

Education Development Center | Developmental_Surveillance_Screening_and_Linkages_to_Services_3_0

Welcome, everybody. My name is Sherrie Rudick, and I'll be facilitating this webinar for the HV-ImpACT today. We'll get started in just four and a half minutes. People are still logging in now. We've got about 67 people on the line. And we've got a little over 100 or more registered, so we'll give people a couple more minutes to find the phone number and find the link and join us.

But welcome to today's webinar on developmental surveillance, screening, and linkages to services. You're in our lobby right now. And we'll get started in about three minutes now. I have 1:57, and we'll start promptly at 2 o'clock.

Welcome, everybody. We're up to 76 people, so lots of people joining. And today's webinar is on developmental surveillance, screening, and linkages to services. It's an hour and a half webinar. We'll start in, I suppose, three minutes-- maybe two and a half-- at two o'clock, and we'll end at 3:30 today.

This is our October webinar-- the October webinar, brought to you by the HV-ImpACT. And today's webinar is on developmental surveillance, screening, and linkages to services. OK, I'm down to two minutes. It's 1:58.

If you're just joining us, welcome. My name is Sherrie Rudick. I'm the product coordinator for the HV-ImpACT. And I'll be introducing the webinar and introducing our distinguished guest speaker. And we'll be getting started in just a couple of minutes.

I notice that-- I'm going to go through some logistics as we get started-- but I notice that everybody is already comfortable with the chat box. So Cathy King says hello, everybody. And [? LeCharica ?] King-- so the two Kings here-- are giving us some greetings.

And our numbers are growing. We are up to 92 people. It's 1:59, and we'll officially get started in a minute. And if anybody else would like to say hello in the chat, the chat is in its usual place on the left, and you can add your greetings to the two that we already have.

OK, I'm glad I gave that idea, because I see at least two people now typing. Oh, and now it's multiple attendees are typing. So I'm going to tell everybody that we have a chat in just a minute, but I know that you all have discovered it already. And we've got a lot of hello's coming through. OK.

And not only do we have hello's from one person, but we're starting to know where people are saying hello from. And we got a hello from Debbie Delaney, who says that not only is she there, but Paula Dye is there. OK. The country is roaming. We've got Nevada, Indianapolis, Louisiana.

And it is 2:00. So I will formally launch this monthly webinar. And here we are. So here it is. Lots of greetings.

Welcome, everybody. In case you haven't heard me already say it, my name is Sherrie Rudick, and I'm the product coordinator for the HV-ImpACT. And I want to welcome you all to today's webinar. And I said while we were in the lobby, this month's topic is developmental surveillance, screening, and linkages to services.

And as with last month's webinar, this topic emerged among the top 10 in our initial regional needs assessments that the HV-ImpACT's TA specialist conducted. So we know that there is widespread interest in the topic. That's why we already have 123 people now on the webinar. And we're really delighted to have one of the foremost experts on developmental surveillance, screening, and linkages to services as our webinar presenter.

Wanted to take a minute or two before I introduce our presenter and before we get started to share some logistics. The first thing I was going to share was that we have the chat box open. I am feeling like I don't have to share that, because Washington state, North Carolina, New York, Chicago, Michigan, and Fort Belvoir, Virginia near me in Richmond. Florida, Louisiana, Louisiana, Texas. So-- ooh, Rhode Island and Michigan. I'm sorry. And North Carolina and New York. Did not mean to miss you.

So you know that the chat will be open during the webinar, and in addition to saying hello as you are now, use the chat to add comments as we go along, to post your questions. We'll be answering questions somewhat in the chat, and also monitoring the chat and sending questions over to Paul Dworkin, our speaker, to answer during the webinar.

The chat will close when we have one of these several interactive polls that we have during the webinar, so that people don't get confused about where to write their answer. But as long as we're not doing a poll, the chat will be open for you to use as you are now.

And somebody said good morning from Anchorage and Fairbanks, Alaska, and not to forget West Virginia. I would never forget West Virginia. Somebody is-- Rosa says hello from sunny Miami, Florida. So hope you're all having good weather.

And let's see. Couple of more logistical things. In the file where on the lower right, you'll see a resource list handout. It's a PDF. And the handout provides links to some excellent resources on the topic. It has a link to a series of resources developed by the Department of Health and Human Services and the Department of Education, called Birth to Five-- Watch Me Thrive, that you may know. And another great resource called Learn the Signs-- Act Early, which is developed by the Centers for Disease Control and Prevention.

And there are two resources that are related to the topic of screening dual language learners. There is, in the notes pod, a link to the webinar survey. So we'll have that link open automatically at the end of the webinar. But

we do want to catch everybody's feedback. And just in case you have to leave the webinar before it's ended, before you have to hop off for another meeting, we'd encourage everyone-- project officers, HRSA regional staff, grantee recipients-- to complete an evaluation.

I would like to say that we take your evaluations seriously. I don't know why I laughed when I said. We do take them seriously. And I wanted to just highlight a couple of changes that we've made on this webinar because of comments that we received on the last one, just to show you how seriously we do take them.

So we had some comments last month that the sound quality was uneven. And so you'll notice that this month, in addition, or rather than having you listen through your computer speakers, we have a dial-in number that we hope will help the sound quality. Please let us know if it did, in the evaluation.

And last month we had some comments that the content in our opiate webinar was really great, but with four presenters, felt a little bit rushed. So this month we have one presenter. And hopefully a less rushed pace, and more time for chats, question, commenting on polls.

So let's get started. So here's what we're going to do today. Here is our agenda. We'll talk about options for early detection through developmental monitoring, the vital and important role that parents play in developmental surveillance, how to build a system to support developmental surveillance. And finally, Dr. Dworkin was on the faculty of the Home Visiting CoIIN, and he'll share some lessons learned through the [INAUDIBLE] process.

All right. We have our learning objectives. And we have four. At the end of this webinar, you'll be able to define the process of developmental surveillance and screening, recognize the importance of parents' opinions and concerns for their children's healthy development, identify strategies to successfully engage parents in the process of developmental promotion, early detection referral, and linkage, and finally, identify methods to enable the successful referral of vulnerable children to early intervention services.

So you may remember that we ask you to help us with two polls on these objectives. The first is a ranking poll. It's the one that's over on the right. And we'd like you to select the objectives that are most important to you, and select all that apply.

And on the lower left, we have a place for you to add your own objective, your own open-ended objectives. And you'll see it says "type your answers here." And this is something that we're very interested in, because it's useful not only for this webinar, but to help us think about follow-up issues. What might you be interested in that maybe wasn't included in this webinar, but might be included in a follow-up issue brief or in the newsletter, or through follow-up with your TA specialist?

So I invite you to consider not only our objectives, but any that you might want to add. And I see that we have at least person-- one person, sorry, who added their own objective. Thank you. We'll give you another minute, because I see that people are just still answering.

And we have couple of people who have added their own objectives. That's great. Thank you.

And it-- ah, no, sorry. I thought it looked like people had stopped answering. But I see the polls are still hopping here. So I'll give it another few seconds.

All right. Now it does look like we've had everybody join us on answering. So Betty, let's take those polls down. And we'll move to another poll.

This is our "jump start the brain" activity. And again, you may remember this from last month. This is our "let's get our brains thinking together about this topic," as we get started.

And this month, we have a scenario, and then we'll ask you to choose the best answer to some poll questions. So here's "jump start the brain-- take one" scenario. "During the course of an otherwise eventful home visit, the mother of an 18-month-old toddler expresses concern that he does not seem to be able to follow directions as well as his young cousins."

All right. Betty's going to bring up the questions that go along with it. We have, again, three truth or miss questions, and one multiple choice question. And I'm going to let you read the questions. I don't think I have to read them to you. But I'll give you a couple of minutes to answer them.

OK. It looks like I'll give it another few seconds, because I do see people still answering.

I'm smiling as I watch-- OK-- to see the proportions, because for a while, people hadn't gotten to question four yet, but I think they're catching up.

OK. So now I'm seeing that almost everybody has had a chance to answer the "jump start the brain" questions. And so Betty, you can take the polls down. And I now get to introduce Dr. Paul Dworkin.

So we really are excited to have Dr. Dworkin with us today to lead the webinar. Dr. Paul Dworkin is executive vice president for community child health at Connecticut Children's Medical Center, founding director of the Help Me Grow National Center, and professor of pediatrics at the University of Connecticut School of Medicine. For 15 years, he previously served as physician in chief at Connecticut Children's, and chair of the department of pediatrics of the Yukon School of Medicine.

Dr. Dworkin's interests are at the interface among child development, child health services, and child health policy.

He has authored more than 175 publications in the fields of developmental behavioral pediatrics and general pediatrics. Dr. Dworkin's honors include teaching awards, visiting professorships, and named lectureships.

In 1988 he was visiting senior research fellow in the department of pediatrics, University of Oxford, and also visiting scholar of Green College in Oxford. In 2003, Dr. Dworkin received the prestigious C. Anderson Aldrich Award from the American Academy of Pediatrics, in recognition of achievement in the field of child development. His vision led to the creation of Help Me Grow, a Connecticut statewide initiative to promote the early detection of children at risk for developmental and behavioral problems, and their linkage to programs and services that is currently being replicated in over 20 states.

He was the editor of the *Journal of Developmental and Behavioral Pediatrics* from 1997 to 2002. He serves on the board of directors for several organizations, including the Urban League of Greater Hartford, and was a member of the first entering class of the Academy of Distinguished Educators at the University of Connecticut School of Medicine.

So our very distinguished speaker, Dr. Paul Dworkin, will take it from here. Paul, thank you.

Well, thank you very much, Sherrie. And good afternoon, and good morning, everyone. It's spectacularly exciting to see all of you who've signed on, and where you are from across the nation. So I'm so pleased and really very, very proud to have this opportunity to spend a little bit of time with you.

And I would be remiss if I didn't begin by sharing greetings from our medical center, Connecticut Children's Medical Center, and the specific unit within which I work, our Office for Community Child Health, which houses our Help Me Grow National Center. So let me begin by acknowledging that over the years, I've become increasingly enchanted with sharing stories while speaking, and have backed away a little bit from our more typical academic approach of exclusively presenting data, facts, concepts, et cetera. While all of those things are certainly important, and I always felt like I needed to maybe softly defend the approach that I was taking, and then I came across this great quote-- at least, I think it's a great quote-- from a preeminent cognitive neuroscientist, Roger Schank, who's a professor emeritus from Northwestern. And here's the quote. "Humans are not ideally set up to understand logic. They are ideally set up to understand stories."

So now I feel totally vindicated, because I have the word of an impressive cognitive neuroscientist backing me up, to share some stories with you, to get across the critical concepts that I hope we will share. So that is, in part, the approach that I will take.

Now, I must admit that Sherrie's very generous and much too long introduction of me undermined my opportunity to do my own little polling on the side, because I was going to ask you, without requiring that you formally respond,

to guess where this is. And many people will point out that it's the UK. And they may then debate whether it's Oxford or Cambridge, because it surely looks like one or the other. And as Sherrie mentioned, it is Oxford.

I could do a further poll by asking you which college at Oxford. That might be a little bit too challenging. But it's King's College, Oxford. And it really does set the stage for my comments, and is relevant to my storytelling, for several reasons.

Number one, it was really my introduction to home visiting. And it was an up-close and personal introduction that I will share with you by just reading the introduction to a blog that I wrote a few years ago, when we were talking about the close, intimate relationship between home visiting and Help Me Grow-- indeed, more than a matter of convenience.

So my introduction to home visiting dates back to 1988, while on sabbatical leave in Oxford, England with my family. My wife and I dutifully visited the local general practitioner to register for care. We were somewhat bemused, and I might say even confused, by the lack of attention afforded our then-almost-four-year-old daughter, only to be reassured two days later, when a nurse health visitor showed up at our door to perform a home-based child health assessment-- a very auspicious introduction to home visiting. And in fact, we subsequently-- my wife, who is a health educator, and I-- conducted research that looked at the perceptions of families with regard to their home visiting services. And obviously those perceptions were extraordinarily positive, and we came to appreciate the critically important role of home visiting within that national system.

So that was the late '80s. And in fact, just a few short years later-- the 1990s-- we entered into what is now regarded as the so-called "decade of the brain"-- a decade in which a-- the explosion in our understanding of early brain development, of early child development, that was amassed, admittedly, over the '70s and '80s, but really came to the fore in the 1990s, in our popular press, like *Time* magazine, in esteemed professional publications, like *From Neurons to Neighborhoods*, of the Institute of Medicine. And these publications were really remarkably effective in capturing that critical concepts in early brain and early child development that informed our approach to early detection and emphasized the critical importance that early detection result in early intervention.

I am not going to go into these concepts in any detail at all, except to emphasize there are a host of critical concepts in early brain development that yield incredibly powerful implications for the way in which we now go about early detection, as well as referral and linkage to programs and services. So for example, the fact that brain growth disproportionately occurs during the prenatal period and the earliest years of childhood. The fact that neuroplasticity, while fortunately the brain maintains some capacity across the lifespan-- think of adults who are being rehabilitated from strokes, for example. The opportunity, the capacity, for neurocapacity-- for neuroplasticity, that is, for a part of the brain to take on the function of another area of the brain that has been

injured, has never been greater than during early childhood. But there are critical periods of childhood in which stimuli must be present in order for the brain to develop normally. That development is sequential, and therefore experiences need be sequential.

So few infants will benefit from an algebra lesson. Few adolescents need to be held and rocked each day, although we all know of some exceptions to that. But nonetheless, development is sequential, and experience is critically important-- critically important for normal brain development, critically important for enabling the child to derive the optimal benefit from subsequent experiences.

And then with the new millennium comes our explosion in knowledge of the biology of adversity. You're all familiar with toxic stress and its impact on early brain development, early child development, and in fact, long-term outcomes. We've also become very mindful of the interplay between environmental circumstances, adverse childhood experiences, and even the expression of our genetic code, through our increased understanding of epigenetics.

So these concepts have incredibly important implications for the way in which we think about early detection, and what we regard as the necessary outcomes from early detection of children who are vulnerable and at risk for adverse developmental and behavioral outcomes. So despite the incredible importance of early detection and all the science that validates the importance of early detection, how to best promote early detection, early recognition, has been controversial, even in the relatively recent past.

So prior to the new millennium, if we surveyed-- and we frequently did-- child health providers, to ask the question, how do you typically monitor children's development? Child health providers would report a wide array of techniques, including reviewing developmental milestones, perhaps using a collection of age-appropriate tasks to demonstrate infant and children's capabilities, relying on our subjective impressions, clinical judgment, based on our interview and observations. And by the way, our clinical judgment is very poor when it comes to identifying young children who are vulnerable and at risk for adverse developmental outcomes.

And then there are the options of formal screening with parent-completed questionnaires or with professionally-administered standardized tests. But it was unclear until recently what the optimal approach to early detection was. And we hadn't achieved consensus prior to the start of the new millennium.

So let me share with you a scenario to lead into a poll that illustrates the range of options available to you. You are seeing the family of a nine-month-old infant for a routine home visit. You have visited the family since birth. No medical issues or concerns have been identified. The parents express no particular concerns, and the interval history since last visit and general observations suggest no issues or problems-- a seemingly quite low-risk scenario.

So with that scenario in mind, let me hand this over to Sherrie to conduct our poll.

Thank you, Paul. So we have a poll question. And we had a question in the chat about viewing polls. This poll, you will get to see what other people's opinions are. So which options do you think represent best practices for early detection?

And we've got the options that-- ooh-- Paul just mentioned. And we've got a favorite so far, as you can see. Oh, maybe you can't see yet. We're going to broadcast the results.

And we do have a favorite and we also have a least favorite. And people are continuing to chime in. It's funny, because we said that you can select more than one. But it's really interesting, as the results are getting posted, that we have very high and a very low, and a few in between.

All right. And I think people are still checking, but the trend has not changed.

All right. Let's broadcast the results. Paul, any comments?

Well, just a quick comment. Indeed, we've already downplayed the value or the dangers of clinical judgment. And it's very heartening to see respondents reinforce that. And then really overwhelmingly, there is enthusiasm for using formal screening with a parent-completed questionnaire. And we will certainly endorse and validate that option, although we will also place it in its appropriate, and I would say vital, context, over the course of the remainder of the webinar. So we're off to a great start.

All right. Poll is down. Back to you, Paul.

Thank you. So let me share with you the recommended, endorsed, evidence-informed approach to early detection. And we'll use the more generic term "developmental monitoring" for the moment, as reflected in the policy statement on developmental surveillance and screening of the American Academy of Pediatrics, published in 2006. And this policy statement is currently in the midst of being updated. But the core components that we will discuss-- that we will discuss will also appear within the updated version of the policy statement.

And what I want to do is define for you "surveillance." And surveillance is, these days, perhaps an unfortunate choice of terms, as it suggests something that is surreptitiously done, peeking around corners and perhaps trying to catch someone doing the wrong thing. I assure you that was not the intent. But rather this really reflects a process as originally defined in Europe to perform child health monitoring in general and developmental monitoring specifically.

So words, semantics, aside, let me offer a definition to you. So surveillance is defined as a flexible, longitudinal,

continuous process, in which knowledgeable practitioners perform skilled observations during child health encounters. And you'll note that that definition is filled with a number of important caveats. And in fact, these caveats are really captured in the specific components of surveillance.

First, and perhaps foremost-- we'll talk more about this in a moment-- eliciting and attending to parents' opinions and concerns. Secondly, obtaining a relevant developmental history. Third, making accurate observations of children, which typically are informed by age-appropriate tasks, which may be taken from a screening tool or some other inventory of milestones.

Identifying risk and resiliency factors. We talked about the biology of adversity. Maintaining a record of process and findings. And particularly when concerns arise, sharing opinions with other professionals.

So consider, if you will, the opportunity to share opinions between home visitors and child care providers, and child health providers. We understand the challenges in sharing that information, and we will talk about some of those challenges during this webinar. But those opportunities reflect a very, very rich process by which key information can be shared and validated.

But it's so important, with regard to surveillance and screening, is that surveillance and screening are both poor components of an integrated, comprehensive process of developmental monitoring. It is not a matter of surveillance or screening, and it is certainly not a matter of surveillance versus screening.

So the AAP policy statement recommends that screening tools be used at periodic intervals to strengthen this ongoing longitudinal process of surveillance. And with respect to the relevance of this periodicity to home visitors, the Home Visiting CoIIN adopted, embraced, the same recommended interval for screening that is recommended in the AAP policy statement.

And there are some choices with regard to the type of screening tool that you may use. You indicated that overwhelmingly, you would employ parent-completed questionnaires as opposed to professionally-administered tests. That is not only completely understandable, but it is also representative of practice within the home setting, within the child care setting, and within the child health provider setting. While select, validated, professionally-administered screening tools are available, they are typically much too time-consuming to administer in the context of a brief visit. And very frequently, providers are not formally trained in these-- of these professionally-administered screening tools.

I am not discouraging their use. I am merely suggesting that there are some additional challenges that are circumvented by parent-completed questionnaires. And then there are a host of parent-completed questionnaires that are available for your use, for use in the early care and education setting, for use in the child health provider

setting, and that in fact are used. And I highlight two here, not to endorse them, but simply as examples-- the PEDS, the Parents' Evaluation of Developmental Status, and the Ages and Stages questionnaire.

There are others. Some of you may, for example, may be familiar with the Survey of Wellness in Young Children, the SWYC, which also has been used, is being used, selectively across the country. The frequency recommended by the AAP is nine months of age, 18 months of age, and 24 to 30 months of age.

In addition, the policy statement recommends that screening may also be used when concerns arise. And indeed, you illustrated this in the scenario. A parent had concerns. Your overwhelming response was to administer a parent-completed questionnaire to validate the concerns, as well as to potentially explore whether there may also be concerns in other developmental domains, because that might well influence what in fact you do with those screening findings.

The really critically important concept here is when we speak of surveillance and screening, we are speaking of an integrated, comprehensive process that engages parents, implements those core components of surveillance, and interprets periodic screening in the context of all that's known about the child. It's not about administering a screening test in isolation, interpreting it in isolation, and acting in isolation. You are so well-positioned to undertake this process in a more comprehensive way, by virtue of your longitudinal relationship with families, and the extent to which families trust and value your engagement and your opinion.

And perhaps the most important reason to place screening within the context of surveillance and screening is the critical importance, the usefulness, the utility of information available from parents. However, we must also be mindful that all information available from parents is not of equal use. Rather, we can think about information from parents as occurring in two general camps. Either there are appraisals-- that is, opinions of children's development, which include concerns, estimations, and predictions-- or descriptions of children's development. And by that, we mean recall and report.

So before I delve a little bit more deeply into the importance of information available from parents, and where the money is, if you will, let me just respond to two queries that came up from you in the chat. First of all, the recommendation for developmental screening at nine, 18, and 24 to 30 months by the AAP was a recommendation that was born out of expediency. And that is, at the time, in 2006, there was not reimbursement for a 30-month well-child visit. In many, many plans, that has now changed. And as a result, nine, 18, and 30 months of age are the recommended ages currently for general developmental screening, with 18 and 24 months of age-- excuse me, 18 and 24 months of age also used for autism screening, which we're not going to specifically speak about today.

And then secondly, I did reference on the slide second-stage screening. And what I mean by that is that

screening, in the most abstract sense, is meant to identify those who are vulnerable and at risk from across the general population. If a parent shares concerns-- and I'll emphasize this point in just a moment-- that child already is at increased risk. That is not general screening. We already have a child who has been identified at risk. So screening at that point, which is a very worthwhile step to undertake, is referenced as second-stage screening, because it's being conducted in the context of a child who has already been identified as potentially being at increased risk.

So I hope that's helpful. Let's look a little bit more in detail at the information available from parents. And let's start with parents' appraisals, and most specifically, parent concerns. If I leave you with no other take-away-- and I hope I leave you with more than one-- in the course of this webinar, it's that parents' concerns are incredibly important indicators of underlying developmental issues. If a parent brings forward a concern for their child's development, that child is at significantly increased risk of developmental delay.

Now, notice I said "if a parent brings forward a concern." We of course must be mindful that parents may not express a concern, or may not observe a child to the extent that they have a concern. So we can't exclusively rely on parent concerns, but when they are present, they are incredibly important from the standpoint of our observations and decision making.

This is particularly true in certain areas of development. So if parents have concerns for their child's speech and language functioning, for their child's fine motor functioning, small motor coordination, for their child's general functioning, if they report that their child seems slow for his or her age, that child is at significantly increased risk for developmental delays in those areas. Certainly this does not diagnose developmental delay, but it behooves us, on the basis of that increased risk, to clarify the reason for the parents' concern.

If parents have concerns in other areas of development-- self-help skills and behavior-- those concerns are somewhat less sensitive, somewhat less predictive of underlying developmental delays, but still important enough indicators that they demand our attention and clarification. How we elicit parents' concerns is extremely important, and I'll reemphasize this in just a few minutes.

The evidence-based, research-validated approach to eliciting parents' concerns is the following. "Please tell me any concerns about the way your child is behaving, learning, and developing." And then you can follow that open question with more specific questions about different developmental domains.

And in fact, for those of you who are familiar with the PEDS, this is the first question in the PEDS. So eliciting parents' concerns, extremely important. And how we elicit those concerns, important. And again, we're going to come back to this very shortly.

So what about estimations? If we say to a parent, "Compared with other children, how old would you say your child now acts?" This is actually a really good question, and does give us a pretty good index of how that child is developing, or at least it's helpful in identifying vulnerable children who may be at risk for developmental delay.

And in fact, in research, responses to this question correlate surprisingly well with children's overall developmental quotients. And again, keep in mind, we're just talking about identifying children who are vulnerable and at risk. We are certainly not definitively identifying or diagnosing delay. This is particularly true in select areas of development, such as cognitive or intellectual development, motor development, self-help and academic skills. A bit less accurate for language abilities. But again, a useful clinical clue.

What about predictions? Well, all of us who are parents are probably guilty of this. We are very likely to overestimate future functioning. For parents of children with developmental delays, they tend to optimistically predict average functioning.

And I'm not critiquing that. We want parents to feel hopeful. But we can't rely upon predictions in order to accurately determine whether a child is or isn't at increased risk. If a child is developing normally-- and how many of us are guilty of this-- we're inclined to predict great things.

Now, in the past, the term used to apply to this phenomenon was the "presidential syndrome." I'm not going to venture into those politics at this point in our presidential election season. You can derive your own conclusion as to whether that's apt or not. Predictions, not very helpful.

What about recall? Recall of developmental milestones. Well, I know I am clueless with respect to being able to specifically pinpoint when my children did or didn't do various tasks, at what ages. These are notoriously unreliable, and in fact, they tend to reflect our prior conceptions of children's development. If we think children begin walking at an early age-- let's say eight to 10 months of age-- we're more likely to report our children as beginning to walk at an early age, as opposed to thinking normal walking, first steps, is 14 to 15 months of age, all of which, by the way, is in the range of normal.

It is true that our accuracy is improved if we consult with our records or baby diaries, baby books, et cetera. But even if accurate, age of achievement of milestones is of very limited predictive value. And the reason for that we've already implied, and that is there's a tremendously wide range of normal around each developmental milestones, and different developmental domains-- cognitive, motor, social, language-- tend to occur at different rates, not necessarily at the same rate.

So we've already suggested, the age at taking first steps may be as early as eight to nine months of age, may be as late as 15 to 16 months of age. All of that is within the range of normal. So not surprising that milestones are

not all that helpful. Recall of developmental milestones, not all that helpful.

In contrast, contemporaneous reporting can be very useful. So accurate contemporaneous descriptions of current skills and achievements can be very, very useful in forming impressions of children's developmental status. But again, how we ask the questions is important. So a recognition question, such as "Does your child use any of the following words?" is much more helpful than an identification question, which really puts a parent on the spot by asking "What words does your child say?" That's tough.

It is true that parents' contemporaneous reporting tends to provide a higher estimate than assessment or even the use of a formal screen. But keep in mind that the child is within a familiar, hopefully loving and supportive home environment, and parents are reporting on skills that are inconsistently or just beginning to be demonstrated-- so-called "splinter skills."

So the fact that there's some discrepancy between parent description, specifically contemporaneous report, and professional estimate does not in any way invalidate the parents' reporting. Rather, it's important for us to take that information to heart and include it within our overall assessment.

So how we elicit opinions and concerns is important. And we talked about the usefulness of the question, "Do you have any concerns about your child's learning, behaving, or developing?" And I would suggest that you contrast that with the question, "Are you worried about your child's development?"

None of us like to acknowledge worries. We all feel that we're being put on the spot, and somehow worries are a reflection of us, as opposed to, in this instance, the child. We are worried. That's daunting. That's intimidating.

On the other hand, if we're asked about concerns, that's very validating. That's saying our opinion matters. Our information is important.

Also, if we ask a parent if they are worried about their child's development, at least within the child health sector, they are inclined to presume that we are asking about physical development-- that is, growth or motor skills. They are not necessarily inclined to presume that we are thinking about a child's emotional development, or even speech-language development, or other aspects of cognitive development. "Do you have concerns about your child's learning, behaving, or developing?"

Also, just a word about cultural beliefs, and here we know that cultural beliefs influence developmental expectations, and developmental expectations influence children. Developmental expectations influence parents' opinions and concerns. So let me give you two very concrete examples based on a study that we did a number of years ago in Hartford.

We asked parents at what age they would expect their child to accomplish various developmental tasks. And we indeed found differences among different racial ethnic groups. And in Hartford, we have a prominent Latino population, primarily Puerto Rican, African-American, West Indian Caribbean, and white Caucasian. And there were differences across all groups that were statistically significant.

The interesting aspect of this was the extent to which differences were actually able to be related to underlying cultural beliefs. So for example, among our African-American families, there was much pride taken in an infant's independence and ability to do things on their own. And indeed, among African-American parents, age of expectations for, for example, increasing gross motor skills and increasing autonomy with mobility, earlier-- an earlier age was expected than across the other groups.

Similarly, within our Latino population, where there is a great emphasis placed upon family care of young children, in a phenomenon that we were informed is best described as "familism"-- and I apologize if I haven't pronounced that exactly correctly-- those parents' expectations for the child's independent demonstration of personal social skills were later, because that was not highly desired. In fact, it was viewed as the responsibility of the family.

Now, all of these expectations were in the broad range of normal. But they were really significantly influenced by cultural beliefs. It's important that we keep that in mind.

So we've had a question, how do we respond to the argument that a second-stage screening is unnecessary when initial observation indicates a child at risk for a developmental delay? And I think in part that depends what do we mean by "initial observation?" So in the specific scenario that I shared with you, if a parent expresses concerns, or if you elicit parents' concerns, you-- that indeed does increase the likelihood that a child is vulnerable and at risk for developmental issues. But a screen at that point, the formal administration of a developmental screening tool, can be very, very helpful in validating and clarifying those concerns.

There is a related question that typically arises, which is once a child has been identified-- perhaps through screening, or even through-- perhaps has been referred on for more formal evaluation, is there a subsequent role for screening? And I know that HRSA has weighed in on this issue. And Sherrie, can I defer to you for a response?

And actually, we had an additional question from Dr. David Willis, about discussing the differences between developmental delay and social-emotional development delay.

Sure. So when I'm referencing developmental delay in the context of this discussion, I am referring to development generally-- that is, across all developmental domains, including social-emotional. The point that David's making is a very, very valid one. And that is, we don't really know the answer, to what extent do our

general developmental screens effectively identify children at risk for social-emotional delays?

And in fact, tools have been adapted, further validated, to specifically increase their utility in looking at social-emotional development. And the most widespread tool in use for that purpose is the Ages and Stages questionnaire, dash SE. So if David means to emphasize that general developmental screens may not be sufficient to identify children at risk for social-emotional delays, that's true.

And by the way, on a related note, we also don't really know the answer-- we don't definitively know the answer to the question, do general developmental screens-- are general developmental screens adequate to identify children at increased risk for autism spectrum disorder? That, the jury is still out. And because early detection is so critically important, the wisdom currently is to ensure that we are doing both general developmental screens and autism-specific screens, as I referenced earlier. So I hope that addresses that point satisfactorily.

Sherrie, do we want to go on and talk about the other implication of repeat screening? Or should we defer that?

Can you hear me?

Sorry, I was on mute and talking away.

Oh, OK, I was just concerned it was me.

So I'm going to invite HRSA, actually, to respond in the chat to this. I know that this question has come up. I heard it first on a [? Dove ?] webinar, and then in the grantee town hall. And I know that HRSA has given a lot of thought to the issue, and so I'm opening the chat box for HRSA response, and invite them. I see Amanda is typing away. Thank you, Amanda.

Great. Thank you very much. So let me just emphasize that there are tremendous advantages to parent-completed questionnaires, as we've already suggested. I am not endorsing any specific questionnaire, but merely sharing with you two that are in very popular use.

So we could end here, and I would be ending this section five minutes early, were it not for a critically important point that we had long worried about in the 1990s, and that was really effectively articulated by our colleague, Ellen Perrin, in an editorial in 1998, in which she pointed out detection without referral and intervention is in-- certainly ineffective, and may even be judged unethical.

So let me introduce, again, yet another scenario. "During the course of an otherwise uneventful home visit, the mother of an 18-month-old toddler expresses concerns he does not seem to be able to follow directions as well as his young cousins." So here, there are a variety of options that you may invoke.

And I would suggest to you that apart from the first bullet, "reassure the parent that her child is doing well," and we often are-- fall prey to that based on our subjective impressions, which we've already said are not invalid, there are a variety of other options, from more frequent home visits, parent-completed questionnaire, the unlikely, but still feasible, professionally-completed screening tool, or referral-- referral to your state's early intervention program, referral to a child health care provider, or specifically referring for another assessment, whether it be hearing or speech-language. That may all make some sense and be quite reasonable.

So let me share with you in just a couple of minutes-- very, very high level-- share with you the story of the evolution of Help Me Grow in Connecticut. And I do not do this to hold up Help Me Grow as an example of what you necessarily should be striving for, but rather to emphasize how the Help Me Grow story and-- when I subsequently speak about the Home Visiting CoIIN story, both reinforce the terrible importance, the critical importance, of our thinking about a comprehensive, integrated process of developmental promotion, early detection, referral and linkage.

So in the 1990s, as we were enhancing early detection, we began to really think about how do we ensure that early detection leads to linkage? And we engaged in a series of crucial conversations with a wide variety of partners in Hartford, including our city's child development program, our child health providers, parent advocates, our early intervention program, and others, who were really essential to this conversation.

And we came up with four assumptions. And I want you to consider the extent to which these assumptions might be relevant to the venues in which you are currently working. The children with developmental and behavioral problems were eluding early detection, but a wide variety of initiatives existed to provide services to young children and their families. But there was a gap between our best efforts at early detection and the linkage of these vulnerable children and their families to community-based programs and services, and that children and their families would benefit from a coordinated regionwide system of early detection and intervention for children at developmental risk.

And out of this came a four-component system that still characterizes Help Me Grow today-- training of child health providers in the process of surveillance and screening. Community outreach to enhance surveillance and screening across all of those within the community-- home visitors, early care and education providers, as well as capture the community-based programs and services that were available to support families in promoting their children's optimal, healthy development. A centralized access point for connecting children and their families to services and care coordination. And then, data collection, because we knew there were gaps. We knew there were capacity issues to inform our system building.

So from the standpoint of the child health provider-- and you could substitute "home visitor," because it's the same

approach-- eliciting parents' concerns, identifies concerns, or perhaps through the administration of a developmental screening questionnaire, concerns for a child being at increased risk arise. Help Me Grow is contacted. A care coordinator identifies the appropriate resources. The parent is connected to the resource, and the provider gets feedback.

And we know from our experience in Hartford, across Connecticut, and nationally, this is the way it works 80-plus percent of the time. The centralized portal of entry in Connecticut, Child Development Info Line, is really the heart of this comprehensive, integrated approach. And in fact, we have the tremendous advantage in Connecticut and in a number of other states replicating Help Me Grow, to have a single portal of entry to provide access to the broad array of developmental and behavioral services available to families and their children across the state. Our Part C system in Connecticut, Birth to Three, our preschool special education system, our Title V children and youth with special health care needs program, and for those children who are unlikely to be eligible for these specific programs and services, there is the linkage to community-based programs and services through Help Me Grow.

Anyone interested in more information can go on our HelpMeGrowNational.org website. I merely want to point out that we now are up to 26, 27 states. I don't do this as an advertisement, but merely want to make sure that if you are in a state that has either implemented or is implementing Help Me Grow, I am hopeful that your program can reach out and make the linkage to Help Me Grow to facilitate your referral to community-based programs and services, and also potentially your other early intervention services.

So if we learned anything through the Home Visiting CoIIN-- and I'll talk a little bit more about that in a few minutes-- and we've learned a lot, it's the challenges in making linkages to Part C, to community-based programs and services. So at this point I'm going to hand this over to Sherrie to lead another poll.

OK. Actually, two polls right here about challenges. And then we'll follow this by two polls about strategies. So as Paul said, when we think about making linkages, we think about it both as linkages to Part C and as linkages to community-based services. So we want to hear from you in relation to this.

And what I'd like to do, because we'll get more answers that way, is if you were born between January and June, I'd like you to think about the answer to what challenges do you face in making linkages to Part C? And if you were born in July through December, I'd like you to think about what challenges you face in linking families to community-based services. And we will broadcast these so you can see each other's answers. So challenges in your states related to Part C or related to community-based services.

And I already see answers related to availability, related to rural, related to the fact that there aren't providers. In relation to Part C, transportation is an issue. Language is an issue. Boy, lots of issues related to availability, for

sure. And how to make initial contact.

So you're starting to think even farther ahead about maybe some strategies that are coming through. So those are some of the responses in relation to Part C. So many remote, rural areas. Alaska. Initial contact.

And just an amazing response in terms of lack of availability. Parent fear, so that goes a lot to a lot of the conversation we've been having with Paul about the role of parents and the voice of parents in this. And over and over again, people are telling us that there are long waiting lists, and not enough services out there.

In terms of linkages to community-based services, again, very similar answers. Issues also, though, related to insurance. Social barriers for services.

Interesting how much overlap there is between the community-based and the Part C. So again, things like transportation and availability. But families not following through due to their own issues, like drug addiction and other kinds of changes. Transportation at both levels. Language at both levels. Lack of services at both levels. So a real dearth of providers, again, especially in rural areas.

All right, Paul, any additional comments on these before we talk about strategies?

Well, these are-- you're absolutely right, in terms of-- there are so, so many challenges. And I would suggest to you this is exactly why we need to think about this entire process as a comprehensive, integrated process that is supported across agencies, across programs, through our system building. And I greatly appreciate that that's a daunting task for a home visitor to think about, given that so many of you are at the front lines. But on the other hand, as a Home Visiting CoIIN demonstrated, and as I'll speak to in just a moment, solutions to these issues that seem so overwhelming can only be successfully undertaken if we think about this as a comprehensive, integrated process that includes engaging parents in developmental promotion, early detection, referral, and linkage. And I'll illustrate that a little bit more specifically in just a moment.

The one other thing that I would add is this theme of the challenges, particularly in the rural setting, came through loud and very, very clearly in the Home Visiting CoIIN experience. And we've certainly learned also, in our efforts to bring Help Me Grow to states across the country-- many of which are very, very rural-- of the tremendous challenges of identifying resources that are even logistically remotely feasible for families to access. That is a real challenge. However, there are some remarkable best practices out there.

And then finally, just a comment about Part C. Many of you expressed concerns with access, delays, et cetera. And yes, that can be very, very challenging. The other problem that almost all of us face is the fact that in 45 of 50 states in this country, Part C is not designed to meet the needs of children who are vulnerable and at risk but do

not manifest discrete delays.

So in Connecticut, for example, as in 44 other states, children must demonstrate delay before they are eligible to receive Part C services. And there are a whole host of reasons for this, including the challenging finances. On the other hand, we know that children who are vulnerable and at risk, and who yet may not fulfill eligibility criteria for Part C, can do remarkably well if they are linked to a community-based program and service like, for example, home visiting, or a high-quality early child care setting, or a family resource center, or a story time at the library, or any number of other community-based resources.

So ensuring that all children, including those vulnerable and at risk, can be linked to better support families in promoting their children's optimal, healthy development is a challenge that exceeds the focus and capacity of most of our states' Part C programs, which is why we highlight both access to Part C and access to community-based programs and services.

So--

[INTERPOSING VOICES]

Thanks, Paul. Let's just take a quick minute now that we've talked about challenges, and Paul already kind of has made his great suggestion for the bottom line in these strategies. But let's put the question out. Betty, if you bring up one more poll, we're just going to take a minute or two to ask you to share any strategies that you've been using and have found successful in making those linkages to Part C and to community-based services for families.

OK, so to Part C, mothers talking to providers, having meetings, case management, emails. A lot of stuff about communication. Referring-- not just the parent referring, but anybody being able to refer. Getting to know your Part C staff, and working closely with them. So that statewide system, where you are linked with other people and build personal relationships with them.

And we've got some answers for community-based services. Brainstorming with families about their goals. One program says that they have a road map that families are provided so that they know who to reach out to. Making sure that you're providing information and talking to parents in their natural language.

Having warm handouts. Being prepared for meetings, and supporting parents in their meeting. And letting parents know what to expect with the initial contact.

So lots of strategies from you who are experts and who have been working at this in your state. And I'm going to turn it back over to Paul before we do our final activity.

Great. Thanks, Sherrie. So-- and by the way, our Connecticut director of Part C, Lynn Johnson, also offered some strategies with regard to linkage between home visiting and Part C-- participation in collaborative events, cooperative training opportunities, and even joint participations by Part C and home visiting to other groups, like your child welfare agency or the medical community. Getting to know one another is so critically important. And this was really emphasized in the Home Visiting CoIIN.

So I'm not going to go into the CoIIN in any detail, except to pay homage to its remarkable evolution. And I know that Dr. Willis agrees with this. At the start, the Home Visiting CoIIN, with respect to the early detection piece, was really focused on what screening tests do I use, and who do I call when the child fails? And its evolution over several years was quite remarkable, too.

And I'm not going to go through the details of this key driver diagram-- I've got about one minute left-- except to say that the notion that there must be a comprehensive, integrated approach was not just recognized, but embraced. Look at these primary drivers-- reliable and effective systems for surveillance and screening. We've talked about that. Reliable and effective systems for referral and follow-up. Home visitors supported to address development in the target population. And engaging families in the promotion of healthy development.

Remarkable evolution from screening to surveillance and screening with parent engagement, to ultimately developmental promotion, early detection referral, and linkage. And many of the lessons learned from the Home Visiting CoIIN are now being prepared for dissemination, for all of you to access. But this notion that there is a sequence here from eliciting concern, screening, referring, and ensuring linkage is so critically, critically important. And with the right process in place, we can do this.

So again, what began with developmental screening ultimately, formally, became entitled-- and this is a mouthful-- developmental promotion, early detection, and intervention learning collaborative. But it really does capture the richness of what the home visiting programs were doing by the end of this CoIIN and are currently doing.

So in summary, I hope I've emphasized the extent to which evidence and expert opinion both endorse the process of developmental surveillance and screening for developmental monitoring and early action, and parent engagement-- successfully eliciting parents' opinions and concerns-- is key to the process. Secondly, referral and linkage is a major challenge. It's a challenge linking to community-based programs and services. It's a challenge linking to Part C and our formal early intervention programs. And it does demand a systems approach.

And then finally, when we think about early detection and think about system building, because that can sound awfully abstract, this can best be framed as an integrated, comprehensive approach to developmental promotion, early detection, and intervention. This will be the outcome of your home visiting impact work. And of course, we are very, very anxious to successfully support you in this work.

So I'm going to stop there, Sherrie.

OK. Thank you. So Paul has some references. And we have kind of come full circle. You remember that we started off with "jump start the brain" activity. And we had a scenario, and I said, be sure to listen for the answers as we go through the webinar.

So our scenario was, "During the course of an otherwise uneventful home visit, the mother of an 18-month-old toddler expresses concern that he does not seem to be able to follow directions as well as his young cousins." And we had those three truth or miss questions down at the bottom of the screen. And don't forget that there's a multiple choice question up on the right, where you can choose one of three possible answers, as well as a "none of the above" and "all of the above."

And we'll give you just a couple of minutes to answer and see if your brain got jump started by this webinar. I know my brain got jump started, and not only got jump started, but it kind of went from first to fifth gear, probably, in the last hour and 20 minutes. So I hope you were going along with us.

And we've got a few answers still coming in. I'm wondering if anybody has different thoughts-- I'm always interested-- different thoughts at the end than they had at the beginning. And it will be interesting to do a comparison with what you thought at the beginning and what you're thinking now.

OK, people are still responding, especially to that multiple choice question up at the top. And yeah, still popping up.

OK, it looks like you've answered the questions. We thought we might actually share the answers this time. So Betty, if you take down the poll. Hopefully the questions were not trick questions.

But here are the answers. The first one is a miss. The first thing you should do is reassure the mother that not all children follow directions well at 18 months, and that he's certainly on track developmentally. In terms of possible next steps, all of the above are good possible next steps.

Truth or miss on number three, I'm laughing because everybody said that number three was a miss on this last go-around. So definitely everybody agrees with that.

And then on the last question, formal screening is a better option. I think Paul really contextualized it for us as an important option, and one of a number of options.

So there's our "jump start the brain." And we have two more final things that we'd like you to do. The first is possible action steps. So I'm hoping that, like me, you had your brain provoked, and during the webinar you

thought about the definition of developmental monitoring and how it is-- encompasses surveillance and screening, that you were reminded and thought again about parent concerns and how to approach parents, and the evidence-based, research-validated way to ask a question, and the importance of responding if a parent brings forth a concern. So those four things, some of the things that I thought about during the webinar.

And I really thought a lot about the intersection between cultural beliefs and developmental expectations, and how those cultural beliefs actually might influence the age of expectations and the difference between independent and the word Paul used about familism. So those are some, at least, I would say cognitive take-aways, or knowledge take-aways or thoughts for me.

But we'd really like you to think about some next steps. I always like to say the proof of the pudding is in the eating. So you've heard a webinar on developmental surveillance, screening, linkages to services, both Part C services and community-based services. And so what are some actual action steps that you might be interested in taking?

Last month we gave you some hints. But this month, we're really challenging you and inviting you to think of action steps that you'd like to share. And I see that you're already on it.

We've got one person talking about using the information in an ECCF CoIIN in the next month, so great. Attached to time frames. Getting more information, again, in the next month, which is exciting, to available services. Sending out information to home visitors, and again, within the next month. Share the webinar recording with colleagues.

I love that we're doing all of these within the next month. And I did want to say that the webinar recording, we are under the responsibility of having it become 508 compliant, and then we send it to HRSA, and you'll find it on the HRSA website.

Somebody's been talking with and about Help Me Grow as an option, and now they have some things to consider and think about and a place, I hope, to go with any questions that you have. So a couple of states that are interested in Help Me Grow.

So we've gone from one month and we have two months thoughts. Lots of gathering of information, sharing with home visitors. So let's see. Give you another minute to add, and then we're going to do our final poll.

OK, thanks for some good ideas. I hope if you didn't write an action step, you might think about the ones that you see in the chat box, and go back and talk with your teams about how you in your own organization are going to share the information and take some action steps.

And the next thing that we're going to do is final revisiting in terms of how we accomplished our objectives. So completely, partially, and not at all for each of our objectives, and for the ones that maybe you hoped that we would accomplish as well. And we'll give you another minute to do that, and then we'll say goodbye.

And thank you. I notice that people are answering not only for each of our objectives, but for your own objectives. So we appreciate that. And it looks like people have finished answering. So Betty, we can take down the poll and say goodbye.

So thank you for being with us for the last hour and 28 minutes. No webinar in November. We thought many of you would be at the Home Visiting Summit. And we will be there as well, so look for us.

And as we close this out in the next minute, we are going to pop up the evaluation form. So we have both "How well did we do on our objectives?" and then we have the evaluation that comes up. It's a quick evaluation. We're hoping you'll take a couple of minutes to complete it now. We'll also be sending it out, a reminder, so that we can get your information. Remember, as I said at the beginning, that we really take them seriously and scrutinize them and keep looking.

So thank you for being with us. We'll leave the chat open for another minute. I see that we still have some questions coming up in the chat. And so let's leave that up and see if we can pop up the evaluation.

OK, we're going to close the room, because it turns out that we can't pop up the evaluation until we close the room, which is why the survey hasn't been active. OK, thanks, everybody. We'll look for you at the Home Visiting Summit in November.