

Moderator: Hello, and welcome to Public Health Live, the third Thursday breakfast broadcast, I'm Joelle Alexander and I'll be your moderator for today. Please fill out your online evaluation at the end of the webcast. Continuing education credits are available after you take our short posttest. Your feedback is helpful in planning future programs. We encourage you to let us know what topics are important to you. As for today's program, we'll be taking your questions by phone or you may send your written questions by fax. We will also take questions by e-mail us, e-mail us at [phlive.newyork@gmail.com](mailto:phlive.newyork@gmail.com). We with like to thank our sponsors including the Centers For Disease Control and Prevention, National Center On Birth Defects and Disability, the Albany Public Health and Bureau of Early Intervention.

Today's program defines *Learn the Signs. Act early. The Importance of Developmental Screening*. Our guest stars, Dr. Judith Lucas specializing in health in Albany Medical Center, and Donna Noise, the Director for clinical Policy, Bureau of Early Intervention. Thank you for joining us today.

Dr. Lucas and Dr. Noise: Thank you for having us.

Moderator: Dr. Lucas, let's start with you. This broadcast is about early intervention, can you tell us about the typical milestones that are associated with developmental learning in young children? Development milestones are a way for folks to track and follow the way their child learns about the world and acquires functional skills of childhood. Some of the developmental milestones are fairly obvious such as physical growth, how big a child is, their height, their weight, their head circumference, all the milestones, the growth motor skills of crawling, walking, those are obvious, fine motor skills, how a child learns how to pick up small objects, a little child learns how to speak, that's a fairly obvious signs. Some developmental milestones are less obvious.

Moderator: Now, obviously every child is going to develop at a slightly different pace, but some of the milestones that you would expect start at or around 15 months of age.

Dr. Lucas: By 15 months of age, most children will make eye contact when a caretaker talks to them. Most children by that age will reach their [inaudible] in anticipation of being picked up, most children have good shared attention meaning that they will look to where their parent is looking, look at the object and then refer back to the parent to show that they're interested as well, they call that three point attention. At 15 months, that's usually well established. Most children by 15 months have a good deal of social limitation that reflects body language, facial expressions. By 15 months, a child should consistently respond to their name, they should fairly consistently turn. They should follow one-step commands, bring me your shoes, bring me your socks; give me the toy. By 15 months, most babies have at least a few spoken words. They should say momma and dada specifically for that parent and on average, 15month olds have a vocabulary of about three words.

Moderator: What milestones would you say you develop at about 18 months of age versus 15 months of age?

Dr. Lucas: They've expanded to about 10 to 20 words, although there is a huge range on when kids learn to talk. Their vocabulary is between 10 to 20 words, so they should point to body parts. By 18 months, you should see the development of pretend play, social imitative play. A child pretends to see a baby, pretends to see a doll, pick up the phone and pretend to have a conversation. They'll do things they see family members or siblings do. They should point out objects they're interested in. They learn to point, in the first year of life. A child will point to something they want, they call that photo imperative pointing, followed by proto declarative pointing; I'm interested in that, I'm pointing to that, by 18 months, that should be fairly well established, and they should be able to follow a point, so if a parent says, look over here, they should follow that and you should see their gaze diverted to that. If a child

doesn't point to demonstrate interest, then a parent should be concerned. If they don't copy, if they don't imitate others, that would be concerning. If they fail to gain new words or if they have words and all of a sudden they are really gone, that would be concerning, or if a child just seems to be disengaged, they don't notice when a parent comes into a room or goes out of a room consistently, that would be concerning.

Moderator: Can you tell us about milestones that we would see at or around 24 months of age?

Dr. Lucas: By 24 months of age, the vocabulary has expanded to somewhere between 20 to 50 words and a child will speak in brief phrases to the four word phrases, they call that telegraphic speech. They should show interest in other children and they should imitate what they see their parents doing, what they see other children doing, and the pointing. They should be able to point to items in a book, if you say show me the picture of the horse. They should be able to fairly reliably depict pictures in a book. If the child hasn't started to use words and phrases, if he or she doesn't know what to do with common household objects or if he doesn't copy the actions or try to imitate the words of others, that would be concerning.

Moderator: Now, you've identified some of the typical milestones that we should be looking for in young children as they develop and you've identified some resources to keep track of that development. Let's talk about what autism is.

Dr. Lucas: Autism refers to a group of disorders characterized by impairments in social interactions, language and behavior. There are a number of autism conditions. There's classic autism or autistic disorder, there's Asperger's and pervasive developmental disorder not otherwise specified.

Moderator: Now, I know there are specific-diagnostic criteria for autism. Can you tell us about the qualitative impairments in social interaction?

Dr. Lucas: Certainly, there's four of each. Under the social impairments, we say there's impairment in non-verbal behaviors such as eye contact, engaging with posture, with movements and with gestures. There's a failure to develop peer relationships, and again, it has to be appropriate to the developmental level. Oftentimes, children on the spectrum appear that they seek out peers and others but they don't keep those interactions going, they'll seem them out briefly and then tend to pullback. There's a lack of what we call spontaneous seeking to share enjoyment. We should see children, you know, constantly bringing their parents and their care takers things they're proud of, things that they're interested in and children on the spectrum don't do that reliably, and then there's a lack of what we call social and emotional reciprocity. They often don't read emotions correctly and they don't reflect emotional states all that well.

Moderator: And what about impairments and communication?

Dr. Lucas: Again, there are four things we look at. There can be absent or a significant delay in spoken language. There are impairments in conversational language. They can't hold up their end of the conversation. Oftentimes, this is tricky and I think this is one thing in the past doctors stumbled upon, these children interview beautifully and answer questions, but to have it be an open-ended question and then kind of expect a full sort of creative response doesn't always happen, so they have a hard time holding up their end of a conversation. They often have a repetitive use of language, one of the more frequent forms this takes is echolalia where a child will repeat the end of a question instead of repeating the whole question, they repeat a certain route phrase over and over again out of context, they offer scripted language where they repeat a phrase of a movie, a phrase of a video, a phrase of a book over

and over, and again the [inaudible] kids can do this really well in context but if you ask a parent, it's the same phrase over and over again. Then we see a lack of make-believe or social and imitative play, those are the things we talked about, feeding a doll or organizing their play, organizing their toys to act out something they've seen their parents do, that's really important.

Moderator: Can you tell us about the behaviors, interest, activities that we may see in these children?

Dr. Lucas: Sure, again, there are four things to consider here. They have an encompassing preoccupation with a restricted interest. Oftentimes, the interest can be inappropriate to the developmental level of the child, but it becomes sort of a preoccupation, it's hard to tease out sometimes because most children through their childhood have something they get stuck on or something they're really interested in but the difference here is for the intensity to be the preoccupation, does all of the play and all of the conversation sort of circle back to this one thing, and can they shift away from that. They often are fixed to non-functional routines and rituals. Now, all kids have functional routines like getting up in the morning, getting out of the house, getting ready for bed, but kids on the spectrum often have a host of routines that really don't have a lot of functional purpose, that's the difference there. They often have stereotypical or repetitive motor movements such as rocking, flapping, doing things with their hands or fingers and they have a preoccupation with the parts of objects, and the classic example here is instead of rolling the car on the rug or pretending to be the car making car noises, they kind of spin the wheel of the car and just kind of study the facet or a part of an object as opposed to playing with the object in a creative and symbolic way.

Moderator: Now, what do all of these diagnostic-criteria mean? How do we know if the child will be diagnosed autistic or maybe given a related diagnosis as opposed to specifically named autistic?

Dr. Lucas: Well, to make a diagnosis, a child needs to meet certain diagnostic-criteria if you have six of what I just mentioned out of the 12 criteria. If six are met, there are two social impairments, one language impairment and one behavioral impairment at least, that children will be diagnosed with autistic disorder. If there's no language impairment, yet there is a social and a behavioral impairment, at least two social and one behavioral, that child would have Asperger's, and if there's less of 6 or if the age of onset is over 3 or if there's what we call sub threshold symptomatology, that would be not otherwise specified.

Moderator: Thank you, Doctor Lucas for giving us a clear explanation of how autism is diagnosed.

Dr. Lucas: The current prevalence rate is 1 out of 88 children are diagnosed with an ASD by the age of 8 with one of 54 boys being affected. These disorders are almost five times more likely to occur in boys. There's been a 23% increase since 2009 and a 7-year percent increase since 2007. A lot of folks are wondering why that is. Why has the prevalence rate grown so dramatically in such a short amount of time? Certainly, we are now streaming for these disorders. I think parents, caretakers, family members, teachers, are much more aware of these disorders now waiting to increase recognition. Pediatricians are now screening for these disorders in their practices because we've come to realize that the more we intervene, the better prognosis, not just for the child but for the family so it's important to find these kids early. Most children however aren't diagnosed until the age of 4, even know it's recognized that early intervention help

Moderator: Thank you for that information. This seems like a good time to view a video produced by the CBS to produce and learn the signs for active campaign to help create awareness of about the topics we've been discussing. (Video being shown).

[Video]: In the U.S., nearly 17% of all children experience some form of developmental or behavioral disability. Recognizing a problem early for disabilities such as autism is key for parents and health care providers across the nation to help children with potential problems reach a healthier future, CBC realized the impact of development disabilities in terms of milestones that monitor just the physical .parents can gauge how their child develops how they play, speak and act.

When a parent is worried that a child may have a developmental problem, there are a number of things they can do, talk to their child's doctor, and contact the early intervention agency if their child is under the age of 3.

The early parents and providers recognize children that are delayed in reaching a milestone; they can help them reach their full potential. All children develop at their own pace and many reach particular milestones late or early.

A parent may notice that a child is not acting like the other children in their play group. The child is speaking later than their brother spoke; this is a time when a parent should go to their child's doctor.

The age that a child takes the first steps, smiles for the first time and waves bye-bye offers important clues. A delay occurs when a child reaches a milestone at an age later than the average developmental rate. By 8 months old, a majority of children turn their heads upon hearing their name, smile back when someone smiles, and enjoys playing games like peek-a-boo. 18 month-olds can engage in simple pretend play, point to an interesting object or speak in single words without prompting. By their second birthday, many children speak to 2 to 4 word phrases, follow simple instructions and point to objects or pictures.

Keeping track of how she plays, learns, speaks and acts is really important. Those are the things that those are the things that you can do as a mom to learn those early signs of child development, follow your gut, you're the expert in your baby and you can make a difference by letting her doctor know if you're worried about something that's going on.

Cindy Gray noticed her daughter, Catherine reach the milestones late. Even though other people were telling me that Catherine was fine, it was that she was premature and very small, I had a feeling it was something more than that.

Acting early and following the steps knowing what was wrong with her made all the difference to her.

To detect a problem early, connect early with your child and observe how they play, learn, speak and act.

We were so grateful that Catherine was diagnosed when she was because it allowed us to immediately get her the help she needed.

If you suspect a problem, act early. If your child's development seems to slow down or your child [inaudible] skills, seek a doctor's advice immediately, most of the time, a developmental problem is not something children grow out of on their own, but with help, these children can reach their full potential

Moderator: Well, that was a very informative video and just one of the many resources provided by the that we'll hear about later on, Dr. Lucas, you shared a lot of information with us as that physicians and parents can use to become familiar with autism. What does the American Academy of Pediatrics say about screening? You touched upon screening and the well-baby visits, can you delve on that?

Dr. Lucas: The American Academy of Pediatrics recommended developmental surveillance where parents were basically asked if they had concerns about anything relating to their child's development. A couple of years ago, they began to recommend developmental screening at various intervals at childhood, at 9, 18 and then somewhere between 24 and 30 months.

Moderator: What can you tell us about departmental surveillance?

Dr. Lucas: Again, that was what pediatricians really did for years where you ask a series of questions about developmental milestones – milestones. How is the child doing? Is he running, jumping, moving? We asked about language or any social concerns. But there was nothing really standardized or formal in the way that was conducted, and just surveillance alone was not an effective way to detect these types of problems.

Moderator: Are there specific screening tools that are used to screen a child with let's say stages of development?

Dr. Lucas: there's an expensive list available in the Journal of Pediatrics, two of the most commonly-used screens are what we call the ASQ, the ages and stages questionnaire. It's free. You can download it. It's very easy to use in the context of an office visit. It's easy to score up and it's also nice because it kind of serves as a parent-educational tool. Here's what we think your child should be doing. So, I like that. It has very good sensitivity and specificity as a screening instrument, the peeves, the parent evaluation of studies, there are codes devoted to developmental screening where this aspect of pediatric care can be reimbursed to help with some of the costs associated with this.

Moderator: Now, are there specific screening tools?

Dr. Lucas: Yes. They recommend a specific autism screen be conducted at 18 months and then again somewhere between 24 and 30 months. The one I think most folks are familiar with is called the MCHAT or the modified checklist of autism in toddlers, if the child screens positive, then a follow-up interview is conducted and that's free, you can download that, it's very easy to administer and then score up. There's also the infant and toddler checklist. Again, that's free to download, and again, the CPT, the screening code applies to this as well.

Moderator: With the incidents increasing so much recently, I would expect that professionals have come up with a list of red flags or signs that would cause concerns for parents as well as physicians. What can you tell us about potential red flags?

Dr. Lucas: certainly, if a child has a delay in spoken language or has what we call an attrition of language, if the language is developing well, you know, until about 15 or 18 months and then the child seems to lose language, that would be concerning. Again, a loss of words that were previously used fairly frequently, that would be alarming. If a child seems to lack non-verbal communication, doesn't have gestures, doesn't reciprocate, doesn't look you in the eye, doesn't gaze monitor, that would be concerning. If the child seems to look through people or parents often tell me, it's like he's looking at me but he's not, he's looking around me, he'll do everything to avoid looking at me or I have to socially coach him a lot, I have to say constantly, look at me, look at my eyes, that would be concerning. If a child doesn't take turns or doesn't imitate, that would be a concern, if the child doesn't do that proto-declarative points we talked about, if he doesn't look at things and point to demonstrate his interest. If the child doesn't have good joint attention, if he doesn't look at things, doesn't engage with a parent, that would be a concern or if the child has an unusual or repetitive movement, rocking or flapping, that would be a concern.

Moderator: And it could be one of the red flags or multiple hens of the red flags. Let's talk about what you would say to a physician who has some concerns about his or her patient's development.

Dr. Lucas: Again, part of the challenge of doing this as a pediatrician is we have a finite amount of time for a well-child visit and there's a lot of ground to cover these days. If there was a concern, by all means, schedule a follow-up visit to really just spend a nice block of time really solely focused on these concerns and on the child's development. You can certainly refer for an evaluation either with a developmental pediatrician, a neurologist or a psychologist, and then you could always refer to the local early intervention program or the local school district.

Moderator: What would you say to a parent who has concerns about how their child is developing?

Dr. Lucas: I think the first call should be to their primary care provider. Hopefully, this is an individual who understands the family and knows the child well and should be able to pick upon these concerns as well. The family can certainly contact early intervention or their school district if the child is over the age of 3 and then can reach out to other parents who are facing the same challenges. Parent to parent of New York State is an excellent group. They can contact their local Early Childhood Education Center.

Moderator: Now, we know that sometimes parents express their concerns about how their child is developing and they're told, wait and see, you know, wait and see. What can you tell us about that?

Dr. Lucas: I think for a lot of years, that was sort of what pediatricians did. We'll watch, we'll follow, we'll keep track. Now that we know so much more about the importance of the early intervention and getting these kids identified, getting services in place sooner rather than later, I think a lot of pediatricians and primary care doctors have moved forward in getting these kids looked at sooner so we've taken a step away from wait and see and let's chase this down and see what's really going on. If a parent comes in at 18 months expressing concerns and they take the wait and see approach for whatever reason, boys talk later than girls, all these things that we used to kind of believe, that can really slow things up. The child then wastes 6 months waiting and seeing. They can lose some valuable time. Oftentimes, these kids weren't picked up through preschool, the age of 3, 4, even as late as kindergarten and obviously that's a valuable time lost.

Moderator: Thank you so much for that information, Dr. Lucas. The message you're articulating today to both physicians and parents. If there's a concern, action should be taken.

Dr. Lucas: Absolutely. If a parent's concerned, talk to your doctor, get an evaluation done and don't be afraid to act on it.

Moderator: Thank you so much. With that in mind, I think this is a great time to hear from a mother about her experiences as a parent of an autistic child and the role of early intervention

[Video]: Hi, I'm Luanne and I live in Albany, New York with my husband Dennis and with my two children Jonathan and Kate Lyn. I suspected that Jonathan had autism early on, even as an infant. He didn't act as a typical child. He took bottle after bottle, he was never satisfied, he was a very fussy baby and then I began to become really concerned about 12 months of age. That's when I contacted my pediatrician. My initial response was that the pediatricians told me they think that Jonathan fit the profile of an autistic child. Again, he recognized Jonathan was social, he had the social smile, he seemed to be connected, but he wasn't listening to these other concerns that I had, and I made numerous calls, five or six calls, frantic, crying. I said "No, I think there's something wrong developmentally here. By the time Jonathan received services from early intervention, it was six months later than when I first

brought my concerns to his pediatrician. He lost six months of intensive services because his pediatrician did not listen to my concerns. I would definitely tell other parents that have concerns about their child's development not to stop, to really try to pursue getting help. If they feel that something is wrong with their child, they usually are right. My daughter Kate Lyn is 7 years old, at 12 months, I asked my Service Coordinator to have somebody come out and evaluate her. I knew new something wasn't right, and early intervention came out and said, you know, I'm not ready to give services yet, let's wait a little bit. I said no, let's have somebody else come out and give a second opinion. That second opinion proved helpful because they shared my concerns with her as well. We as parents of autistic children have different stressors than typical parents. I want them to be a little more sympathetic of our needs. Waiting an hour and a half in a waiting room is not good for a child in an autistic spectrum. Typical peers can handle things better, they cannot wait, so if they can come up with some strategies to help the parent out a little bit and to not make us wait so long in the waiting room or to understand what we're going through would be really helpful.

Moderator: What an incredibly powerful video! It's really great to hear from the parent's perspective of what their needs are and what their experience is like. It's just tremendous, now, Dr. Lucas. You gave us important information for development screening and early intervention. Dr. Noise, we'd love to hear from you no. What is New York State doing to promote early-intervention screening?

Dr. Noise: I would be happy to. I would like to tell you about the Early Intervention Program in New York State. It is under the federal Individual Disabilities Education Act. Part C of that act, in our state, the service system has been in place now for 19 years, going on 20, and we serve about 70 thousand young children and their families every year, we have a whole variety of therapeutic services that is a program designed in conjunction with the family, so it's a family-centered service delivery system and families play an important role.

Moderator: Dr. Noise, what can you tell us about the different grants that the department has received?

Dr. Noise: We have several grants specifically related to Autism. Two of them are funded by the Health Resources and Services Administration. There's one under the [inaudible] Autism act funding at the federal level, one is a state implementation grant that's designed to help us design and implement the plan to improve services for children in autism spectrum disorders and the second one is the Maternal and Child's Health Autism Research Program. We're looking to evaluate the impact of early intervention services in New York State on children and families with autism spectrum disorders and we have two grants from a private foundation out of New York City that really provides funding to support children, families and communities in need. One of them will expand their efforts to train physicians in early identification and interventions related to autism and the second will help us update critical practice guide laws that New York State issued in 1999. We were the first state to issue clinical practice guidelines related to the assessment and treatment of young children with autism.

Moderator: Now, what are the key goals of the state implementation grant?

Dr. Noise: Our key goals are really to promote the AAP guidelines for universal screening for autism-spectrum disorders that Dr. Lucas was describing for us earlier. We wanted to make sure we're engaging and supporting pediatricians and family physicians, not only to refer children to intervention services and once they have a family engaged in early intervention, to stay involved in those services

Moderator: What can you tell us about training for physicians?

Dr. Noise: We have designed a program for physicians that are really a two-part evening training session. It provides CME credits for physicians and the first part is on early identification and screening so we describe how to incorporate universal screening for ASD's and other developmental concerns in MD practices. We have a developmental pediatrician practicing who does that for us, we have intervention screening and surveillance and how important that is, we introduce doctors to resources that are available to help assist families in their practice and to help them assist their practice in screening for autism spectrum disorders, as well as other developmental concerns.

Moderator: I understand there are some online resources as well.

Dr. Noise: Yes; we have developed in our state a portal for physicians that are housed by our Department of Health Commerce System that DOH Commerce System is a secure network and physicians access that routinely for a whole variety of functions. We have a portal that's specifically designed to help physicians learn about autism spectrum disorders and the resources available for autism spectrum disorders.

Moderator: Well, before we delve more into the online resource, I'd like to go back to the physician training, that's important. If you can give us a little more information about the two-part evening training and what's entailed in that

Dr. Noise: Sure, sure, so we talked about the first part of that training really being focused on early identification and screening. The second evening is focused on how to communicate with families once you've made a diagnosis of autism and we have families participate in that session with us. We also talk with physicians about what the best interventions are for young children with autism spectrum disorders and again the importance of staying involved in the early intervention and we also talked to them and Dr. Lucas has done much of this training with us. We talk about the medical needs of children who have autism spectrum disorders.

Moderator: Back to the online resources. When the physicians go on to that -- into that portal, what do they see when they go into that first page?

Dr. Noise: It is the welcome page for them. It features a navigation bar that tells them about all of the resources that are available in the portal.

Moderator: What resources are in that portal?

Dr. Noise: Lots of resources or suggestions. We have designed the portal so that there are links to many pages that describe what's available in New York State, what some of the most current information is available for autism spectrum disorders and where they can find local resources in their communities.

Moderator: The physicians would also be able to locate information regarding additional resources through that portal?

Dr. Noise: Absolutely; for example, if they have a concern about a child in their practice, they can go right to that portal and find local resources, how to refer the child to early intervention, what parent supports might be available. There are many resources that would help them support the family.

Moderator: What about if a physician needs to refer a child for early intervention services?

Dr. Noise: The portal will direct them to the county that -- so, let me step back and say that in New York State, early intervention is administered locally by New York City in the 57 counties, most often in county health departments, so the portal will direct them to the county department responsible for early intervention and give them really explicit instructions on how to make that referral for a family.

Moderator: And what if a physician wants to ask a question via the portal, is there an opportunity to do that?

Dr. Noise: There absolutely is. In fact, we are collaborating with our university centers for excellence and responsibilities we're able to have three of those in New York State. We have psychologists and developmental psychiatrists who are available to answer any questions that physicians may have.

Moderator: Those are just excellent resources that are available online for physicians. Are there other training tools that the department provides as well? Are you conducting other-- are there other training offerings for physicians?

Dr. Noise: We are, in addition to that two-part series that mentioned, we've also been working with the American Academy of Pediatrics and the Academy of Family Physicians to try to incorporate our training activities into their meetings with physicians, so our staff and our trainers have gone to state-wide meetings where physicians have gathered for example to learn about immunizations for children and we've incorporated training into those forms for physicians, that's been a great way to reach physicians. We also are currently working with the Academy of Family Physicians to do series of ground rounds in hospital settings based on the CDC case-- autism case training so we've made an effort to try to reach physicians where they are with this important information.

Moderator: What resources are available through New York State's Early Intervention Program, if you can take us through that, that would be helpful.

Dr. Noise: Sure, we have a whole variety of resources available. As I mentioned earlier, the services for families are at no cost to families, so there are a whole range of services for families available. We have a wonderful home page, on the Department of Health Home Page for early intervention and that includes information about the program itself, information about our parent guide for families, we have our clinical practice guidelines posted, anything you want to know about the early intervention program can be found on that website.

Moderator: And are there other websites where viewers can find information as well?

Dr. Noise: There are. There's an inter-agency website that's been sponsored by our Office of Disability Responsibility, it's called New York Acts. It's a resource for families and professionals, the Office of Professional Disabilities provides a whole range of services for individuals with developmental disabilities including individuals on the autism spectrum, they have a great website, our State Education Department provides a whole host of educational services for children with autism spectrum disorders and other developmental concerns, they have lots of information on their website. Finally, we want to highlight the [healthytransitionsnu.org](http://healthytransitionsnu.org) website, that's specifically for individuals, young --youths who are in the 24 to 25 age range and are transitioning from childhood services into adult services.

Moderator: Terrific, and in addition to the resources available through New York State, can you tell us the resources that are available through CDC?

Dr. Noise: CDC has a wealth of information on their website around early-childhood development. We have taken advantage on the *Learn the Signs Early*, all of these brochures are free, they can be ordered on line.

Moderator: Does the CDC have resources, you know, that go more specifically into acting early? Tell us a little bit more about that.

Dr. Noise: They do, they have again a whole host of resources geared towards early childhood professionals and families that provide good information about child development, how to monitor child development, what you should be looking for, what you should know, really all the things that Dr. Lucas was mentioning earlier are well explained and well accessible to people on the CDC website.

Moderator: This has been such great information and what's even better is that that you provided contact information where viewers can obtain more information if they'd like. We greatly appreciate that and we do have questions that have already come in that we'd like to get to you.

Dr. Lucas, the first question is for you, if there's a concern of autism on a screening test, what's the next step?

Dr. Lucas: Certainly, I think the first step would be to schedule a follow-up visit with the child's pediatrician so that the concern can probably be flushed out by someone who knows the child well. The next step after that is in fact the positive screen would be a referral to either a developmental pediatrician, a neurologist or a psychologist. Again, also there can be a lengthy wait to see one of these professionals so the next call should also be to an early intervention agency if the child's under 3 or the local school district if the child is under 3.

Moderator: When you say a lengthy wait, can it be months?

Dr. Lucas: Yes, it can be months. The recommendation is don't wait until a diagnosis is formally applied. Get services in place, assuming that there's an issue. Contact early intervention, get services in place, and see what the diagnosis is after that.

Moderator: Thank you, and Dr. Noise, here's a question that's come in for you. If parents have a concern and think that their child needs early intervention, how do they get a referral?

Dr. Noise: Well, there are a couple of ways that that can happen. Again, we also would really recommend that families contact their primary care physicians first and have that initial conversation about their concerns. The physician can assist the family in that referral, or a family can directly refer their child to the early intervention program if they have concerns, so if they're feeling like they need to reach out directly to the program, they certainly can do that and make the referral directly.

Moderator: Thank you. And now, I'll direct the next question to you, Dr. Lucas, if my doctor says wait to see but the parent's concerned, what should I do to get a second opinion. Is that something that's routine if the doctor in fact says wait to me, everything appears to be okay to me, the child isn't staring off, don't worry about it, calm down, you know, you're a first-time parent, these are the type of things that a parent may hear. Can that parent call for early intervention?

Dr. Noise: Absolutely. I think there's certainly no harm in getting another opinion, so whereas years ago, we would take more of a – not a laid back approach, but we would wait and see and give it a couple of months. I think now that most folks are more proactive.

Moderator: Okay, Thank you. Now, you mentioned earlier that there are support groups for parents, please repeat the names of those support groups because some of our viewers are wondering about the names of those, or how they can gain information from the support groups.

Dr. Noise: Yeah, Parent to Parent of New York State is really a wonderful resource for families in New York, so I would – and I think that we actually had provided earlier information about Parent to Parent. I think that's a great place for families to start.

Moderator: Thank you. Let's see if we can go through some of these questions here. Here's one for you, Dr. Lucas, are there any special medical needs or concerns for children with autism?

Dr. Lucas: Certainly, I think it's important to recognize that it may be hard to address a medical concern in a child with developmental delays and/or autism in the span of a brief 15 minute office visit, so I think it's important for clinicians to give these patients and these families extra time if it's at all possible. Kids on the spectrum do face a higher risk for certain medical disorders and medical conditions among those, children on the spectrum have a fairly high incidents of GI related issues, issues with reflux, constipation, abdominal complaints, and especially if the child is non-verbal, it's difficult to figure these out. Behavioral changes, irritability and aggress, so GI complaints, they can be seen in upwards of 75% of kids on the spectrum, very common. Sleep disturbance is very common; anywhere between 50% to three-quarters of kids on the spectrum experience significant sleep disturbance. Sleep plays a very important role in development and in behavior, especially with unwanted behaviors, irritability and aggression, very important to make sure you know what's going on with the child's sleep. These kids are at higher risk for sleep disorders. Other concerns, seizures are also much more common in children on the spectrum, other neurologic conditions, so certainly these kids have other medical issues.

Moderator: Thank you. Here's a question that perhaps either one of you can address. If someone's received a script from their MP with the diagnosis of provisional autism spectrum, what does this mean and what advice should this physician give the parent?

Dr. Lucas: Probably the best advice there would be to give services in place, to have an evaluation through EI or through the school district, get services in place while you're waiting to get the diagnosis confirmed by a psychologist, a developable pediatrician or a neurologist.

Moderator: Thank you, how can medical folks attend training, where are they held?

Dr. Noise: Oh, that's a great question. Right now, we are planning some training sessions for the Long Island Area of New York, and I think the best way for them to learn more about when those training sessions will be happening, if they're in that area of the state, would be to contact our office and we've already provided information about how to reach us, so I would say contact us. We are also posting information about our training sessions on the physician portal, so it's a great place for them to check about what training sessions are up-coming and how they can access them.

Moderator: Are resources available in the State of Pennsylvania, do I have access to the New York State portal if this person is in fact in Pennsylvania; if not, is there something for me here in Pennsylvania?

Dr. Noise: Only physicians have access to that, it's a special site for them. Our public website is available to them. I know the State of Pennsylvania has a very interactive early intervention program and there's some wonderful websites to help families and providers to help about early intervention programs in their state, there's an organization called NEC.TC. It gives families and professionals access to that website. It's a national technical assistance center funded by the Department of Education that

provides support to both states and all folks involved in early intervention services. It also provides information about every program in the United States.

Moderator: Two quick questions before we close out the program, can you comment on people's first language, a child with autism rather than an autistic child?

Dr. Lucas: I think that's an excellent point. Certainly, there's no two children with autism that are alike, you know. The mantra is if you met one child with autism, you've met one child with autism. This is a polymorphous group of disorders. Just like no two children are alike, there are certainly no two children with autism that are alike. It's important to remember that first and foremost, they're children, they're children with issues but first and foremost, they're children, so that point is extremely well taken.

Moderator: Thank you, and for the parent who suspects that they may -- their child may be on the autism spectrum but perhaps has missed an early diagnosis and they're now in their teen years, is there help or support for that child who suspects that their child may be along this spectrum but did not receive any of the early diagnosis or any of the early intervention and did not have access to those resources and now they're in their teen years.

Dr. Noise: There are services available. Certainly, I think we would also again say that physicians are important in helping families find resources, even when their child is in their teens. Actually, many of the physicians who attend our training have specifically asked that question of us too. What resources are available for older teens, in our state? The State Education Department again, school districts provide a lot of services for people in youth with autism spectrum disorders. The Office of Persons with Developmental Disabilities is a very good resource and there are regional disability services across the street. Another great resource is the Developmental Disability Planning Council. They have lots of information.

Moderator: Thank you very much, thank you for being here today and providing this comprehensive information. You've got just a tremendous job and continue to do tremendous work both in New York State. We both appreciate your being here and helping parents and physicians. Thank you so much.

Dr. Lucas and Dr. Noise: Thank you for having us.

Moderator: Thank you for joining us. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs and continuing education credits are available. To obtain nurse continuing education hours, CME and CHTS credits, learners must visit [www.phlive.org](http://www.phlive.org) and complete an evaluation. The post test for today's offering for this show will be on our website in two weeks. Please join us on May 17 for the public broadcast on Public Health Live which our topic will be HIV and Aids, and Strategies from the Field. I'm Joelle Alexander; thank you for joining us on Public Health Live.