Presenters: Sharon Newburg-Rinn, coordinator; Rebecca Wolf, CDC; Jacquelyn Bertrand, CDC

Joe Bock: [00:00:05] Hi, everybody, it's Joe, welcome to January's E-Lunch. I want to thank Sharon Newburg-Rinn for all of her diligence and hard work in arranging this, and I particularly want to thank our colleagues from CDC for their willingness to do this for us, and without further ado, I will turn it over to Sharon.

Sharon Newburg-Rinn: [00:00:25] Okay. Well, we've sent out the presentation that our CDC colleagues sent us, and also -- I don't know if everybody has it or not -- but this morning I also sent out a little blurb kind of explaining to you why you should care about this, or what's important about it for the field of child welfare. And our CDC colleagues, Jacquelyn Bertrand and Rebecca Wolf, who are from the Division of Birth Defects and Developmental Disabilities at CDC are going to be talking about fetal alcohol spectrum disorder, and also about autism spectrum disorder. And both of these are important to us in the child welfare field.

When you have issues like these, they can have serious consequences for the children who come in contact with the Child Welfare System, and it's important for them to be detected early. And I'm not going to go into more detail on that, but I'm going to just turn it over to Jacquelyn Bertrand and Rebecca Wolf. So you folks can go ahead, okay?

Rebecca Wolf: [00:01:35] Okay, thanks very much Sharon. This is Becky Wolf, and I really want to thank you all for the opportunity to present to you today. I also want to mention that on Line 2 are Camille Smith and Nancy Cheal, who will be available to answer questions that you might have at the end, and also to help us with some discussion. So I'm going to start us off, and Jackie Bertrand will speak as well during the presentation.

I do hope to leave some time, and I don't think we'll take much more than half an hour, maybe forty minutes. So I'm hoping that we can have some good discussion at the end, because we are really interested to hear you all's reaction to what we're going to be talking about. So please keep that in mind as we go through, and even take notes or comments as you see the materials we're going to be talking about, and please feel free to voice your opinions at the end. Because in the long run, that's what's really helpful for us.

So I'm starting out with telling you the four most important things that I'm going to be covering. Developmental disabilities are really common, and early identification of those developmental disabilities is extremely important. All early childhood providers play an important role in developmental monitoring and early identification, and we offer resources and tools, and even people to help you with that.

And just a note as I go through these slides -- we're used to talking about parents in the traditional sense, but when I say "parents" I also mean to include foster parents and adoptive parents and guardians, and other caregivers as well.

Developmental disabilities are really common, more common than most people are aware of. One in six children in the United States has a developmental disability; so when you think about

it, your providers are seeing a lot of kids with developmental disabilities. One in eighty-eight has an autism spectrum disorder.

And Jackie is going to talk about fetal alcohol spectrum disorder prevalence.

Jacquelyn Bertrand: [00:03:44] Yes. Fetal alcohol spectrum disorders, like autism spectrum disorders, it is a variety of disorders that are talked about under the spectrum umbrellas. So like autism spectrum disorders you have autistic disorder, you have pervasive developmental delay or a disorder not otherwise specified, you have Asperger's. So you have this collection, and we call them autism spectrum disorders.

The same thing goes on with fetal alcohol spectrum disorders. It's a variety of specific diagnoses collected under a single umbrella, each with their own specifications and level of involvement of the different systems. But if you look across that spectrum, our newest numbers sort of seem to indicate that 1 in 167 children have one of these fetal alcohol spectrum disorders.

And we tend to think of them in terms of an iceberg, in that historically mostly we've talked about the most involved aspect of fetal alcohol spectrum disorders, that is fetal alcohol syndrome itself -- FAS -- and that's characterized by four diagnostic criteria.

You have some facial dysmorphia, minor facial anomaly, like small eye openings; a smooth philtrum, which is that little ridge under your nose; or thin upper lips. And those are kind of the characteristic facial features, although some others may appear.

There's growth deficiencies -- either prenatally, postnatally, or both; there's CNS involvement -- that's functional CNS problems such as low IQ, attention deficit disorders, executive functioning problems, some social interaction problems and things like that -- and there's a wide variety of those CNS problems depending on when prenatally the child was exposed to alcohol and how much alcohol he or she was exposed to; and then finally we like to document the history of prenatal alcohol exposure, because that's really important. Because many of the functional things we talk about overlap with many other behavior disorders, such as contact disorder and oppositional defiance disorders -- those disorders that are very related to early trauma, early disruptive caregiving environments -- again, the children that are in your system.

Partial FAS or PFAS -- there's a few more of those. Those are kids that don't have all of the facial features but may have some of them; they may or may not have growth deficiencies; they may have some mild or partial problems with CNS; and then we have alcohol related birth defects -- those are children that had major organ defects, such as kidney problems, heart problems, lung, those kinds of things; and then I've included this term called FAE, or fetal alcohol effects, and that's an older term that sort of encompassed everything but FAS.

But historically, people hear about fetal alcohol syndrome and they think it's very rare, but that's really just the tip of the iceberg. Most of what we are encountering and learning about these days are that big piece of the iceberg under the water, which are these other diagnoses under the umbrella, especially alcohol related neurodevelopmental disorder.

[Note: The iceberg image in the slide is representative of the fact that more children suffer from FASD than is seen or recognized.]

Also, our estimates would get higher as children get older because more of these CNS and functional problems come online, and you see many more mental health problems and some of the higher-order cognitive problems like math disabilities come in.

And the news gets even worse if you start thinking about how many children are exposed but don't actually show up in the clinical setting and aren't meeting criteria to receive service and things like that. Because 12-percent of women continue to drink during pregnancy. And depending on how you do the math, if you look at which denominator you take -- if you take the number of pregnant women or the number of births in a year in this country, that could mean up to half a million children each year prenatally exposed to alcohol and at risk for one of these fetal alcohol spectrum disorders.

So it's really a bigger problem than we've realized, and it's a problem that very much interacts with the foster care and adoptive care system.

Becky, can we go to the next slide?

And this just kind of shows some of these special populations that are particularly vulnerable and we see particularly high numbered, including the U.S. Foster Care System. There was a study done in Washington state that documented 1 in 66 children having one of the fetal alcohol spectrum disorders, and in particular FAS, because they focused on facial features and photographs to first identify the children.

Studies that look at children in Russian orphanages, again, a very high number, 1 in 66, and we have Dashi here who lives in Atlanta, and she is from a Russian orphanage and has fetal alcohol syndrome along with her brother from the same orphanage; but you see an adorable child there, but a child that needs a lot of help and has come to the Foster Adoptive Care.

We see a lot of children running into problems and showing up in the Juvenile Justice System, so they've calculated about 1 in 100 children; South Africa, which has a very high incidents rate because of the wine producing there, and historically workers being paid in wine, and alcohol is just a very prevalent problem there, so 1 in 33 children.

Native Americans, we hear a lot about Native Americans having fetal alcohol syndrome. I got, when I looked at the literature, 1 in 300 to 500 children, depending on which Native American population, but that's probably not the most accurate estimate. But you can see in these, there are populations that are particularly vulnerable, and foster adoptive care is one of them.

Is there another slide, Becky, for me?

Rebecca: [00:10:06] No, I think that was it. So thanks, Jackie. And as Jackie has alluded to, we can probably expect even higher rates of developmental disabilities in children in foster care protective services than in the general population. And as we know, and it's no surprise, children with developmental problems are at increased risk for poorer outcomes, including poorer school performance as well as overall health status. And we also know that children from low-income or minority families can experience longer delays in receiving services. So early intervention makes a difference. And the studies referenced here focus primarily on autism spectrum disorders, but I think the principle hold -- early treatment can improve skills and outcomes for children in

preschool readiness, help families; services are provided that you all probably know by the local IDEA Part C Program publicly, they can also be covered by insurance in some states.

But too many children don't have the opportunity to get those early intervention services because they're identified too late. Again, talking about autism spectrum disorders, most children identified later with an ASD had a developmental concern documented in their records before they were 2 years old, but the diagnosis was not often made until after age 4; and many children with fetal alcohol spectrum disorders are not identified until school age, and that's if they're identified at all. So when that happens, I'm missing the opportunity for early intervention.

There are many paths to early identification and diagnosis. And the first step in identifying potential disabilities is to be aware of healthy developmental milestones, to know what they are, and to know that it's important to be looking for them.

So developmental monitoring, using checklists to track a child's developmental milestones, is an easy thing for parents and providers to do, and that's what we focus on, and I'll spend more time talking about it.

There's also a formalized developmental screening recommended by the American Academy of Pediatrics at these ages you see on the slide; of course physicians can refer children and families to specialists for their evaluation; and what a lot of parents don't know is that parents themselves can call their local early intervention program directly, as can other providers.

So then, moving to talk about "Learn the Signs. Act Early." which is one of the programs that we represent. And the goal of "Learn the Signs. Act Early." is to improve early identification of autism, fetal alcohol spectrum disorders and other development disabilities, so children and families can get the services and support that they need.

There are three components to the "Learn the Signs" program; I'm going to talk about each one of these, but I'm going to spend most of the time on the Health Education Campaign -- that's the first component; the second is the Act Early Initiative; and then we also have research studies and evaluation projects going on to support the first two.

So component one, the Health Education Campaign, aims to change perceptions about the importance of identifying developmental concerns early, and give professionals and parents the tools to help. We are specifically targeting underserved populations by working with other federal, state, and local programs that serve young children and their parents. And we are working to build relationships with programs just like yours, that have an interest or mandate in child development, but not necessarily the resources to address tracking developmental milestones or encouraging early action. So with this strategy, we believe we are significantly increasing our reach with target populations.

So just a second on Campaign Impact -- we have some data that show we've had a positive impact with pediatricians, and we believe that we have helped to change how child development is viewed now, in the seven years since the "Learn the Signs. Act Early." campaign was launched.

But one more word about Impact is that, really, none of us expects printed materials which we offer and promote, to change behavior by themselves. We know awareness of the importance of

identification is still an important issue to be working on, but awareness alone isn't enough to affect that behavior change. So we're addressing that with our implementation approach, and that is to work with federal, state, and local partners to integrate "Learn the Sign's" messages and materials into day-to-day operations of a wide variety of programs.

We believe that our resources can actually solve a problem that many early childhood providers face in many circumstances. It can be difficult for a provider who has a developmental concern about a child to bring that up with a family; having that conversation based on an objective checklist -- like I'll be showing you in a minute -- can be much easier. And we've found in WIC clinics that using "Learn the Signs" materials actually solved that problem for the WIC staff. They were able to show the parent the basis of their concern and recommend next steps appropriately, instead of having what could be interpreted as a purely subjective conversation.

So using our materials on a routine basis for every child made that process a whole lot easier, and on this slide you can see just some of the problems that we have been working with.

So you've heard me mention about the materials, we offer free materials that can be downloaded and printed or copied online, they're very easy to access; we have milestone checklists and booklets and brochures, and a broad variety of other resources. Providers and parents can easily use them as monitoring tools, and they encourage parent/provider dialogue; and as I've been saying, they are useful for any program that serves young children.

All the materials are customizable, they are research-based, and the milestone checklists are based on the Gold Standard Milestone List from the American Academy of Pediatrics. They're all written in plain language, and as you would expect, there are no copyright issues to using them. They're available in English and Spanish, and a few of the things are available in some other languages as well. And you can download and print them readily, and it is a true statement that they have been very popular. And here you see our website and our email box, and I'll give that to you again, too.

So here are four of our most popular materials, and I'll talk very briefly about each one of these to give you a better idea of what we have to offer; and so I'd just like to ask you as we're going through them to think about if these might fit, if they might be useful for your program or your providers. And if so, how; and if not, how might we adapt them.

So to start off with, there's the single-page milestone checklists. As you see, there are lists of developmental milestones for each of the four domains; in the purple box there are warning signs or red flags of particular note for parents and providers to pay attention to, and also referral information.

[Note: The document on the slide is an example of a milestone checklist. The checklist details the types of activities a child should be able to complete at a certain age. For example, at age 2 your child should be able to point to things or pictures when they are named, and say sentences with 2 to 4 words.]

The milestone checklists are NOT -- I should make the point -- a formal validated screening tool. They are for developmental monitoring, but they're not a standardized screener. They are

available online for ages 2 months to 5 years, and they are especially helpful for stimulating dialogue between parents and the child's doctor or healthcare provider.

The next thing I want to talk about is the milestones brochures. This is a single sheet that's a trifold. On the left you see the front cover, and then opened out what it looks like with this kind of gameboard scheme. This has a few milestones for ages 6 months to 4 years. This is really more for building awareness than developmental monitoring, and so it's easily used at conferences and health fairs or in information packets, etc.

[Note: The photo on the slide is a gameboard that depicts a child's developmental milestones.]

And then our most comprehensive product is the Milestone Moments booklet. This is about 40 pages long, it includes all the milestone checklists as well as more, so let me go to the next slide so you can see what an inside spread looks like. There's the milestone checklists on the left -- this is page 2 of the 6-month checklist, with the cognitive developmental milestones and the movement developmental milestones; on the right are parenting tips for age 6 months -- there are things that parents can do to help their child's development; and then at the bottom are the warning signs -- these are the same as on the individual milestone checklist sheet, as well as referral information.

So this booklet is great for developmental monitoring, it's something that a parent could keep from birth through 5 years for their child, but it can also be a great supplement to developmental screening for parents. So some programs who regularly do developmental screening, using ASQ or some other tool, have been handing these Milestone Moments booklets out to parents as part of the process.

And then our fourth product I want to talk about is something that's just kind of fun, it's a growth chart. It's about 3 feet tall and 1 foot wide -- you see the full image on the left there, and then a close-up on the middle -- it has the traditional height measurements on the left, and then matched with those are developmental milestones along with a place for a photo. So this is kind of a fun thing for parents to put on the wall, or for providers to put on the wall in their office to raise awareness about developmental milestones.

And we do combine those last two items -- the growth chart and the Milestone Moments booklet -- into an individual parent kit. It can be ordered in English or Spanish, so it's kind of nice for individual parents to obtain.

We have some other materials as well, I'm not going to go through all of them, but it's kind of fun to talk about our children's book. It's aimed at 3 year-olds, it's a children's story featuring Joey, a 3 year-old kangaroo who goes through his typical day. And as he does, he illustrates developmental milestones which are called out for parents at the bottom of the page. And then in the back of the book, there's a parent section with a full 3 year-old milestone checklist, parenting tips, and what to do for referral information. We have a limited number of these, but they are available for order on our website.

And soon, not quite ready yet, but very soon, we'll have a fotonovela targeted to primarily Spanish-speaking parents and providers; it's in English and Spanish, and it focuses on the importance of acting early when there's a concern. It's called "It's Better to Know."

We have some condition-specific fact sheets, a developmental screening fact sheet, resource list, and lots of outreach materials including flyers for conferences as well as online tools.

So we offer all these things, and then you're probably wondering: well, how is one supposed to get them. On our website -- and here again you see our website address, and I know this will be archived online afterwards, too, so hopefully you'll always be able to find it. You see the purple navigation box on the left -- Free Materials -- and that's how you can find them for downloading and ordering.

We do limit the number of copies that can be ordered for free, but we also recommended and can help you with customizing the materials. And this is something very popular to do, and we think it serves families and providers well when materials can be customized with state or local contact and referral information, rather than sending everyone to the CDC 1-800 number, which is not quite as useful.

So we make this very easy for you. We can provide print-ready files of any of these materials, as they are in InDesign format which is an Adobe product. And you can plug in your logos and contact information; or if that's difficult, we can do that for you actually, and then send you the completed file. And then in that case you will need to take the files to your local printer. And if you'd like to do this we would love to help and you can email us at this address.

So on that previous slide there was an example of the milestones brochure that was customized; and here's an example of the Milestone Moments booklet, you can see Wisconsin information on the back page.

And Jackie, did you want to talk about the fetal alcohol syndrome materials?

Jacquelyn: [00:26:45] Yes. I just wanted to let people know that there are a variety of materials on fetal alcohol spectrum disorders and prevention of alcohol exposed pregnancies that are available, also free of charge from CDC; and you go to the CDC website, http://www.cdc.gov/fasd, and order those materials; you can call our CDC info line; or if you want a large number of materials you can contact our communications person, Elizabeth Dang, and there's her email there; and there's just a variety of things you get. Including posters, brochures, tip sheets, stories of children and families who are living with FASD; and right there in the middle you see our new mobile app on prevention and information about FASD. So that's accessible, too. Again, at our website. So, Becky?

Rebecca: [00:28:11] Great. Thanks. One other thing to mention, we do have training available online on autism. It was developed by a big collaborative group of people – both CDC, HRSA, Yale, and a large number of authors -- developed originally as a curriculum for residency training for future pediatricians, and then subsequently adapted into continuing education modules that can be taken individually online. So there are two versions: the classroom version, and the online modules for a continuing education version.

Both include videos, handouts, and lots of resources; and on this slide you can see the topics that are covered in this training course. So this also is a great resource with the prevalence numbers unfortunately increasing, as they are in the 1 in 88 children with an autism spectrum disorder,

more and more people are finding it very helpful to learn more about autism. So I just wanted to let you know that this resource is available.

[Note: The slide briefly details the Autism Case Training curriculum.]

So that was all talking about our Component 1, the Health Education Campaign of Learn the Signs, and I'm just going to talk really briefly on the other two components.

So the Act Early Initiative is in collaboration with the Health Resources and Services Administration, the Association of Maternal and Child Health Programs, and the Association of University Centers on Disabilities, and the point is to improve collaboration among early childhood programs at the state level.

As I'm sure you all know, there are many and very complex funding streams at the state and local level, and when we began this in 2008, not all of the folks in those various programs were used to talking to each other or working together. So we convened regional summits and brought together teams of early childhood leaders representing those programs in each of the states, and they developed state plans for improving early identification of autism and other developmental disabilities, and since then we have continued to fund them with small state systems grants and Act Early Ambassadors, which I'll also talk about in a second.

The results of those regional summits have been pretty positive. We interviewed the state team leads from those teams, and most of them felt that as a result they had improved early identification in their state and they had strengthened partnerships and built new [ones]. They were mostly focusing on education and training, public awareness, and policy change, and they do continue to meet even now, a couple of years later.

I especially wanted to talk about Act Early Ambassadors, because this is a resource that may be useful to you all. These are community champions at the state levels, individuals who receive a really tiny stipend -- they get about 4 thousand dollars a year, so they're not in it for the money -- but they're very impassioned about improving early identification in their state. They support the work of the Act Early state teams that I was just talking about, and they also use and promote the Autism Case Training.

And their contact information is available online; we don't have ambassadors in every state, but between the Act Early team leads and the ambassadors, we have all the states and territories covered. So you can find their contact information on our website, it's not exactly as intuitive as we would like; but on the map, if you click on the links that I have highlighted in red here or circled in red, you can find the names and email addresses for all the ambassadors and the state team leaders. So think of them as a resource.

[Note: A CDC Ambassador is an employee of the CDC whose sole purpose and responsibility is to disseminate critical informational to the masses and spread the word about specific topics.]

And then these are just a few examples of what some states have done with the "Learn the Signs" materials as a result of the Act Early Initiative, and they are quite varied as you can see. Working through home visiting and birthing hospitals and childcare centers and Head Start; and Alaska actually uses their vital records list and mails "Learn the Signs" materials to all new parents. So there's a variety of ways these materials are being used.

And then finally Component 3: research studies and evaluation projects. We're always trying to figure out how we can do this better and how we can better tailor our materials to reach our specific audiences, especially special populations; how we can better improve collaboration across state systems; and also how we can better improve campaign strategies. What are the best, most feasible, least resource-intensive strategies for incorporating "Learn the Signs" messages and materials, and enhancing that developmental monitoring leading to early identification?

So that brings me back, and this is the next to last slide with the take-home points that I showed you at the beginning and just want to highlight again that developmental disabilities are very common; early identification is really important; and all our lay childhood providers play a role. And we have people and materials to help.

So Jackie and I, and also Camille and Nancy are happy to answer any questions; and like I said to start off with, we're really interested in your reactions to these materials, and if you can see your programs or your providers using them, how might they; and if not, what are the barriers? And that would be really helpful to us. So I'll stop talking now and hear from you all.

Operator: [00:35:11] If you'd like to ask a question please press Star 1, please unmute your phone, record your name clearly when prompted; your name is required to introduce your question. Once again, to ask a question please press Star 1, and please stand by for any questions.

Sharon: [00:35:32] This is Sharon. Do I have to press Star 1 here, can you hear me?

Rebecca: [00:35:35] This is Becky, I can hear you...

Sharon: [00:35:37] Okay. Well, let me-- I don't want to prevent anybody else from speaking, but I had a couple of questions. On your slide earlier, where you talked about ways to identify potential developmental disabilities, and you were talking that parents could call to get more information. But I wasn't clear on- that's a little bit too vague advice for me. I'm not sure what I would be saying to the regions, or what advice the regional staff should give to the specific social workers in the states about how to figure out where to call to get information. Would you have advice on that?

Rebecca: [00:36:13] Yes, and that is a harder question to answer than it ought to be. Every state has a publically-funded early intervention program that is charged with conducting an evaluation of a child to see if they are eligible for early intervention services.

The problem is, those programs go by a different name in every state. And most people have never heard the term "early intervention program," or "Part C program," which is also called after the section name of the law that established it.

So some states have 211 numbers sponsored by United Way; some states have their own Child Find numbers, which is also part of that same Part C program -- it's a very difficult call to action message, and it's actually something that we're working on, trying to refine.

But it is true that any parent can call their own state Early Intervention Program and ask for an assessment without having to be referred by a healthcare provider.

And Camille, I don't know you want to just say something to add to that about where families should call if they have a concern.

Camille Smith: [00:37:23] I think our -- I hope you can hear me -- primary call to action messages have been to encourage families to either talk with their healthcare provider and/or the early intervention/early education systems. Whoever within their community provides that additional support for families.

As Becky mentioned, it's different from state to state in terms of the eligibility criteria, of which who is actually eligible for early intervention, but it is part of the individual to fill these education acts that all children can receive an evaluation to see if they're eligible for service.

Rebecca: [00:38:04] This is Becky again. If you remember, I was talking about customizing the Learn the Signs materials. And that's why that's so helpful for parents. Because if a program -- and there are some states that are already doing this -- wants to use the materials, then it's really helpful to have their own state's contact information on the piece of paper or the product, whichever thing is being used.

Sharon: [00:38:30] I wonder if you have materials that you've helped the state create that you might see, or the state might will willing to share with us so we could what that looks like.

Rebecca: [00:38:41] Yes, there are several examples. And let me -- so I'm going to escape out of this and let's see if I can get back to this other -- yeah, here I am, anyway. Let me go back up, if I can just navigate here for a second and find the pictures of this... I may have gone by it. Yeah, here we go...

Here's an example of the trifold brochure, this is showing just the front and the back of the brochure that Missouri has used. And so you see in the middle, it's actually the back panel, the middle of the back panel, the Missouri First Steps Early Intervention -- that is the name of Missouri's early intervention program. And so they have a couple of different -- which actually isn't always optimal -- but they have a couple of different phone numbers there for parents or providers to call for help. Parents and teachers in Missouri First Steps.

So that's one example; and then here's another example on the Milestone Moments booklet which shows the back panel on the left, and you can see that Wisconsin has put their contact information -- actually it's their logos on the booklet. Does that answer your question, Sharon?

Sharon: [00:39:13] I guess partially it does; now who would you typically work with in the state to produce one of these.

Rebecca: [00:39:21] Honestly, whoever is interested in working with us. So it's been a wide variety of programs. It's been Head Start, it's been WIC, it's been Home Visiting, Child Care and others.

Sharon: [00:39:42] Okay. So if people in the regional offices who are on the phone today wanted to give some advice to the states for which they are responsible, what would you suggest that they do as a first step to getting the ball rolling on producing something like this that's co-branded. Call you? Or...

Rebecca: [00:40:08] One thing that might be helpful -- and I'm just offering it out there -- is if one of the regional directors is interested in doing that, we would be more than happy to do this same kind of presentation for that group of states.

Another option is just to work directly with the folks in the state through the regional administrator... there's a number of ways we can do it. But I think it might help if the state directors had a chance to see -- I mean, people need to understand the need for it. So if we had an opportunity to do this same kind of presentation for the state directors that would be great; and if not, we are happy to work however you like.

Gail Collins: [00:41:12] Hi, this is Gail Collins with the Children's Bureau, we've just been sort of trying to think, as, you know, I think there are any number of opportunities from-- there's a lot of steps between us and families in terms of layers in organizations, as we deal primarily with states and tribal agencies, and then they contract with people and then have individual-- anyway.

In terms of our policy framework, there are any number of kind of cross references. There's things in CAPTA that relate to making referrals to the Part B agency; there's requirements I think it's working to do about addressing the developmental needs of children under the age of 5; so I think we could probably approach it in a few different ways; and certainly we could add a resource kind of thing to our next guidance to the states in terms of IV-B; I think we could highlight this maybe through CB Express, which is an online newsletter that goes through our Gateway, or...

Joe Bock: [00:42:10] Yes, I asked them to do an entire issue on any kids' developmental needs and I'll screen it [unclear].

Gail: [00:42:31] So that would be great; and like my colleague Catherine Keith was just saying to get to the foster parents to try to tailor something to them, I think the question is how best to do that [fades out].

Catherine: [00:42:41] I wonder how much if you has something that was customized that says: meeting the developmental needs of your child and your foster child, how much that would help even foster parents think about their important role as doing that work; and if we have materials for them, I know some of them are at least able to navigate the Internet and try and find resources like that, and if that would create a higher level where they would actually be able to get to those resources and be able to utilize them.

Rebecca: [00:43:12] Yes, I think that sounds like a good idea. The truth is, we don't understand your programs well enough to really be able to say: how can these things best be used. I mean, it would be great if we could talk further about some other opportunities, just like the issue of the CB Express or whatever, about how...

But it seems to me it could be valuable for individual case workers, I mean, even down at that level, to have this kind of information to provide to parents. Foster parents, adoptive parents.

Joe: [00:43:53] Right, this is Joe. I was thinking we could approach it from the perspective of both CAPTA and IV-B required... stuffs related to meeting kids' development needs, and hear from a training perspective for workers, a training perspective for foster and adoptive parents, doing assessments for workers around case planning...

So kind of like: here's how you can build in these components into your compliance with this requirement across a number of aspects of your system. So if we could put something together like that, it certainly could be a big part of it.

Rebecca: [00:44:39] That sounds wonderful.

Operator: [00:44:47] We do have a question online if you're ready to take that.

Rebecca: [00:44:50] Yes, go ahead.

Operator: [00] Pat, your line is open.

Pat: [00:44:54] Yes, hi. I'm Pat, I work out in the regional office in San Francisco. And I don't really have a question, other than it was a question mostly for the Children's Bureau staff or for us internally, and I've liked the discussion around how to kind of move some of these forward. So I think those are some good ideas that Gail, and Catherine, Joe, you're talking about; and I would add in there the CBCAP folks or the CBCAP piece of things. I know they do the peer-to-peer, or I don't know. They sort of do some peer kind of calls that maybe our CDC colleagues could do a presentation on one of those calls, because it does seem like it's very useful information, and it would be useful information for folks to have.

So my initial question was really around where can we go from here with this. I didn't have any questions for the CDC colleagues. Thank you.

Gail: [00:45:59] I think to our very prevention related things of Prevention Month. [very soft]

Speaker: What are you saying? Gail's talking. (laughs)

Gail: [00:46:05] I'm sorry. I think certainly Pat was referencing our CBCAP, which is focused on child abuse prevention, and is our most prevention oriented type program; but also April is Child Abuse Prevention Month and there's always a resource guide that goes with that... that's not saying child abuse prevention can be in the top majority. But it has a lot of positive parenting kinds of aspects to it. So I think building in some of this in terms of the resources that are distributed, the context would be in April Prevention Month things.

I think there's a lot of different angles, it's just figuring out how to make the leap from the federal level; because we're different from say Head Start, which funds more direct grantees who serve children, because states... but then contact with various providers, and then who have -- there's just lots of-- sort of often more layers between us and the people actually doing direct care or direct services.

Rebecca: [00:47:09] Yeah, I see; which does make it more complicated.

Catherine: [00:47:13] This is Catherine. But I think one of the benefits of the resources that you have is that you can use it based on the child's age and be able to take a snapshot picture, which I think is really critical; and I know that also the court improvement has done some work around looking at documents that you can give judges to be able to make assessments about developmental capacities of children who are coming into their courtroom, and I think that's really helpful and recognizes the fact that many of our children are very mobile; so you don't

have that perspective of being able to look over time at the improvement of the child, but in fact you really and see where they're at the time that they come into your home or purview.

Rebecca: [00:47:56] Yes, an interesting point. Makes sense.

Operator: We have another question, if you're ready.

Rebecca: Sure.

Operator: Jack, your line is open.

Jack: [00:48:10] Hi, this is Jack Beniston [ph] calling from North Carolina. A question about how this fits in with what we've been learning about trauma, for example, both in terms of screening and assessment, and in terms of treatment; and if it's possible, how could CB help states make sense of this latest information so that it doesn't come at them like the flavor of the month, but so that it's a logical piece, and build upon other information and expectations that have been delivered to them recently.

So what I'm thinking is the children who are experiencing fetal alcohol spectrum may also be experiencing trauma, and may also have autism. Or two of the three, or just one of the three, and so how do you screen for all that; and what are the priorities and how do you treat differently, depending on which two of the three that they have. Those are sort of the questions that are bubbling around in my head.

Jacquelyn: [00:49:26] Becky, do you want me to answer that?

Rebecca: Yes, go ahead, Jackie.

Jacquelyn: [00:49:31] That is an important question and it is one that really bogs down clinicians and researchers. How do you differentiate these etiologies for behavior problems and for cognitive learning problems, so you're right, that's an important question. And one of the big things to do is document, document, document. Document what happened to the child, and also documenting prenatal exposure. So that you can start to look at the different threads with any particular child.

And so that's one of our emphases, is that documenting what traumas have happened to the child at what age, but also documenting what prenatal exposures are there; and then using materials like Learn the Sign's two documents, behaviors, and developmental milestones, and how the child is developing. So that a provider or a clinician can start looking at the threads of a particular child and start pulling them apart.

Research is advancing greatly in that area right now, and we're starting to learn that children who have early trauma, abuse, and neglect with prenatal alcohol exposures, you'll see a slightly different neurobiological profile of those children, versus children who had those adverse early effects but without the prenatal exposure kinds of things.

So we're getting better at it. We don't have a definitive list of: if you see this, this and this, it's got to be due only to early trauma; and if you've got this, this and this, it's due only to prenatal exposures; and then we know many, many children have both.

But it is important to document things and then thread through them, and research is getting better and better. So keeping up with webinars like this where we can go through those different behavioral phenotypes and discuss them and learn about them is extremely important. But nobody is saying that any one of these things happens in isolation. So... that helps.

Camille: [00:51:48] And I just want to reiterate something that Becky said earlier, too, is that bringing it back to Learn the Signs, back to early materials. I just strongly want to emphasize that they're not designed to replace any kind of a formal validated developmental screen, or evaluation, or assessment of the diagnosis. The purpose of them is to create an awareness about the importance of paying attention to developmental milestones, and then the importance of monitoring and tracking.

Because we really found that if a family has kind of a good understanding or at least somewhat of an understanding of what that typical developmental trajectory looks like, then they can either validate that their child is doing this kind on the right path, or if they have a concern, then they can-- well, what we have heard from some of our evaluation and research is that it makes it easier for a provider to have a conversation with the family about that concern, and they're more likely to refer, and to go and try to get an in-depth evaluation in the hopes of getting treatment and service.

So again, the materials are not a screening tool, they're a monitoring tool.

Charlene: [00:53:17] Hi. This is Charlene, PA in the central office. And I just wanted to say this was really informative, thank you. And to also thank you for underscoring the importance of documenting children's exposures to various risk factors, and that sometimes there can be more than one reason for the child's developmental delay.

As I was listening to the presentation, a couple of years ago I worked in the New York City Family Court, and there was sort of a movement that really was gaining momentum. Our office is nonprofit, and the primary goal was really to I guess reeducate people about fetal alcohol syndrome disorder, and essentially their objective was to sort of inform people that the number of developmental delays that had been attributed to fetal alcohol syndrome disorder were actually less than it should have been.

So as I looked at your slide with the numbers, the statistics of children in foster care, for instance, or Russian orphanages, or South Africa, I wonder how these numbers were tracked, and that's why I think it's important that you said it's important to document. But I wonder how the children were tracked. How the numbers were tracked. If you could provide some information of where the numbers were...

Jacquelyn: Where they came from?

Charlene: ...came from. Exactly.

Jacquelyn: [00:55:06] Okay. Unfortunately, they came from a variety of methodologies. And their methodology for tracking children with these disorders, *and* our understanding of the disorders, so our diagnostic capabilities and case definition capabilities are really quite evolving right now.

For both the first one, where 1 in 167 children for the entire spectrum, that's through a system called In School Studies, that's four pilot studies that were done where they went into first grade and they looked at all the children in first grade, or all the children that agreed to participate. And they looked at their facial features, their growth parameters, and collected information from the parents about exposure, and then some basic CNS kinds of things.

And that's the same methodology that they used in South Africa and the Russian orphanages. By the way, that number I had there for Russian orphanages is just for children with full FAS. Not the entire spectrum.

Another way of doing it, and a way we typically at the CDC did it with young infants, children very near birth, under the age of 5, was looking at records. Hospital records, birth records, specialty clinics, developmental clinic records, and trying to abstract the information back out. And what we found is that a lot of the information you needed was not documented; even though the child had been through many social services, they just weren't documenting that there was evidence of mom drinking during pregnancy and things like that. And they weren't documenting whether the child was meeting their early milestones and keeping track of that across case records. So it makes it very difficult to do surveillance when information is not documented in the records and do that kind of record review.

The U.S. Foster Care done in Washington state -- Washington state has a passport program where every child coming into the system, a judicial photograph is taken, and a particular researcher who is quite good at working with photographs looked at the photographs for evidence of FAS facial features, also went through their other records looking for information about growth and CNS problems, and had done a lot of in-service education with child foster care workers and case workers about documenting prenatal exposure. So that's how that one was done.

The Native Americans -- which my numbers are wrong here, don't go by those numbers, I'll fix them in the final slide presentation -- that was done through a combination of looking at clinics, looking at records, looking at Indian health service clinics and things like that. I'm not sure which Juvenile Justice program I'm citing here so I'm not going to talk about what their methodologies are.

So unfortunately we do have a variety of methodologies, but what we do know from these more systematic studies *and* our clinical wisdom of working with these populations is that foster care, Juvenile Justice, some native population are very vulnerable and you see very high incidents. And I'm not surprised at your experience in a Juvenile Justice or a court system. So I hope that answers your question.

Charlene: It does. Thank you.

Rebecca: Are there other questions?

Operator: We have a question online from Tracy; Tracy, your line's open.

Tracy: [00:59:05] This is Tracy in Region 4. And I really had a comment about several states in our region, two in particular, that are feeling fairly overwhelmed with the number of FASD cases that they're coming into contact [with] and ask us... specifically with the reauthorization of

CAPTA and the attention being paid to those cases, and a lot of concern about: what do we do about these children now that we've become... the awareness is heightened.

So the tools that you've shown today I think are really exciting, that it's just something we can present to states about something that we can offer them that's off-the-shelf, if you will, that's useful, that they can offer to their staff to use. And I think oftentimes that... you talk about families, that they can really start to track their kids and do something about it; but there's not a lot that we offer foster parents. That they're the ones that have contact with these kids.

We talk about services and what services to get to them, but don't offer a lot in the field about how to empower foster parents. So I see these tools as something to hand a foster parent to empower them, and to provide them with dialogue.

And also, passports, health passports are something that is utilized in the field a lot, and this is such a nice piece that can be part of a health passport; that oftentimes information is lost as kids change homes so frequently... these tools are really nice just to add to passports that may already be out there in the field. I see it as very exciting.

Rebecca: [01:01:03] Thank you. And I think that's a great idea of incorporating... I'm thinking of the Milestone Moments booklet in particular, the one that has all the checklists and parenting tips from the past 5 years would be great to go in that health passport.

Tracy: Absolutely.

Jacquelyn: [01:01:20] And I think it's a great idea that we develop some information directly for parents that can go out with caseworkers and go to the parents about resources and specific tips. There's the National Organization on FAS called NOFAS, and they have a website, http://www.nofas.org/, and they have lots of information that's very specific about parenting techniques and an awful lot of support in support groups just for foster care parents.

Their group is really... while it's made up of both birth parents *and* foster parents, they have a large proportion that are raising foster children and adoptive children. So they're a great resource in getting that information out to parents and caseworkers. I think it's very, very important. And I'll see if I can add that into slides, also.

Sharon: [01:02:14] This is Sharon again. I really appreciate your thinking of adding that, because I think that could be a very good resource, a very good starting point for some people to try to get...

Jacquelyn: [01:02:24] And there is recognition that parenting children with FASD is different than parenting other children. I've worked in clinics, and I see many foster parents come through when we're doing a diagnostic evaluation and hear: well, I've raised ten other foster children and I never had this problem before; all my parenting techniques worked before, they're not working this time. Which is a big clue to us.

So when foster parents tell you that, it's real. And NOFAS has lots of tips for how to parent differently, they call it, and things like that, and support groups and all of that. So we can certainly get that kind of information out to where it's needed.

Rebecca: [01:03:17] Sharon? This is Becky. I don't know if there are any more questions. But I know we're pretty well past the hour. We are, yes. I don't know, I didn't want to shut off the conversation if somebody was asking more questions. But I haven't heard anybody speak up and say they had another question, so does this mean we're finished for the day? Or does anybody want to say any famous last words?

Jacquelyn: [01:03:46] Well, we want to say thank you... thank you very much for listening to us, and the great discussion afterwards. We really appreciate it.

Sharon: [01:03:56] And we all appreciate the work you've done in preparing for this, and your challenge with all of the technical complications that we've had in working it out. So, okay, that's great. And I think we've got some directions to go and a lot of information that we can use. So we appreciate it. Thank you, everybody.

[multiple "thank yous"]

[End webinar]