Catherine Lord:

But on the whole, there are so many people with autism and just other people who are not thrilled with Zoom and so that's when we sort of jumped in and tried to create the BOSA, because the ADOS really doesn't work long distance or remotely or with masks. And so we were just like, what can we do to help?

Spectrum:

Yeah. Let's start with kind of taking us back to when the pandemic first hit and what were your kind of initial thoughts about how to do autism assessments and diagnosis when you couldn't see people in person?

Catherine Lord:

Well, I think initially the first thought was, well, why would we do them? What is an autism assessment give you? And what is it that families really want to know that they're asking us for? Is it they want entry to services or do they want information? And I think there are lots of ways of getting information from families and so I think one thought was, for families that just, they want to know, does their child have autism and then they're going to think about what they're doing. There were lots of things to do, not perfect, but lots of alternatives in terms of interviewing families in terms of getting videos.

Catherine Lord:

For families who need services, part of it initially was they weren't getting anything anyway, because everything was shut down by the pandemic, but then gradually people started to say, "Look, I can't wait forever." That's when we sort of jumped in and tried to create the BOSA because the ADOS really doesn't work long distance or remotely or with masks and so we were just like, what can we do to help? And WPS graciously, let us set it up without costs to the people that are using it. And so we just jumped in to trying to train as many people wanted training as we could.

Spectrum:

Yeah, tell me a little bit about what some of the issues or why you can't do the ADOS remotely or with a mask, and then how that led you to create the BOSA instead?

Catherine Lord:

Well, when we first looked at what does it look like when you're doing an ADOS with a mask? I mean, partly if the child, even if you have an adult, you can't see their face and part of the diagnosis of autism is based on eye contact, facial expressions, gestures, tone of voice, all of those things are much harder to see, not gestures, but certainly facial expressions, eye contact, and tone of voice when somebody is wearing a mask.

Catherine Lord:

But even if the participant or the patient isn't wearing a mask, if we're wearing masks, we look different and certainly in our hospital, I mean, people are really decked out covered to try to be safe and so there's all sorts of sources of distraction, which it's really not fair to say that a child doesn't look me in the eye if you're wearing a mask that goes, a transparent mask that goes over another mask, that's taller than you are, I mean, so we really felt like this is just not going to work.

Catherine Lord:

I mean, there is one study where people did some of the ADOS remotely with, I think they were young adults, they didn't compare them to anybody else and they didn't do all of the tasks and they felt like they could get good information. I think with some people you might be able to, but on the whole, there are so many people with autism and just other people who are not thrilled with Zoom recordings.

Catherine Lord:

And there's so many complexities that we really felt like the strength of the ADOS is that it's a standardized instrument and that it is standardized by teaching the examiner who's giving it to modify what they do around the needs of the person that you're interacting with.

Catherine Lord:

And so if you can't see that person or be with them, except remotely, that's much more difficult to do, so we felt like it was easier to say, "Don't do it." Now, the reality is we, and lots of people are still doing tasks from the ADOS, remotely or even in person with masks and it's fine to use those tasks to get general information, it's fine to look at the codes to think about what would you want to be looking at, it's just that you can't add it up in a standardized fashion. We just have no data to support that that will work and a lot of reason to think that it would be variable.

Spectrum:

So are there concerns that the children are going to act very differently than they would have normally acted in an evaluation situation because it's so stressful and it's so different for them now?

Catherine Lord:

I mean, that is a concern and I think that's a concern on multiple levels of just the whole assessment experience, it can be difficult for kids and families anyway, in the current circumstance where you can't stay in a room for longer than a certain time, and you can't have your ordinary flow of going from the waiting room to checking in and I mean, there's just a million things that are different. So we just felt like we shouldn't allow people to sort of plot numbers onto those differences without being sure that they didn't affect those scores. Not that you can't glean informal information from seeing what kids do, but just that you should not be totaling them up.

Spectrum:

So tell me what the BOSA is, what that stands for, how it's different from the ADOS and how you developed that?

Catherine Lord:

So the BOSA stands for Brief Observation of the Symptoms of Autism and what we wanted to do was we realized that for example, in our own clinic at UCLA, people could do cognitive testing wearing a mask,

they could do parent interviews remotely, they could do adaptive skills remotely, they could ask parents, but you never really got to see the child play or interact with anybody in a sort of relaxed way.

Catherine Lord:

So what we decided to do was we took another instrument we're working on, which is called the BOSCC, which is only 12 to 16 minutes long, so it's much shorter. And in the BOSCC, what we're really interested in doing though is not making diagnoses, but looking for social behaviors that might change over the course of say three months of treatment, a relatively brief time.

Catherine Lord:

So we had that in place, we knew what tasks we wanted to do in that short period of time and the kind of toys or objects with adults you might use if you wanted to get information about social reciprocity and conversation and social interaction in, say 16 minutes.

Catherine Lord:

What we decided to do with the BOSA, was try to take some of those tasks and see what we could do in 16 minutes or in some cases, 12 minutes and what we wanted to do was have the parents do it because they can take their masks off around their kids and so we wanted something that was clear enough that a parent walking into this, we could say, we could show them a little video of what it looks like, give them the materials, give them a laminated set of instructions, which basically just say, "Play with your child, with the toys in this box for four minutes, get your child to clean up, do something else," which in some cases is blowing bubbles, in some cases, it's having a conversation without toys, then come back and do the same thing again, with a different set of toys.

Catherine Lord:

So that's what it is. And then what we do is we use ADOS codes to code that observation. The difference is though that in the ADOS, every single code goes from like zero to three, zero, meaning no evidence of anything abnormal and a three, meaning whatever this behavior is, it's so difficult that it actually interferes with other behaviors. So that, it seemed ridiculous to have those codes for 16 minutes.

Catherine Lord:

So what we did was we used our existing data to look at the items and look at where in that zero to three sequence, we could differentiate really solidly between kids who were very likely to have autism or adults and kids who were very unlikely to have autism and that's where we drew a line.

Catherine Lord:

So the person who's watching this observation either live or on video, just codes it like in ADOS, but then you go back and you say, "All right, I saw that child one time fail to look at someone." But that's not abnormal, that would be a score of one, but that's not abnormal. So we made it into binary scores, which basically just means, "Yes, I saw the child doing something that I think would be quite unusual." Or "No, I didn't see it."

Catherine Lord:

And it doesn't mean that the child never does these things, it just means you didn't see it in the 16 minute period. So when you take all that information, you can basically lay it out on DSM-5 criteria for

autism, and you can say, "Okay, I saw in 16 minutes, this child did things that met the criteria in this way, this way, this way and this way." "I didn't see anything that met the criteria in these ways." And then your question that clinicians should ask themselves is, do I need more information? Do I need to get more information to see if the child ever does these things? Or do I have enough information to say, "Look already, I can say this child meets criteria for autism."

Spectrum:

The parent can do this at home with the child while a clinician is watching over video, for example?

Catherine Lord:

Right. The easiest thing to do and we've been sending out these kits like mad right now, is we talked to the parent beforehand, we send them a kit and then we actually walked through them, like let's find a good place to do this, put the box of choice here, where's your camera? You can just use a cell phone and then ready, set, go.

Catherine Lord:

And then we say, "Okay, four minutes are up, please get the bubbles," or "Please have a conversation." So we can literally walk it through, but we can also send it and gives people instructions, and they can send it back to us, either way.

Spectrum:

I understand a lot of other researchers are using this tool now, how kind of have you been getting the word out about it? What have you been hearing about other people's experiences using this?

Catherine Lord:

I mean, initially we just offered live trainings like webinars and people could just sign up for it and because WPS has let us do this without charging people, we just needed them to register and basically say they would use this ethically and that they do need, somebody needs to be an experienced ADOS user to code, because if they've never coded in ADOS, this will not make sense.

Catherine Lord:

So they just sign a statement that they understand that and then we can send them the instructions, we can send them what materials to get, most of the materials are in ADOS kits so we thought this would make it easier for people. There's a couple of new things we've added that are a little bit different, but there are toys are materials you can find easily.

Catherine Lord:

So we did it and we've had thousands of people, I mean, it's been a pretty amazing. So we just did one in Latin America, we've done them otherwise all in English, but definitely people from all over the world, as well as literally thousands of people in the US so.

Catherine Lord:

I don't have a good sense of how many people are actually using it, we'd ask people, "If you can keep your data and let us know what you get," we would love to see this, because at this point, we don't have

proof that this works, we've been collecting it ourselves and so we think we can show that it's going to be quite sensitive to autism, but we really have no sense of how specific it is to autism.

Catherine Lord:

That is it going to diagnose everyone with autism? We don't know, but we thought maybe people could send us their data, but on the whole people have not been very good about that.

Catherine Lord:

But it's been, I mean, we were glad we did it. I mean, we just ran around like crazy for a couple of weeks, testing this out and trying this out on different people to see what we could get out of it. And then also trying, practicing, scoring so that we weren't misleading people about what they could get. But I think it's not an ADOS, I mean, for people that like the ADOS, it doesn't give you the sense of what is the child like in a way where you can experiment as an examiner and be quicker or be clearer, or be more vague or be more animated and get a sense of what's going to help this child. But diagnostically, I think it's not going to work with everybody, but it's going to work with probably a majority of people who have autism.

Spectrum:

I'm curious what your thoughts are in terms of how this will affect autism research that's been done in the last year and kind of moving forward when people will reflect back on this year, they have all this data from 2020 when things were done differently in the past. Yeah, how do you think that will sort of affect research for the next couple of years?

Catherine Lord:

Well, we hope this could help. I mean, we are trying to come up with sort of algorithms, because what we have mostly our data from kids who do have autism, so we will be able to tell people, of the 300 kids or 200 kids that we have seen now in the last [inaudible 00:14:18], I guess, year, or maybe not quite, this is their average score, and this is what it looks like, so that researchers who were stuck needing an ADOS and who've not been able to do this can say, "Yes, my data looks like your data." That was one of the reasons we wanted to try to do it.

Catherine Lord:

I mean, other people have proposed other approaches, which involve videoing kids at home, which also could be good, we're not trying to claim this is the answer for all times, but we also felt like particularly if you use information from parents like the ADI, which is a long interview with parents and you use sort of standard measures, for example, of adaptive skill or questionnaire measures, and this, you can get a pretty good picture, not a hundred percent of the time, but often, and be able to say, "Yes, this child does have autism." Or "Absolutely not."

Spectrum:

And I understand you've kind of been, or you've heard stories of people being kind of creative about how they can do do assessments remotely, what kind of things have you been hearing about how people are getting it done?

Catherine Lord:

We now can do remote assessments and we can build for them, which was not true before the pandemic. So I think that does mean both, absolute tele-health, but you actually could, I mean, technically, somebody could see kids in their backyard. I've seen a couple patients who had people in private practice come to see them and do assessments there, we saw a child who was seen in a parking lot, was just certainly not ideal, of this school, but I think the school psychologist was trying to respond to the families, need to figure out what was going on.

Catherine Lord:

So I think that there's a lot of things we can do. And one of the always ongoing issues, at least for me in autism is, I often can get so much more information sometimes by, for example, going to see a child in school, and it's very difficult in a medical system to bill for that the way the American system is created and I think that that for example, backyard assessments would make sense.

Catherine Lord:

If you can see people where there's more space, where they may be in masks, but you could also have the parent interact with the child, 12 feet away and be able to watch what they do without a mask and coach them to get more information that may be easier than being in a little hospital room with everybody, wearing double masks and worried about the air filtration.

Spectrum:

And if you think about, if we get to sort of a post pandemic world where people are comfortable being inside, not having masks on, kind of what we used to think of as normal, are there elements from the last year that you think would be good to maintain?

Catherine Lord:

Well, I think one of the ongoing issues in autism is that kids may not get services because they don't have a formal diagnosis and I'm actually involved in Atlantic commission on the future health care for autism and one of the things our commission is recommending is that that should not be the case. I mean, kids should be able and adults, should be able to get services on the basis of symptoms that look like they might be autism without waiting to have an ADOS or a formal long evaluation and maybe the BOSA will help with that.

Catherine Lord:

I would hate if it replaces a decent evaluation. I still think there's something really important about a family who comes in and people look at the range of the things the kids do, so cognitive skills, language skills, motor skills, and behavior in a calmer way with more skill and more deliberately looking at the symptoms of autism that you would do in an ADOS than in the BOSA.

Catherine Lord:

But certainly if you're trying to just get kids in, the idea that somebody has to wait to get services, because they can't get an ADOS is a terrible thought for me. The one other thing is just that I do think that there are some things, there are many things that you can do remotely, and some people would probably rather have them remotely and some people not, but for some people, traveling particularly depending on where you live is a huge issue. So I think, for example, to be able to do parent interviews remotely, and to be able to do feedback with families or check-ins, where really, what you're mostly

doing is talking to parents is a huge advantage and I would imagine that many people will not want to give that up, both the providers and the families.

Catherine Lord:

On the other hand, trying to watch a four year old with autism, remotely, I mean, it's nice to see what they're doing around the house, but it can just turn into chaos if a family is having to follow them around with a phone and to set up the circumstances that we'd normally see doing a decent assessment, even in an hour, not a 10 day assessment, an hour assessment is very, very hard to replicate remotely. So I don't want us to be forced to do everything remotely when we don't have to, but I also think there's a real place for busy families and people that live far away or people who are just more comfortable talking over Zoom.

Spectrum:

Yeah, it sounds like, just like a lot of elements of our lives, it's like we found some great elements of doing things remotely, so maybe a hybrid model going forward will be what people are looking for, yeah.

Spectrum:

Great. Well, thank you so much for talking to me about this.

Catherine Lord:

Sure. Nice to talk to you.

Spectrum:

Thanks, you too. Bye-bye.

Catherine Lord:

Bye.