

Transcript

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Alright, I am thrilled to be here, and I'm gonna be talking this morning about Improving Developmental Trajectories of Toddlers with ASD, Autism Spectrum Disorder, Strategies for Bridging Research to Practice. And I'm going to begin with my disclosures.

I'm employed by FSU. I receive grant funding from NIH, U.S. Department of Ed, and the CDC. I... am the author of the CSBS and the SCERTS model, and receive royalties from Brooks Publishing but not for the research studies that I do. Own, I'm owner of a new company called Autism Navigator LLC, and I do not earn any salary but and, 100% of the profits are donate to nonprofit support to disseminate the courses and tools to families. And lastly I received a speaker stipend from ASHA this year; I think it's my first in 35 years, and, preregistration, which is much appreciated. So I'm thrilled to be here and be part of this.

What I hope to cover... sorry about the frame of my articulators. Um... what I'm planning on covering today is to start to do a quick overview of what does the research tell us about early intervention for toddlers with ASD. And then I'm gonna share with you how we, how we can change developmental trajectories of toddlers by starting early, and share some of our findings on the early social interaction project. But probably more ec, I'm more excited to share some of the video clips. And then... so that'll be kinda the first half-ish. And then I'm gonna in second half talk about how do we bridge the research to practice gap, and talk about rolling out Autism Navigator which is a collection of online courses and tools using extensive video footage.

So I wanna just frame my presentation with a problem. It is a financial one, and that's a reality that we need to think about. The lifetime societal cost for one child with autism ranges from \$1.4 to \$2.4 million, and the million dollar difference is whether there's a comorbid intellectual disability. So if you can prevent that you can save a million dollars. And you also can improve outcomes dramatically. But we also hope the next generation we can improve the social communication symptoms as well and improve outcomes in adulthood. And that's gonna save a lot a money, but most importantly quality of life. ‘

So the American Academy of Pediatrics recommends developmental surveillance of every well child visit from 9 to 24 months, and to screen for autism at 18 and 24 months. For all children. Imagine that; all children. Autism can be diagnosed at 18 and 24, between 18 and 24 months, which is why we should be screening. And yeah, here's the bad news; the median age of diagnosis in our country is 4 to 5 years. So that's a gap that we need to close. Children of minority, low income, and rural families are diagnosed a year to a hear and a half later. That's a disparity that we need to address.

So this is a huge problem that costs a lot a money and impacts families for the trajectory of their child's life. We need to do better as a society, as a country, and we're probably doing better than most countries. So how do we mobilize community systems to overcome these barriers? And really it's gonna require a pretty major system change. The, the issue relate to being able to

screen in primary care. It's recommended, but the quality of screening tools, the actual getting people to screen in primary care, getting them to share the results with families if they do screen. Getting them to stop saying let's wait and see. Uh, family acting on the screening. So early on they don't know it's autism yet. They are just noticing a communication delay or language delay, which is why SLP's play a critical role. And they may hear the positive screen for autism, but not buy into it, and not act on it. So helping families the engage and act, and then lastly; woops, too quick; and then lastly, is there really aren't sufficient qualified professionals who can make an accurate diagnosis, especially that young, and provide evidence based service delivery. So all of you who are here today, are the professionals of the future who are going to train the workforce, and so you are critical to this system change. So you have job security. There's a huge need for you.

So there's this really nice article that's an open access article as a reference, which was a consensus statement developed by a group of autism researchers, which coined the name and defined... really ABA for young children with autism, which the evidence base suggests that it's naturalistic developmental behavioral interventions. And this is a really nice article that indicated the empirical data on toddler intervention supports the use of naturalistic approaches, as well as incorporating developmental orientations. Um... and there's another really nice set of research articles that are synthesis of the research by Zwaigenbaum et al, and on early intervention for children. This was both early detection; this article's on early intervention. So these are great resources. This review 24 interventions, and concluded that the central role of the parent and interventions designed to incorporate learning opportunities into everyday activities, capitalize on teachable moments and facilitate generalization skills. And so the one thing I hope to leave you with today is a idea of what this looks like.

How do we, what do we know about toddler treatment/ Really there's not that many studies published yet. But there are a growing number, including RCT. So we know there are clinician implementer interventions, a large study done by Dawson et al. Dawson Rogers et al, and study by Landa, Becky Landa who's here today. And they were able to demonstrate improved outcomes of children, the Denver model uses 20 hours a week. And Becky was able to in 10 hours a week, over 6 months, a little less intensive, but still more than the State of Florida would provide, and many states. But it still was able to demonstrate improvement. Now there have been a number of parent implemented. But the, the in—outcomes have been much more modest on the children. So the parent implemented RCT's, there have been quite a few now, have in, been able to demonstrate change in the parents. So parents can become more pa—responsive, more synchronized, improve interaction skills. But they have not overall found significant effects on the child outcomes, particularly on standardized measures. And I think a big reason is they're so low intensity. Like the amount a time that they spend with a parent and the length of time is so brief, that who could learn in that amount a time? And you're not gonna see the change in the children. So this just shows some examples of the main studies that have been done, and these children range from 20 months on up to preschool age. The Green et al; study. And many of these are really 3 months; 2 months, 3 months. The 12 months are once a month, or... so the most is 3 times a week, for, for 2 months. 18 sessions over a year. So that's probably not enough. I think what we can conclude is you can make some change as a parent, but not enough to change the child or measure the change in the child. Now there's a new study

by Green et al, the team in England that followed their sample till 10 years later, and they continued to get changes. So some of this, the change to the child may take a while.

So what we know is it, it, intensity matters. So if we look at the early start Denver model, the 20 hours a week, the National Research Council recommended 25 hours a week for preschool children. This is really needed to actively engage the child with autism and change their trajectory. So we need to figure out how do we get this level of intensity, because it is, it can be a really significant disability that can get worse if they're not actively engaged in a good learning environment.

So we tackled this problem when we developed the ESI model, the Early Special Interaction Model. We got funding from the National Institute of Mental Health, and we started with funding from Autism Speaks to get started. This, this study took 7 years. Treatment research is not quick. And this was collaborative with, um... myse—I was the PI at FSU, Florida State University, and Cathy Lord was at University of Michigan at that time. And we did publish these findings, in *Pediatrics*.

I'm gonna do a quick summary of what ESI is. It's family centered, the principles. It's, oh, I see. (laugh) Thank you. This is, (Laughs) this is Sherry Stronich(?) one of my former doc students, who's at the University of Minnesota and they know me well. And then my current doc students are here too, and made sure I had copies—good copies. I had copy, but not good copy, you know. I'm good now.

So these are the principles of ESI. A family centered approach, 'cause we're talkin' about birth to 3. You know we're talkin' about something that should fit within the part C, IDEA Part C Early Intervention System. It's embedded in the natural environment. So again, that is what part C is, is all about. So we wanna do that. And that's gonna enhance generalization, for not only the parents but the child. Parent implemented. So we wanted to tackle this parent implemented. We wanted to figure out a way that we could coach parents and they could learn and they could change their children, significantly. We wanted to get the 25 hours. So basically we were asking parents to do intervention with their child 25 hours a week. But we did it in a way that they were doing it in activities that they were already doing. So we used activities they were already doing, we just helped them spruce up those activities, so that their child with autism would pay attention and then learn.

And then we wanted to incorporate evidence based strategies, really blended behavioral and developmental. So Helen mentioned that Barry, Barry was actually a student with me. I think he claims he's a mentor, but, and he is, but I, I've mentored him as much as he's mentored me. He was a graduate student, I was an undergrad at Buffalo, that's where we met. And then I went to school. So my mentors were at UC Santa Barbara, Carol Prodding, learned everything so important from her. And Bob Kegel. So I got this pragmatics and behavioral. And then I moved to San Francisco with a joint program and got to work with Adriana Schuler. So those were my mentors. And then yes, wonderful. So I am thrilled to pass on my knowledge to you; it's an honor and privilege, 'cause neither Carol or Adriana are still alive, so I treasure what I learned from them.

So then we needed a curriculum, so we used SCERTS. And SCERTS is a curriculum that was developed by Barry and myself and Emily Ruben and Amy Lorentz. And it's an acronym. It stands for Social Communication, Emotional Regulation, those are the child targets, and Transactional Support, which is the teaching strategies, TS, which is what we taught parents. So that was our curriculum that we used. So we had to come up with a way to do an RCT that I could live with. And what that means is I didn't want a no treatment group. I just didn't feel right about that, and I'm not judging anyone else to do that, that was just not something. So we put a lot of thought into how could we do this, and it leads to, to complications. Every decision in research leads to a complication. So what we did was we... we decided to have 2 conditions, and the, the families were randomly assigned, so there's dyads. We had 82 children and their parents in the study. They entered at 18 months, and an age. So we identified them and they were diagnosed and entered the study at 18 months. They were randomly assigned to either individual or group ESI for 9 months. And then that we had a crossover design. So then they crossed over and got the other condition. And that's where the confound is. So they got both conditions, so at 36 months we know less than if we had a no treatment. But I could sleep at night.

So we employed this crossover design, parents, and I think it also helped with attrition. 'Cause parents, if they didn't get the treatment they wanted, they knew it was coming. So really, the first condition was the most important, so we were able to compare. Individual was 3 sessions a week, two in the home, one in the clinic. We wanted a treatment that was feasible for the states like Florida, that pr—don't provide intensive early intervention. So 3 sessions to, for 6 months. And then we went down to 2 sessions. And then the group was once a week, and a group community, uh, play group, 3 to 5 families. So it was actually more like the intensity of the, many of the other parent treatments, but it was for 9 months.

So what we taught parents is how to incorporate strategies into everyday activities. And this was the grouping that we taught them. So these are the things you're doing with your child, let's help you learn to do them better, so that your child with autism will learn. So play with people, play with toys, and then meals and snacks and caregiving are things they should be doing if they're not already doing every day. Book sharing, and then family chores is, I don't know that others do this, but we find that great; if you're doing your chores, why not incorporate your child into that. We have a very specific coaching model which is really based on the notion of deliberate practice, so we wanna get the parents ready to reflect, because we're only with them 2 sessions a week, or 3 sessions a week. So what they do when they're not with us is what matters. So we move them up this coaching arrow as quickly as possible. We start with figuring out what works, we first build consensus on what we're targeting, and what activities, figure out what works. We explain and we only model if we have to, 'cause once you model then they think you have the magic. It can undermine their confidence. And then as soon as they know what we're working on, then we, let's do it together. Guided practice with feedback. Then we try to back out as quick as we can to caregiver practice with feedback. So now the parents are running it, but we're there helping and giving feedback. And then we completely back out and they're doing it on their own, and they're reflecting and we give them feedback on the reflection.

So we move up the model. Within every session, we usually do 3 to 5, we try to do 5 activities. Our targets are organized around our operationalization of active engagement, and we have 8

components. Is the child well regulated; if they are, we teach the parent that’s when you push. And this is really the behaviorist in me, which is really important. So if they’re well regulated, you need to be pushing. If they’re dysregulated, then you add support. And if the moment they’re regulated, then you push. So you can move back and forth within an activity. Is, are they actively participating in, in a productive role? Are they engaging in reciprocal interaction? And we have 4 different components here. We start with socially connected, and we don’t push the eye gaze until next. We start with are they socially connected with you. ‘Cause if you require them to look at you it can overwhelm them, and we wanted to first get them connected. Then we teach them shifting their gaze to your face ever so briefly. And then we want them to respond to verbal bids for interaction, and initiate communication. So those are the different components of what becomes si—reciprocal social interaction. Then we layer on it after that, are they flexible, and generative. And generative means do they actually come up with the ideas on their own. ‘Cause we know the children with autism tend to be a bit rote in what they learn. So we wanted to try to preempt that from the beginning.

Our TS’s we organize them into a layer cake where you’ve gotta make this fun. You gotta make it as simple as possible and fun for parents so that they’re gonna learn it and incorporate it. So we have a layer cake. This became really, um, they liked it, popular.

So the first layer is supports for a common agenda. You are working together to have a common agenda, and there’s 5 evidence based strategies in the first layer. The activity should be motivating or you need to make it motivating, figure out. The child should have productive roles, there should be predictability, beginning, middle end, and then you build the middle longer. There should be good positioning. So you saw his bad positioning but it wasn’t enough. And you didn’t have all of these strategies. And then you follow the child’s attention and focus. That’s at the first layer. You don’t follow the lead forever. You do it when you’re tryin’ to get a common agenda. Then we layer on to that supports for social reciprocity. And we have four; promoting initiation, balance of turns, natural reinforcer, and clear message to ensure comprehension. So we layer this on, and the layer cake metaphor’s important, ‘cause if you, you have to keep using the first layer supports or the cake will cave in. So this is cumulative, and then the top layer is supports for better skills. Model, and build language play interaction skills, extend the activity. So now you have a beginning, middle end, you extend it. Build the middle longer. At, ec—add more child roles, and add transitions between activities. And that is how you get the 25 hours. You adjust expectations and support. The moment the child’s well regulated you increase expectations. The moment they’re dysregulated you add supports. And you wanna have more and more moments of, of good regulation. And then balance of interaction and independence. So we don’t only wanna work on interaction, even though it’s im, it’s critical. We’re tryin’ to get kids ready for gen ed kindergarten. That is ultimately what is going to change children’s lives, is if you can get them ready to succeed in general education kindergarten, the rest of their life will be much better. In order to do that, they need to be able to manage themselves in a preschool classroom and be ready to be around a bunch of other kids. So we need to not only build interaction but also independence. So we help them balance their week, so that—the parents need down time. Their kids need to do some things independently. So that’s kinda the last piece that we wanna leave them with to get them ready for preschool.

I wanna show you our findings, and then relate it back to the video. So we were able to get a significant time by conviction interaction comparing the ESI group or the ESI individual in the first 9 months on the SCBS social composite, that so those in ESI Individual, did significantly better on the so, on the social composite, of the CSBS, which is the sampling procedure where they're, we're looking at their use of social communication in a naturalistic, but yeah, contrived, uh, clinic sample, on the Vineland Adaptive behavior and Communications Social and Daily Living domains, and the on the Mullen, the most, I'm the most proud of is Receptive Language. And I think it's what you were seeing that builds receptive language. And significant time effects on many other measures. We found significant main effects, no interaction, children in both conditions. So this was the benefit of the group only, but we have also the children in the individual showed significant improvement in speech and symbolic on the CSBS, on the ADA social affect, and on the Mullen Expressive Language. So this shows what the group only can accomplish and the advantage of those extra individual sessions. And these are the charts. This is in our pedes article. So I, uh, you can kinda see the you know big change over 9 months in the two groups.

I also wanna mention we have an ESI website. There's no www before this. So it's esi.fsu.edu, and especially for those of you that are listening to this after, and can't see the videos, we do have 3 families of videos posted there that you can go and see that we take you through change over time.; And Isaac's one of 'em, Devon's not in that. But all of these are in the Autism Navigator professional development courses as well.

So in terms of our TS, we have a measure to, to parcel out what the parents are learning. We have 8 different components that we're looking at and comparing across conditions. So this goes along with, I went through the AE, the, the child's active engagement. These are the things the parents are doing to try to get the child more active engaged. So this shows a chart of our change in that measure of TS comparing the two groups. So by 58 days, we were seeing the individual condition pull ahead, and continue to stay significantly ahead. Again, the, the in, the group was learning something. and we're working on, so our next steps with this, um, we're working on sorting out the active ingredients of treatment. So, so we're hoping that these 8 different components just sort of, um, what's showing up now is for example, in group parents learn to follow their child's, uh, their child's focus of attention, so that TS we're not seeing differences, 'cause both groups are getting it. But, productive roles, they're not getting that from group, they're getting that from the individual. So we're beginning to look at which of these can they learn in which conditions, and then what makes the most difference. So we're real interested in, woops, let me, alright, sorry, they keep. Oh well, it's not gonna go back.

So we're sorting out the active ingredients of, of the treatment, and the characteristics of the treatment responders, 'cause not everybody responded as big as others. So tryin' to understand that. We're following up our first ESI RCT group, these children into school age. So we're bringin' them back at 6 to 8, to see how they're doing. Now the confound there is they've had both conditions. But... but it's still interesting to see did it matter if you had the individual first. So we're following up the sample. We're also comparing, this is really exciting to me; we're comparing, 'cause I'm a tech person, we're comparing mobile coaching, using telehealth with face to face coaching. So our further, our previous study we went to the home. Well can we just mobile in? You know like the parent can wear somethin' like this, or just a, uh, earbud and they

have their phone or their iPad, and then we can talk to them, we can be there, we can see what they’re seeing and coach them. The thing we can’t do is model, but that’s actually good. So we’re having fun. We just finished a feasibility study with 15 families, and then we’re gonna be tryin’ to get grant funding to study this and do an RCT.

So then we’re also studying the effects of ESI as part of the Emory ACE, Autism Center of Excellence. They just finished their last 5 years with their ACE One, where we started ESI at 12 months. We’re still running it, so we’re sort of a year behind, ‘cause they recruited the kids. We have one more year of treatment. Um, and then we, they just got a new ACE, their ACE Two where we’re gonna down to 6 months. And we’re, so I’m very excited. And we’re doing a smart design that you’re gonna learn about from Connie, so I’m real excited about that. We got a new ACE network which I’m really excited about. I’ve tried and failed, so that’s a lesson for those of you. You gotta try, and Judith taught me you gotta have perseverance. And you taught me about that, and the grants, right. You gotta stick with it; and manuscripts too. Don’t get bothered by the rejection, just keep trying. Use the feedback and make it better.

So we study in our new ACE Action Network which is with folks in Florida at FSU in Miami, and Boston University, and, um, elsewhere, we’re gonna be training family navigators. So a bit more cost efficient workforce on ESI and on an engagement strategy including problem solving education and motivational interviewing, and really trying to reach, engage, and coach underserved families. And then we’re gonna go to California through Kaiser Permanente. So I’m very excited.

And then lastly we’re very—the Autism Navigator which I’m now, um... and I lost my time log ‘cause I started over. So I’m hoping I’m a little more than half over. So, stu—um, we’re gonna study community implementation of tryin’ to train others the Autism Navigator and other materials, to bridge the research to practice gap. So that’s what I’m gonna turn to now.

So, we, we need, we have a very, very broken system. And I’m here to say that we’ve, have a lot a different grants, that we’ve tried a lot a different things, and we failed; a lot a things don’t work. And then I just get up the next day and go well you know, this is really hard because it’s very broken. So there’s, you gotta try and learn and make it better, and then try again. So we think it’s gonna require this, to build the capacity of community, is to improve, in order to improve early detection and access to care, we really need to get the EI system to work with primary care. And when we say primary care, we mean everything from primary care physicians all the way out to childcare. So we mean anything in the general population. So we gotta work together. And then woops—and then the family. So, we gotta work together as a care team, and then the family needs to be in the driver’s seat. So this, does it look like a shape? What shape is that? It’s kinda like a tricycle. So the family is the front wheel, the EI provider and primary care are the re- rear wheels, and the reality is, we don’t even have the tricycle build yet. So we gotta get the wheels on, and then we gotta get some momentum going to change the systems, what’s up, what’s in for us. So we’re hoping to contribute to that through Autism Navigator. We have developed a collection of courses. So the first one that we built is the Autism Navigator for Early Intervention Providers, the knowledge and skills level, it’s 30 hours, and the videos you’re seeing are all in that course. It’s 30 hours of professional development, it’s completely self-guided, self-paced. We got funding from the State of Florida to build this. They see this as cost

saving. It’s a good investment. They invest in us. Because we’re, we’re improving kids in Florida and then hopefully around the world. And they’re going on and we’re tr—our target is to increase getting them into kindergarten. And we’re doing good. We’re way above the state average. About twice the kids that come here are project.

So this is the content we teach. This is to teach people that work for Part C which I hope is speech pathologists and other early intervention providers. What does autism look like, how to coach families, what is normal development, and then, the me, unit 4 is 11 hours, is this evidence based strategies of how to coach the families and how to, what’s the A, the AE and TS’s are all about. and then Unit 5 is on addressing challenging behavior. . So it’s a really meaty course. we’ve been rolling it out. We really have several thousand users, and it’s very exciting. And we’re in 7 or 8 states and in a couple countries, so we’re excited.

So then the, we also have primary care and family tools. So we more recently built the Autism Navigator for Primary Care. And it started with one hour and then we literally had doctors on our advisory board say well we need this information, and then it was 3 hours, and then it became lo and behold 8 hours. The funniest part of the end of it was they asked to see the EI course and I showed it to them, and then they were like well doctors need to see that. So we added Unit 6, which is sort of a re, a brief overview of a, the early intervention basics. So they could see good quality early intervention for toddlers. And then they said, so then, now you have an 8 hour course. Well we don’t, we don’t have time to take an 8 hour course on autism. And we’re like okay. So we created the jumpstart unit. So we also have a jumpstart unit that’s 90 minutes. So, we are unstoppable. We may not be able to solve the problem but we’re not gonna stop, so. So they are happy about that. So 90 minutes, and then we, we make sure they have the whole course, so if they like it they’ll come back, or if they have a child in their office with autism, they can open it back up.

So our courses look like this. We have a lot a side by side videos, and other videos to illustrate. It, of the, of, all of our courses are probably 75% embedded video and then 25% narration to make it make sense. And then we have print materials; we have print materials for the provider, as well as for the families. And we have English and Spanish, and we’re working on Portuguese and creole, because they’re Florida languages, and then we’re workin’ on Canadian French, and, Russian in, in the future. And, probably other languages; Vietnamese. We’re workin’ on more languages, so we’re very excited.

If you go through the primary care course you can apply to use, we have a brand new screening tool that’s been funded by our work from NI, uh, really our foundation work from NIDCD, and then we got funding to build this from NICHD. Online screening parent report, 10 questions to screen for communication delay followed by 20 questions to screen for autism. And so if you’re in the primary care course, you’re trained to use it, and you can apply to use it. It’s a, it’s a HIPAA compliant health record. And so it’s really a whole, we’re calling it a family ecosystem. It has a provider portal where the reports are generated, it’s the child—children should be invited to be screened at 9 months for communication delay, and then the autism screening starts at 12 months, and parents are re-invited at 15, 18, 24 and 30 months, and then the report’s all there; all they have to do is push some buttons. They gotta learn to use it and push some buttons. There’s also a parent portal. So I want to focus on the whole resources that the parents get if they come

in and get screened with a (sounds like Smarty Sack). And we call it smart partly because we’re gonna make it smarter. So as we have data, we can improve the sensitivity and specificity with different algorithms, or we have a few experimental questions that we can add in and remove questions that aren’t working as good, as we have more data. But ultimately what’s important is to get the parents to, we’re calling it our seamless path for families. So there’s 5 components. I’m gonna go real quick so I can show you a few more video clips.

So for all families screened with a Smarty Sack, they come in, in their portal, they get invited to our 16 by 16, which is a camp, a campaign, our 16 gestures, by 16 months. And they get invited to our social communication growth charts. These are, come from the First Words Project. So everybody, it’s free access to the 16 by 16. You can click on the tab, and you’ll get to this. And then if you launch, click the button, launch the look book, it’s free, you just have to put your name and email address in there. And it looks like this; it looks really cool on a tablet computer, but it works on a smartphone or notebook computer. So if you open it up, this is our 16 Gestures by 16 Months. Just a few quick examples. At 10 months children should be reaching out and raising their arms. They should be waving by 11 months. And by 12 months, we have the open hand point, tap, by 13 months, we start to see children are watching and imitating, so we start to see clapping and blowing a kiss. 14 months we see the “sh” gesture. Now we’re gettin’ into symbolic gestures as words are starting to unfold. Thumbs up at 15 months, “I don’t know” at 16 months. So we take you through the 16 gestures children should have by 16 months. There’s also a print document you can get, and it’s also in a couple different languages. More languages coming.

So that’s a 16 by 16. You all can get to it, please share it. Doctors love the idea of it. Again I don’t know that it makes them scream, but if we can teach the parents what the parents what the gestures are early, and I know ja—you know you’ll hear more about the importance of gestures. The lack of the “show” gesture from our research is the most early robust sign of autism. Show gesture comes in 11 months. So we, at least if we can teach the parents the gestures, then they can start to see my child is communication delayed. We don’t have to wait for language delay. So instead of waiting for the word gap, we can look for the gesture gap between 9 and 16 months, and try to get parents moving quicker. And then they’re gonna come to you the SLP. So you need to be ready then to be thinking about, not just communication language delay, but autism.

So doctors regularly monitor physical growth as part of their well checkup. They’re very comfortable with that, but how do you monitor social communication growth? So we have a brand new really cool tool that we’ve been working on for several years, called the Social Communication Growth Charts, and it is launched completely. And we view this as something that’s going to help support parents in the most important role of their life, being a parent. And so we have launched now on our-- if you go First Words and click on Social Communication, or click on the homepage, check out our growth charts. You’ll get to this page, and you’ll see these circles. We’re adding 7 to 8 months next week. If you click on these circles, you’ll get to a print document. Again, this is free, and we have milestones that are different than other milestones out there. These are very specific, they’re every 2 months. They’re across 5 domains of development, and these are what the average child should be learning instead of the second

percentile, the bottom, you know, second percentile. So we hope these will help parents know what their children should be doing, aspire how to learn.

So please look at these, share these, they're free in print version. Now then you see a button where you check out how do I join. So the social communication growth charts are actually a whole collection of videos. We have hundreds of videos of typically developing children, to illustrate the milestones, and, chart development. And so you can get to "How do I Join?" You can now purchase it \$4.99 a month. Or, you see, or you can join for free. How do I join for free? You join for free if your child gets screened by the Smarty Sack. And we're doing research; if your child's between 9 and 18 months, there's a "Screen My Child" button, parents can stream it from anywhere. They, right now we only have English, but Spanish will be coming, and they can screen and we will give them the results, and they can get the free growth charts. Or if their provider has access to the Smarty Sack, and more and more providers do, in our research and beyond. So we want families to get it for free, but if they want to purchase it.

This is what it looks like; it has an explorer function and a chart function. So the print documents are free to the public. You, you gotta pay at least \$4.99 or screen. And be in our research, and we have a huge research network. And then you get it for free. So the explorer function looks like this. When you get in, you just click "Explore" and you get to this video player. We have 5 domains of development; language play, emotional regulation, social interaction, emotional regulation, and self-directed learning. So it's really a before preschool curriculum. Getting kids ready for preschool between, and it's 9 to 24 months going down to 7 months very soon. And so you get to two threads in every domain. So this is social interaction, social attention is on the left, intentional communication. And let's see. This is the milestone. I don't have this video to show you 'cause I'm just gonna show you kids with autism. But these are all typically developing kids. And the milestone. So this is I can watch you and immediate what you do and say. So our milestones are real specific every 2 months. So check 'em out. then the parent can chart their child from it will be 7 to 24 months. They get every 2 months questions about the milestones, and they can say not yet, sometimes, often, and then, the provider will get a chart that looks like this to chart their growth in the 5 domains, and then you can pick a domain and see the two threads. The parent gets a chart that looks like this; lily pads filling up because the doctor at advisory board said that the growth chart would alarm them, and they would be calling their doctor. Which might be a good thing. But there you go. So the parents can see it this way. It's friendlier. So this shows a gap between sounds and words, and gestures and meanings thread, this, and then they can see all 5 domains, and see if there are domains that are falling behind.

The really cool thing I forgot to mention the video player. They get to see, they can pick a child and see the milestones, and then there's a Support button and they can click it, and then they hear an audio explanation of how the parent's supporting development. So it's really to teach parents of all children, typical children, all children, how to support these milestones from 7 to 25 months of age, to get ready for preschool.

Now if it's a positive screen for autism, then we have 3 more tools specific to autism. The first is about autism in toddlers. This is the first course that we have developed and launched. It's free to the public. You can all get to it on autismnavigator.com. Click on "Courses," and then just

click on “Get Started”. Again, you have to register, give us your name and email address, then you’re in. It’s free. It’s 3 hours of the primary care course. It’s 3 hours of the 8 hours. So you’re gettin’ 3 hours for free. It shows you about a dozen toddlers 18 to 24 months of age, so it should show you what autism looks like. Please share this. It looks like this inside. It’s got 29 slides. We launched it in April 2015, a year later we have over 3,000 users from 21 countries,. A year later we had 13,000 from 119. 6 months later we’re at 18,000 and counting, from 120 countries. So if you build it and it’s free, you do get people to come if it’s about autism, there’s clear a need for this. Uh, so when we got to 10,000, we’re at 10,000 strong, the urban dictionary definition is a gathering of people ready to take on the world. So we are ready. I don’t know what happens at 20,000, but. So when we launched it, it looked like this, which is what our techy team could come up with, and then we got our graphics design team, to improve it. So we had to just, alright, let’s start it, get it out there. Isn’t that boring/ and you know it was over, a little scary for parents, ‘cause it’s just too much to push that button. So we built a whole new landing page, and it now looks like this. You get to friendly questions, so you can just get to single slides. We got, we got our whole team together what are the most common first questions parents have. And then we slipped in, “Can you spare 2 minutes?” Just get ‘e in there for 2 minutes, it takes even less time to learn the early signs, and then we have our “Can you spare 2 minutes?” So please go look at this; it’s free to the public. This will teach you what autism is in a toddler. So we have 9 different um, what do you call these, buttons that they can push, with questions, or they can just launch the course and go through it. What’s next then, once you have a positive screen and the parent suspects they have autism, then we have our ASD video glossary. We’ve rebuilt it. there’s a single sign in now, that we just launched this past year. So once you sign in, you get to both. There, this is all free, to the public. So you can toggle between the two. We recommend you have parents go to About Autism and how they’re spurred, ‘cause it’s friendly, with audio narration. But once they’re really ready and go “I think my child has autism,” let ‘em go to the video glossary. It’s now organized around the DSM-5, we’ve updated it. In our building we say you never can have too much purple, so it’s now purple. Hated the yellow colors. And, it’s got our, this, a lot a the same videos, but we’ve added a few new ones. It, it used to be in collaboration with Autism speaks on their website, now it’s pulled into the autism navigator collection. Because they weren’t, didn’t wanna host it anymore. So we have been able to keep it going. We host it now, and it’s, and we owned it all along, and we’ve rebuilt it to be around the DSM-5. So you see the symptoms down the side, you can click, and then see overall a few different examples of clips of each symptom. Most of the kids are 18 to 24 months. At the very bottom, the treatment section, which I know a lot of you have used this; so it’s back up, it’s there, and you can click on “Treatment” and see the common name brand treatments, that colleagues who are their name is on the treatment. Connie has; I think Jasper, has some clips, Early Start Denver has some clips, um, teach ABA, (sounds like Lobous) and so on. And certs, and ESI. So parents can look at what is this, what does the treatment look like. And last but not least are what I, I’m the most excited about that we just launched this year, is number 5. So if the parents now, we hope they ‘re learning their milestones, they’re seeing their child’s delay, they’re ready to hear the word “autism”, they learn what autism is. Now, let’s get them started immediately. So we have built a how to guide for families, which is a online course for families, and we’re calling it a course because it’s meaty. It’s 7 hours of content. There’s a description on Autism Navigator, so you can go and, and get this document, and get this document, and, you can, uh, learn more about it. So there’s a 2 page document describing it. It’s, um, it’s got 4 guidebooks, and it’s got, um, 7 hours of self-narrated content,

with lots of video embedded. Um, and then it has... 5 hours of video library. And I wanna show you a little bit of it as I wind up.

So this is what our learning management system looks like. So we have a learning management system for our courses. Au—the “About Autism” is free, it’s not on this, so it’s built separately. But when you go into our courses, it looks like this. And so we have our 4 guidebooks. What’s really neat is that, you know, Big Brother’s watching you. So we know in our Learning Management whether you open it, how long you spend, whether you click on videos, whether you finish the unit. So it’s great for research to be able to document who opened it and who didn’t; how much time did they spend in it. Well so we’re very excited about it.

So this is what it looks like. Social—it starts with Guidebook One, which is really on autism, as well as development, how autism impacts development, and early development. And again, it’s all self-narrated, and these are animated slides. Um, and then when we get to woops, Book Two, is about collaborating to make intervention work. So helping them to collaborate with your team. And then the meat is in Book Three, starts in Book Three, getting ready, to... getting ready and begin, and then we talk about the everyday activities. We teach them the layer cake, we teach them the active engagement. So that’s I think a really important part of why we got improvement in comprehension, as well as initiation and social interaction. So our layer cake, the parents can learn about that. I, I’d love to go on, but I’m gonna just wrap up with, so Book Four is on challenging behavior. We have content on the functional assessment process, helping parents learn, what their care team should be doing to examine the triggers to describe the behavior, and to identify what’s happened immediately after. We, we teach them the ABC; the antecedents, the behavior, the consequences in Unit 5. It’s about 5 hours. We show kids with significant challenging behaviors. In our How To Guide, we developed it for toddlers, but we’re also doing it with preschool children. So we think it’s good for preschoolers as well.

So we’re adding on now, I’m very excited, we’re starting this Guided Tour to go with the How To Guide. So we’re, it’s like a group, but it’s virtual. So the parents, it’s like a book club. They can once a week come. It’s, so we have a 6 month curriculum. If you’re in the EI provider course at the advanced level, you can get the slides to run the groups, and the parents are in this. And so then you can coach them and they’ve already learned some of the content, and you can focus your section, sessions to really give them specific feedback. So those are starting. And those, I wanna end by saying, um, you know, of course individually these are cool, but it’s really this combination which is this partnership of First Words Project and Autism Navigator. I hope that you’ll check out both websites. So we have our seamless path for families. We have an ecosystem gallery that you can learn a lot more about these, and there’s quite a few videos and family stories. so we have materials for all families. If there’s a positive screen for autism, and how to get started right away with the How To Guide. We also have a grid version so you can poke around.

So as I said, if the solution was easy, it, it would have been solved already. And I think SLP’s need to play and can play a critical role in solving this huge challenge to our healthcare and education system. It’s gonna take a team. You can play many different roles. We need screeners who know what they’re doing. We need better screening tools, we need encouragers to encourage the families. We need service providers who know how to provide this kind a

coaching, and we need champions. We need champions for the families and for the EI systems and for the states to make this happen. And we need to work as a whole care team for the families. So I think SLP’s again, to help collaborate with all these different systems who are gonna be on the parent’s care team with the primary care in the middle. Help those care teams work together. We hope that Autism Navigator will help you sharpen your observation skills. We have lots and lots of video with explanations, so you can learn. You’ve just gotten a little sampling. Don’t be the one who said wait and see when you had a chance to help a family act early. And share that message with doctors. So check out what’s free on Autism Navigator. Go to First Words Project, share our new milestones. Refer families to our tech, uh, Screen My Child Now, so they can get free resources. And really what it’s gonna come down to is yes—if we can invest 20 minutes to screen for social communication delay at 9 months, give, the parents get this whole set a tools, I think that we can change children’s developmental trajectories as a team. So please share our resources with professionals and families. And, check out our Facebook posts as well.

Thank you.

HOST: Alright, thank you very much. Oh, we see some orange cards.

Q: Thank you. So thank you so much for this. Oh hi. I’m Dana Battaglia. So I just wanted to thank you for all of this because, um, it’s just going to help so many families

AMY WETHERBY: Good, thank you.

Q: I have like 7 questions but I, I will only ask one. Um . . .

AMY WETHERBY: We’re here, we got all day, so. the other one’s later.

Q: (Laugh) It’s really kind of twofold. The first is, do you have any outcomes data so far in terms of the screener? How many times it’s been used, what have the outcomes of, **(Yeah)** of those uses been? And, the, the second level of that would be, um, if you have data on the sensitivity and specificity of the screener **(Yes)** at this point.

AMY WETHERBY: Yes, yes. All of the above. (Thank you) And we, I presented on that on Thursday, so that’s why I didn’t include that.

Q: Oh. (Laughs)

AMY WETHERBY: but, um, we’re workin’ on a lot a management. So we’ve screened about... 5,000 children in our new study in 4 sites, and then we screened about 4,000 in, in the Tallahassee region on the, the new Smarty Sack. So we have data that we’re working on. We’ve analyzed it, presented it. Our sensitivity and specificity is in the point 8’s for 18 to 24 months, and it’s just like .78, if you go down to 12 months. So we’re very excited about the potential.

Q: Wow, that’s awesome, thank you.

AMY WETHERBY: Yeah. So we're real excited. It looks promising. But more importantly, we're catching 12 to 14 per thousand, compared to other screeners like the M-Chat even in the best primary care study, with the follow-up interview they're getting about 5 per thousand. Our Mullin scores, cognitive nonverbal are much higher, about 10 points higher. So we're catching the milder cases that other screeners are missing. And the reason that's so important is if you get a negative screen, and you're telling the parent your child doesn't have, is not at risk for autism, but in fact they are. So that's a concern. And we know from the 1 in 68 that there should, we should be catching around 14 per thousand. So we're working really hard to do that in a primary care sample. The other reason that's so important is that our EI system now misses 80% of children who are gonna qualify at school age. So if you're just screening an EI, you're just screening the 20% that get there, and they're like the more severe kids. (Right) So the challenge is getting those milder kids, and we've been workin' for years on this; for years. (Thank you) So we're hopeful. Now in terms of the Screen My Child, we just launched that. So we're, you know, 'cause we tryin' to get providers to do this and we just finally said, well, you know, families can just go do it themselves. So we have where we can schedule a 30 minute window to give them the results. I have staff, it's automatic calendars, we're, we're launching a chatbot next week that will greet you on the website. And we're just tryin' everything we can. And so we're launching it and we're looking at social media posts, advertisements. So I know I have a new marketing director he just launched an ad on Thursday and I think 20 families already screened on Thursday. So it's gonna be interesting to look at what gets the numbers up. So we're trying everything and trying the monitor, and it's fascinating.

Q: Great, thank you so much.

AMY WETHERBY: Thank you for the question.

Q: Hi, I'm Bridget Wright. My question for you is I was just wondering what your thoughts were on how to continue the support for these children as they continue on to preschool and kindergarten. **(Yeah)** Because I know they might get different strategies used in the school by the teachers and other, um, aids. **(Yeah)** So I was just wondering what you thought about that . . .

AMY WETHERBY: Yeah, it's a great question. We hope that the How To Guide will be a booster, so that they can stay in those guided tours. We also have a Facebook group that goes with it. What can happen is if they go into a more traditional behavioral structured program, then they can lose some of the spontaneity, and, that they've gained. So, but the parents have learned so much So really what we're tryin' to teach them, from 18 to 36 months is to, the skills and what works with their child and how to advocate. So by the time they're 3, ideally, most of them are going into a preschool setting that has some typical peers. And then we're finding, we followed our ESI children into school age in Florida. We were able to follow that sample. And the state of Florida has an average about 32% of children with autism are in the general ed kindergarten. We are 65%. So we have doubled it. And the, we're following those children, they're doing great. So I think we wanna expect, you know, maybe even more than that if we can catch, start at 9 months or earlier. So we're very excited. I think it's the key is really having an, your eye on getting ready for general ed kindergarten, blending, having the parents be able to blend the developmental and behavioral. It's really the solution for kids with autism. And I'm

so grateful for my mentors and my opportunity to have both. And I think ESI very much reflects that. So thank you for the question. Support groups, having a healthy child. We’re starting to hire; just one last thought. In our guided tour where we have a leader, it’s all virtual, but you can zoom in. We zoom. We’re starting to have a parent co-lead. So I love the, the model of you know the parents who come through and get the coaching and they fully get it. And we’re having them co-lead the guided tours. So there’s a parent and a professional which is a really nice model for the parents.

Q: Hi, I’m Thelma Uzonyi from UNC Chapel Hill. Always a pleasure hearing you talk Dr. Wetherby, and **(Thank you)** personal plug for your 16 by 16; my families love it; EI. **(Good, thank you)** So I have a question about, um, the measure of, uh, active engagement in spectrum support. **(Um-hm)** Uh, I’m curious if the... how the parent transaction supports were measured. Was it coded, interval coding, frequencies? **(Yeah)** And if the measure is publicly available.

AMY WETHERBY: Yeah. So it’s called the MAETS; Measure of Active Engagement and Transactional Supports. It’s part of the Autism Navigator for Early Intervention Provider Course. So we actually teach it in Unit 5. We have the manual, we have the, a fidel—a manual to, to teach you know the, operationalize every item. It’s a 0 to 3 rating, so we don’t count every item. You could go back and do that for research if you’re interested. We have done that for a long time and wanted a more of a... friendlier for clinicians in the field tool, measure. But it’s sensitive to change. So we’re excited about it. Um, so it’s coded through, we have an hour video that we get in the home and we code the first 12 minutes and the last 12 minutes. And We’ve studied every 12 minutes, and what works best is an average of the first, or it’s a summons, same difference, of the first and last. ‘Cause the first you can do really well, but to get all the way through the hour and have 12 minutes at the end, it’s a great combination. So that’s how we score it. And we watch. And we have a whole training. Next year I hope we, that we’re gonna come up with a, a course that will teach you how to code NAETS to fidelity. We also have an observational measure called the Source, and have an, a coding of that. ‘Cause we have all the—we train coders. So we have all these training clips, so we wanna put them into Autism Navigator courses. I also forgot to mention if I could, we have Autism Navigator for Kindergarten Classrooms coming next year. We’re working on that for the kindergarten classroom teacher. So that’s another part of. ‘Cause what can happen in kindergarten is the kindergarten teacher says “Well I don’t know how to deal with a child with autism.” And so we have, will have, it’ll be about a 10 to 15 hour course that will help them know that they’re a good teacher and they can do this. It’s like being a good teacher, is what you need to do. So, thank you for that question. So it is, and if you write me, I can give it to you, but it’s not publicly available. But it is part of the course. Say that you were at this meeting.

Q: Hi, I’m Andrea Barton-Hulsey at the University of Wisconsin-Madison. **(Hi)** Hi. Um, this is a wonderful presentation. And I’m sitting here thinking, um, with our increasing evidence that speech generating devices are really important in early intervention, especially for that population of minimally verbal in the long term with autism, and I know Connie’s gonna talk about that some more later. **(Yeah)** But I’m curious how you see, um, the introduction of speech (inaudible word) devices and the fitting in the training in the Autism Navigator.

AMY WETHERBY: Yeah, um . . .

Q: What experiences there?

AMY WETHERBY: I'm a big believer in all modalities, and all augmented systems that are gonna work for the family and the child. So I'm gonna let Connie take that question. We did not deliberately use speech generating devices with the kids. They left us at 3. We did deliberately use you know vocal and gesture, and sign, and then brought pictures. So we brought picture or you know done boxes and picture. So I think it's, it's gonna naturally build the foundational communication and symbolic skills that could move nicely too, now with iPads, you know, too. So some of the families will move to a, an app that has speech generating device. But we didn't. By the time they were 3, I'll be honest with you, most of the children were talking. Um... so we, it, it wasn't like, but after 3 I think would be the point, 'cause we were still workin' on getting the kids that were less likely to talk we were still workin' on kind of a foundational communication symbolic stuff. But I think by 3, some of them would move into that.

Q: Hi. Is this on? Okay, here we go. Um, thank you for your presentation. I appreciated witnessing both in the results and in the videos, the, the fact that your intervention had an increasing parent knowledge, confidence in self-efficacy. And so as you follow the children who participated in ESI, into the school years, I'm wondering if you have considered the role of parent knowledge and self-efficacy, uh... in the education system. specifically how they, well they're able to advocate for the child. Wherever their education frequent may be.

AMY WETHERBY: Yeah. It's a great question. I did have a doctoral student who graduated. We gathered data from 6 to 8. So we have some parent questionnaires. We haven't analyzed it yet. We are like, have data spilling over. So, if anybody wants to come and study with us, we have great current doc students and we're workin' as fast as we can. And even when they graduate. So we, we haven't analyzed the data, but we do have parent questionnaires that get at self-confidence, self-efficacy, at school age. And we have them from early on. the problem with our early on measures is a lot a the pa rents, by the time we got to the end a the study, they didn't fill 'em out, 'cause they knew, oh, there's that packet, I don't need to fill this out. So we only have it from about half. You know it's tricky, this research stuff is tricky. So there's a lot a things we'd do different. But... but I can just tell you one personal story too, is that when I saw the parents when they came back at 5 or 6, one a the parents said to me, "Dr. Wetherby, I'm still doing my 25 hours." So that to me is like they know that's important, and that they're, you know, would articulate. And then another parent said, "The thing that I got the most out of ESI is being able to advocate for my child." So I think that they know, and I'm not sure we can document in research, but I'm hoping, as we analyze the data. And we also got, you know Dos, we got some IQ measures and the ADI, and all this stuff at school age. So, and we got 79% of the kids back. We were so hoping for 80, but that's still pretty good. given that unit UMAC is no longer there. That was the tricky pa rt. To follow longitudinal research that has its challenges. Other, any other questions?

Q: Okay, hi. My name is Jenny Burton and I'm from the University of Cincinnati, and Cincinnati Children's Hospital Medical Center. My question is, do you have any hypotheses regarding child characteristics that best predict positive response to the early intervention your team implemented?

AMY WETHERBY: So that’s a great question, and I think that’s the first bullet that we’re kind of looking at treatment responders. I think that what we know from analyzing the data so far, is... that, that the key beyond the, um, for the child to be able to take on a productive role, and then the other components, of, that’s sort of, you gotta get that going in addition to the regular and emotion. And then the other components come together. So we see those as pivotal. So we’ll know more. That’s kind of what we’re gonna dig into. Our sample size is almost big enough to get at this. I mean that’s the trickiness that you really need larger groups. So we’re hoping. We have 2 other RCT’s that are going on. One is at the Emory ACE, and then we’re starting a new one. So I hope with our next samples and our Screen My Child button, that we really, and we can mobile in, we can have much bigger samples, much more cost efficiently. So the hope is we can get larger ends to be able to understand that. And then the Smart Design is a way. So both of our new ACE studies are Smart Designs, which you’re gonna learn about, so that we’re starting on my, uh, a less intensive treatment, and then when we have a, a tailoring variable 6 months later, 3 months later, we then see who are the responders and we re-randomize. So I think the Smart Design, which I’ve, you know, Connie’s been the mentor and we’ve seen that, really excited us. So to me, the Smart Design is a way to not only understand the responders, but do something about I before the end of the study, and then learn from that. So it’s, I think that’s the way, one way of the future that’s quite exciting.

Q: Hi, I’m Jonet Artis from UNC Chapel Hill. I’m really interested in the early identification of children and the disparity. So I was wondering about the Autism Navigator. Have you heard any feedback as far as low income families? Are they able to access this, or?

AMY WETHERBY: It’s a great question. So, um... number one, we’ve gotten feedback across, so part of it is you know when you say low income, the reality is there’s a interaction of income and race. So just to kinda put that out there. So we were very thoughtful about trying to have a diversity of races represented in the families in the videos. And that has resonated well. We also have, we partner, we have a partnership with the National Black Church Initiative. Reverend Evans who’s the president of that network is the co-investigator on one of our studies, and he had a, a group of, um... the literature committee is what they call themselves, in his church network where they reviewed our materials to give us feedback about the appropriateness for black families. So we tried to improve things given their feedback. So we did what we could do make it meaningful. The other part of it is really it works across platforms. So it’s a matter have, of having connectivity. That’s really it. And... you know, we need to make this happen. We need to find ways, there are ways, but sometimes we need to help pa rents figure out, okay, if you’re low income, you could qualify for connection minutes, and get them. Or you could go to a certain community center, or the library. So it’s helping the families know where to go and partnering with the community agencies to make that happen. But if we can provide nutrition wi—through WIC, why can we not provide brain nutrition through connectivity at the same, you know? Food is of course important, but for the parents to have internet to me seems like one of the most essential things, along with eating and shelter, to try to raise children in this day and age. So I think that that is an important gap that we need to make sure. There’s a lot a agencies that can help with that. So it’s sorta knowing where in your community, in your region. We can give stuff away to families. So if they’re low income, we can make things free, so that’s the one thing we can do. So we all need to work together. There are, I know, I think Verizon gives, I, I

think a lot a the different... companies that provide connectivity, do give minutes for low income families if you qualify for a Title One school, if you're on WIC. So it's just a matter of reaching out, and the family has to fill a form out, and someone has to help 'em with that, right. We're also partnering with Early Head Start. There's all these different agencies in that group of, we're working in our state across many agencies, departments, which is very exciting. Early Head Start, Healthy Start, Healthy Families, that reach low income families, and families at risk for abuse and neglect, which are often more like to be children with communication delays, and behavior problems, which could be a child with autism.

Q: My name's Connie . . .

AMY WETHERBY: Yes way, uh, way in the back.

Q: (Inaudible)

AMY WETHERBY: It's a great question. So are the, you know particular doctors or other, but particularly doctors or other providers more likely to wanna screen and have 'em do it there or do it at home? Is that what you're asking? Yeah.

Q: (Inaudible)

AMY WETHERBY: Right. So time is a huge issue, yeah. yeah. So time is a huge issue. So yeah, um, so ours is set up that the, they could actually invite the family at the 6 month visit to fill out the child and family information. The family could get into the growth charts at 6 months, and then they can send them the Sm arty Sack at 9 months before, like the week before the 9 month visit and get 'em in. So they can do that. Now we're, we just, opened it up to 6 months, but they could of done that at 9 months. And some of the doctors do that. I mean I, there's so many barriers here. Some of them they don't have time. So they, so we've given them an alternative. But they don't necessarily do it; some do it. The other barrier is giving the results. So the doctors are, have, and we've had lots of focus groups, I have doctoral students that have helped with that. We're, um, have, analyze them. The doctors clearly say they don't wanna share those results with family. They're comfortable sharing other results, like that their child has cancer. But, there's something about autism. And I think it's a combination of they don't have control of the treatment. It's out of their domain, the treatment. Out of their realm. And they don't necessarily, they're not convinced the treatment matters. So we, we need to help them know that it matters, and as they see our kids in treatment, they're gonna learn. So those are some a the other barriers. And they wanna say just wait and see. i mean we're now doing a study, where we're recording what they say when they share the screening results. And so the doctors have an iPad, they do that, and they hit record. And we're listening to 'em, and, you would be amazed what happens. And they're voluntarily recording. So it's gonna be fascinating. So this is why we added our Screen My Child button. Because after screening 5,000 children, asking the providers to do this, um... we, you know, we see that a lot of them are reluctant. So we just have an alternative path. We're not gonna... we're unstoppable. We're gonna try something different. Now where their parents will go, I don't know. We're just figuring if we can just get parents to go who think their child is typically developing, that's who we're looking for. 'Cause they're not gonna know at 9 month if their child has autism. So it can

go any which way. We have incredible champions. So we try to use the champions, who are doctors to let other doctors know. It's a process. It'll catch on. We're working on, we gotta get publications out, we are applying for an MOC, maintenance of certification; that'll help. Incentives. We do pay them in the study and that's made a difference. We give them an iPad, you know, for the research. So we're just tryin' to figure out what is gonna engage them and some of them, they love the course. Most of them give very good feedback to the course; some of them love it. But, but doing the screening, finding the time, but I think it's more giving the screening result that's, because it's not, it doesn't take that long to screen, it's giving, it's having that discussion, that your child has a positive screening that can take on. So we are screening, we are scheduling a 30 minute window for that, and that's not feasible in primary care. But there's part- there's ways to get around that. So there's partnerships with speech pathologists/ If there's a positive screen you could give the results. With a lot of pediatricians with larger practices have a behavior health specialist. So they're great to be the one to give the results. That's more cost effective. So we need to be very sensitive that the doctor's don't have the time and they're very expensive. Why would we pay, you know, using their time is gonna be the most expensive way to screen kids. But, but, if they say wait and see, what are parents gonna do? They're gonna wait and see right? If their doctor's saying oh let's wait and see; it's just a baby, that they're gonna wait and see. So that the pa—the, the doctor yields a lot of power in what they're saying. So if they can partner with a behavior health specialist, of whom could be a speech pathologist, who can give the screening result and have like a 30 minute conversation with the family. But then not say wait and see, right? To buy in. Then we can really do somethin'. So we're, that's kind of our new thing that we're trying and we'll see. And if it doesn't work, we'll try somethin' else.

Q: Hi, I'm sally Yowell, I'm from UNC Chapel Hill. And I had another similar question before we leave to, logistics and (inaudible words) between providers and parents who initiates those roads for sharing (drops her voice) And having either side, help (drops her voice).

AMY WETHERBY: Yeah. So consent. Great question. All parents the driver, everything's parent consent. So that Smarty Sack, the parent signs like 3 levels of consent. The first is a very broad, they have to watch a movie, we have a 4 minute movie to explain that they're a part of a research network. They have to consent. Then we say we can come back to you and invite you to be in research studies. You can say no, we can decide later. So then we do the, the consent for the specific rese arch study. So we have a mechanism all online, that works pretty well. But it's all parent consent. Now if they do it at their doctor, it's part a their medical record. But if they hit the “Screen my Child” button, and we do it, it's part of their research record. They could then decide whether or not they wanna share it. The growth charts are not part of any health record unless you're coming in through your do—the Smarty Sack through your doctor, then it is. So if, if you just come in through us, or purchase the subscription, the parents have it. Now the parents don't have to share it with anyone beyond the provider screening. So the provider screening in the portal, and the parent knows this in the terms of use, see their utilization of the tool. But the parent can add others to be able to see it. So they can add... a family member, they can add up to 5 people to who could then see if they wanted gramma, or an aunt, or a friend, to see their child's growth charts. They, they could do that. Or to see their portal. So they have the right, so that's all up to the parent. But it's a great question. It's somethin' to think about, and

parents worry about it. And again, it will be interesting to study screening through the doctor versus the Screen My Child, who do we get, and how do they compare?

Q: It’s Kim Muller, from the University of Memphis. I, I bet I’m asking a question a whole lot of people would be asking. Could you just estimate for us at this point, how many of the children in these interventions, the RCT’s? I’m progressing far enough that they’re actually all fine to lose their diagnosis.

AMY WETHERBY: Oh... (Laugh) Interesting question. How many are progressing? So I can say of the 82 children um... in the ESI study who we got really... um... significant change in the children, in Florida, 64% are succeeding well in gen Ed. We have had 2 or 3. I view autism as a lifelong disability. And I think it’s very dangerous to love the diagnosis, because I, I view it more like diabetes, or high blood pressure. You can have it under control at a certain moment. So, like we ha—even the kids didn’t move off. Um... once you get to middle school, or stress, or something. So I think, I think as a field... we need to view it more as a con—it’s a, I don’t wanna say health condition, that’s a whole nother buzz word right now. Bu tit’s a... it is a, a lifelong disability that can be treated, and children can do very well but you need to have your eye on what’s happening coming around the corner in terms of social demands which increase, and the child may not be able to keep up. So it’s making sure. So we, now I, my team is very highly trained, and they probably would keep people on, children on the spectrum when others might not. So our kids, mo, many of them, you, or, or in kindergarten they may not pick ‘em out. but they still meet criteria. The other part of that is using the right module of ADOS. So you need to, you know, our team is very well trained, they get a booster every year. There’s a lot of nuances to the ADOS, and keeping up with it, and using the right module. So if you use the wrong module it’s easy for the child to move off the spectrum, but you had not administered it correctly. I think it’s very rare. Our children are doing magnificently. I didn’t have time to show you a lot a the later videos. Ryan, that little Ryan, he is almost movin’ off the spectrum. But we’ll keep him there, but he’s doing great. So what’s important is for, and that’s part of the stigma is to move away from, from you know the, your child only successful if they move off the spectrum. That’s not fair. And that’s not attainable for most children if you’re accurate in diagnosis. And I don’t think having autism is all bad. There’s some really good things. That children with autism are really good at. Um... recently we had one of our children that we identified through First Words, at under 2; she’s 20. And he came to our autism center. You know, and she now, she still has autism, and, and this was 20 years ago so her treatment wasn’t as good as what we can do now. But she is going, she wants to be an engineer, she’s a college student. She just got a job from a community provider who’s willing to help do the extra little supports that she needs, which are pretty minor. So to me that’s success. Having a job in adulthood is a success for any of our children. Um, and that’s what we wanna aspire, not moving off the spectrum, right? I speak as a parent. We’re thrilled that they have jobs, and are not living at home anymore. (Laugh)

Q: Hi, I’m awe. But I’m also . . .

AMY WETHERBY: thanks Paul, it’s good to see you

Q: And it’s . . .

AMY WETHERBY: And you, I'm always, it's always, I'm, I'm, I know I'm gonna get a Paul Yoder question, so I'm ready. (Everyone laughs) I am ready!

Q: You're not getting my question. **(Okay)** (inaudible words) answer the question. **(Okay)** who had to go to (inaudible words).

AMY WETHERBY: Oh, okay.

Q: But she's from China, and she's saying that there are no established programs for children with autism (drops his voice)

AMY WETHERBY: There are no what?

Q: Established programs for children with autism. **(Okay)** she's also saying... okay. she, she's also saying that there's a, um, a... a group here at ASHA who have a survey from parents and pediatricians from 26 provinces in the mainland. And they've identified 3 potential areas of problems. One is the lack of assessment tools. **(Um-hm)** And, she says the treatment tools, but those are kind of linked I think. the other is misinformation. Um, there's a fair amount of alternative treatments and alternative facts in a sense, that are prevalent in the stream of information that the parents of children with autism are getting. Um, they're, third they're very stressed, the parents are very stressed. If you were gonna give her one place to start, of those 3 areas, what would you recommend?

AMY WETHERBY: Yeah. Well I'm gonna do what the press does, I'm not gonna answer that question. (Several people laugh) I'm gonna answer a different question that'll give you some information towards what you're asking. (Laugh) I mean I don't, I don't know that we wanna pick only one. I think you might wanna prioritize and go alright, start here. But I think all 3 are critical. And we have, you know we have the same problem in our own country. There's disparities here, that you know autism is a huge business. A lot of money that's made from autism. Whether it's therapists who are charging a lot of money and not necessarily are using evidence based practice, or being accountable for change. We have alternative treatments; the parents are desperate and they try, and they, if they have money, they pay a bunch of money, they, and they get something. And often those are not necessarily the children that do better. So I think, we need more information. And think it's a global world, so I hope that we with Autism navigator, I hope that, that she can bring about autism. We can work with them on translating. We've already been approached by folks in China. it's not next on our list, but it's in our top 10. Translations; translations is an enormous amount of work. You know, but I think it's getting good quality information. But I think it's the early detection. The culture I'm not gonna begin to say I know much about the culture of China, but I know that there's pressure on parents. and I think that it's changing. We had some visitors come to our center and talk to us about some of the changes that are happening in China. With the different, um, regulations on how many children you can have, and so on. So I think it's a changing time. So, is it, can we bring the milestones there, can we, you know, we're willing to translate the milestones; can we help parents know what their children should be doing? I think the parents there feel a lot of pressure because of the culture within their country. So, um, but if you have a child with autism, it can be

scary. I mean we have, we'd had a hard time getting parents who have Asian and particularly Chinese children, agreeing to give, let us use their videos because of the ramifications that they still have a family back in China. So there's a lot; there's stigma; there's stigma in every culture. But I think the stig—how do we change the stigma? We start to show kids doing good, and this is not that scary. So tryin' to bring that. So I'm hoping we can collaborate and let's, we're very eager to bring our stuff there and everywhere. We're, we're in 120 countries, so I'm guessing China. But I think you start early. (Thank you) It's a way easier early. It's a way easier thing to change if you start early.

HOST: And we have time for one more question.

Q: Hi. My name's Jenna DeCarlo, I'm from Ohio State. And, I was wondering if you've noticed any patterns with siblings, and the data specifically with the social interaction project. I know it's obviously parent centered, but, in the one video with the twins and the mom, with the twins, I was wondering if there are any better outcomes with children with autism who have siblings, older, younger, if you've looked at that at all.

AMY WETHERBY: Um, so do, have we seen patterns in the younger sibs doing better than if they're not younger sibs?

Q: Or any, or any that . . .

AMY WETHERBY: or other, ki—yeah. You know I went into that project thinking, oh, they're younger sibs. They're gonna wanna do this, they're gonna jump in. (Laughs) It doesn't work that way. You know, every, everywhere you turn it's challenging. It, you gotta have grit, and perseverance. And so I think the reason it doesn't generally, I think the literature shows that younger sibs are higher functioning generally. On average. And so I think what happens is they have an older sib, who's demanding, who takes up a lot a their time, their life is devoted to services, and the younger sib looks pretty good. Now the other side of it is all kids with autism when they're babies, look pretty good compared to the older sib., who it, you know may have a lot a challenges. So, they see the baby as lookin' pretty good. they don't see the early signs. Now we hope our new ACE is going to have, we're starting wat 6 months, teaching them the milestones, so we're gonna see if that help. Then by the time child's 12 months, that they understand the gap that's starting. So we're tryin' to get better and better to help them see what, what babies should be doing. 'Cause most parents and doctors, and I have to say some speech therapists, don't know what babies should be doing. So it's learning that will help. But in general, the baby sibs are not more engaged in acting on screening results than the primary care population, and I would of not predicted that. And then I, we've talked to other baby sib projects, it's the same. It's pretty much the same. So you're up against that part, just getting them to buy in, getting them to... So that's comparable. I do think the baby sibs, you have an opportunity to catch them earlier, 'cause their cap, more captive, like you can screen 'em. Right. They have more of a reason to screen, even if they don't act. Whereas in the primary care population, it's much harder to get the screening out to them. So I think that in general maybe part of the reason they're, they're functioning higher is that they're caught earlier and they're getting something. Then lastly, it may be genetically, I, and I'm not a genetic expert, but it, it's my understanding that some of the comorbid intellectual disability is not necessarily related to

the autism gene. So it may be that the, as you see the autism running in families, that we see the, the higher functioning kids can emerge from that. Whereas the kids that have more intellectual disability or may have more other syndromes, or different situations, it may not be common among the sibs. May or may not be. Anyone wanna add to that? Any other experts here?

HOST: I would like everybody to thank Amy Wetherby for her wonderful presentation.

AMY WETHERBY: Thank you. Thank you. Much appreciate it.