AUCD-Caregiver Coaching through Telehealth: Benefits, Challenges and Opportunities

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MAUREEN JOHNSON: Let's get started. Hello and welcome to the Caregiver Coaching Through Telehealth, Benefits Challenges and Opportunities Webinar. This webinar is part of the Autism Acceptance Month Series, sponsored by AUCD's Autism Special Interest Group.
My name is Maureen Johnson and I'm the program specialist on AUCD on the technical help assistance team. Thank you, all for joining us today.
Before we begin, I would like to address a few logistical details. You will be muted throughout the webinar. Please feel free to submit questions at any point during the presentation, via the chat box. At the end, there will be a time for questions. Feel free to unmute yourself during that time. All questions will be read aloud to accommodate all attendees.
We do have CART captioning available for this webinar. If you would like to access it, please click the CC button to view subtitles. This webinar is being recorded and will be available after the event as well as the transcript.
Please join me in welcoming our Autism Special Interest Group Cochair Dr. Laura Carpenter.
>> LAURA CARPENTER: Thank you. Hi, everyone! I am Laura Carpenter. I'm a clinical psychologist and autism researcher at the Medical University of South Carolina. I cochair the AUCD autism sig with Brian Bee. We are a group of people within AUCD that are very interested in autism. We're a very inclusive group. We really want autistic adults to participate, along with clinicians and researchers who are interested in autism so that we can all work together.
This year, our SIG has put together an Autism Acceptance Month webinar series all focused on telehealth because that's something that's been on all of our minds.
And so that is where today's webinar came from.
At the end of the presentation today, we're also going to be giving some information about a stakeholder meeting that we are going to have later this week and we'll give you a little bit more information about that at the end, but we definitely would like folks to join us if they can.
So now, I'm going to turn this over to Aubyn and Sarah.
>> SARAH DUFEK: Great. So I'm Sarah Dufek, I'm a psychologist and behavioral analyst at the Mind Institute. Aubyn, do you want to introduce yourself or when you speak?
>> AUBYN STAHMER: I can do it later.
>> SARAH DUFEK: We'll introduce ourselves as we go. So today, our focus is on caregiver coaching and in particular, delivery via telehealth. So to that end, we're going to cover sorts of sort of that why and how of caregiver coaching. We'll talk a bit about how it can be adapted for the use of telehealth technology, and then we'll talk a bit about an example of this through the Early Start Denver Model and then some real-world telehealth lessons that we would love to talk about as a group. Feel free to use that chat box and ask any questions and we may stop to answer them as we go or we'll sort of push them to the end if we know we're going to cover that topic.
So feel free to ask any questions.
In terms of caregiver coaching benefits. So in terms of us really selling it to you, what are some of our benefits through caregiver coaching? What do we find when we do this kind of approach with families? Usually this happens in the early intervention context, so we'll kind of be focused on that today.
But we found one of the main benefits is that we're really increasing the amount of time the child is engaged with the active ingredients of treatment. So if we're coaching the caregiver to use these treatment techniques themselves in the child's everyday life through mealtime and bathtime and bedtime and play time, it really gives a chance for the child to not only practice these skills in their daily life, but also just leads to more intervention time in addition to what they're already receiving in terms of their intervention program.

This just gives more opportunities to work on those skills.
But to put this benefit into context, we always want to make sure that this caregiver coaching piece is in addition to what the child is receiving as a full comprehensive program, so we want to be careful that parents or caregivers don't feel like they're solely responsible for all of their child's intervention. This is certainly an opportunity for increased time when caregivers are with their children to do these intervention techniques.
Also, it is really more developmentally appropriate, this age, for the child to be interacting with their caregiver as much as possible, so we don't want to take away from that relationship time and so we find that doing some caregiver coaching as part of an intervention program can have these added benefits of reducing parental stress, increasing family time together and does help primary caregivers think about their child in a more hopeful and optimistic way of they themselves being being empowered to help their child grow.
Sometimes, this piece takes a little bit of time. So you know, initially, it can be stressful on caregivers during especially the initial diagnosis time to add an extra thing, so in terms of this piece of the caregiver coaching being an added benefit, we always allow time for that to unfold, and you really want to partner with the family to decide when and if it's the right time to add the caregiver coaching.
Another benefit that we find from caregiver coaching is it really allows the caregiver to be an active partner in the intervention team, right from the beginning. So it really sets a tone of, you know, sort of actively involving the family in decision making about the child's program and what to do next, and since, you know, most of the time, the caregiver is the consistent person across the lifespan of the child, we want to make sure we involve the caregiver right at the beginning so that we're partnering together to make a plan.
And you'll notice today, one thing I forgot to mention is I'll intersperse parent and caregiver. We tend to think of parents and caregivers as the -- when we say parents or caregivers are interchangeable and caregiver coaching can be done with any primary caregiver or family members, anyone who's really interacting with the child on a regular basis.
So just a general definition of caregiver coaching so we can just get on the same page about what we're describing here. We tend to think of caregiver coaching as a real partnership between the caregiver and the provider, so you know, the idea is that the coaching is going to help the caregiver use these effective strategies, right? These active ingredients of the intervention techniques, and that the caregiver coaching process is just designed to work with the caregiver to apply these strategies in daily routines and interactions that the family and the caregiver is having with the child.
One thing to remember here, though, is many of these strategies have been designed with the provider in mind, right? That we've been using it in this more provider-based context. So initially the treatment techniques that you're so comfortable with and used to using as a provider may not be natural for families, and so they might need some adjustments there about how they're going to work in-home and when delivered by a caregiver or other family members.
And then in order to do that, we need to create this collaborative partnership with a caregiver in order to make it work, and we tend to think of caregiver coaching and the intervention time that results from that as being very relationship-based.
So the ideal situation is that you're preserving the relationship and strengthening it between the caregiver and their child.
So this is different from what we think of traditionally as psychoeducation. So caregiver coaching is quite different than sort of, you know, training, parent training or psychoeducation model. It's really more of a collaborative partnership to coach the caregiver to use these

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techniques in the context of their regular day. So we avoid at all costs this expert model of "I'm there to teach you to do something." It's really more about the collaborative partnership to how is this going to work in your daily life, and how can we collaborate on that to make it work?
To that end, we find that we really have to change our thinking in thinking about the relationship between the provider and the parent and the child, and how this works. So we're really coming from this quote from Nicholas Hobb, from the 1970s, that really encompasses what we're trying to say here, which is that parents themselves or caregivers need to be recognized as special educators and true experts on their children, and the professional people, providers, some of which are listed here, are really consultants to parents or caregivers. Our role is really to be in a consultant manner, rather than the expert in the room on how this intervention is going to work at home.
So in thinking about the actual caregiver coaching process, like what does this look like? It really helps to think about these roles then.
So you know, for the coach role, the coach is really there to collaborate with the caregiver and develop child goals, like thinking about what's important to the caregiver in terms of their child sort of moving through the world, right, on a daily basis in terms of social communication or play, for example, and how can the coach, coach the caregiver to use these strategies to address those goals?
And then the caregiver role is really to partner with the coach to help do this individualization. So the provider themselves is not going to be able to do this job right without the input from the caregiver.
And so the caregiver provides that valuable information on how these strategies will work for their family and with their child in particular.
And they give valuable feedback on how those strategies work during the daily routine and interactions with the child on an ongoing basis so that it can be adjusted properly, as an ongoing relationship there that can help this to work in an ongoing way.
And the ultimate goal for the caregiver and the coach is to sort of help the caregiver and child engagement in general routines and play while using these strategies, and that will help ultimately facilitate the child's skills that we're working on to target those goals, usually around social communication and play and maybe if there's any repetitive behaviors that are popping up or behavioral challenges that the caregiver wants to address.
In terms of the coaching procedures, there are a lot of different versions of this out there, and we'll talk about a couple of examples today, but essentially the session sort of looks like this. These are the things that are happening during the session.
So typically the coach will sort of describe the skill or activity, and then may not explicitly model it. When we get to telehealth in a minute, you'll see how this can be a challenge in the telehealth context. We use a lot of video instead of modeling it ourselves.
And there's also these very key components, you'll notice that 3 and 4 we bolded because we tend to think of these as the most valuable components of the coaching session, is allowing the caregiver to practice these skills in a session, and then get opportunities for reflection and immediate and specific feedback for the caregiver, and then we always transition into sort of a review of what just happened and then developing between session practice, because usually this occurs maybe one hour a week or one hour a month.
So we want to make sure there's a lot of planning time built in so that the caregiver feels supported to learn these strategies. And then we always sort of summarize the session and then do a lot of checking for understanding and collaboratively develop together what's the next step? What do we want to do here? What do we want to tackle together?

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This again is like one overarching plan and most of these elements are usually reflected in the caregiver coaching session.
Adjustments for telehealth. So you know, we actually started thinking about telehealth prior to the pandemic, but it's become much more timely now. Caregiver coaching does lend, because of the strategies that have to happen, the coaching procedures, really do lend well to telehealth. So we're sort of already thinking about this, but then, of course, really hit the gas when the pandemic came on about how we're going to do this.
Things in thinking about for telehealth in particular is access and use of technology. This is where the pandemic helped us a bit in that schools had to figure it out, how to give families access and training to use types of technologies. So, for example, we're all more comfortable with Zoom now than we were a year ago.
I know for myself, I was using telehealth technology quite a bit, but I think this has definitely sped up my understanding of how and when to use it. You want to think about those things as you're adjusting to do this in a telehealth format.
It's really important to set caregiver expectations about what the sessions will be like. Many caregivers have experience, even in early intervention, where the provider comes, they say okay, I'm going to work with your child, you know. I'll see you in a couple of hours. And they don't necessarily have the expectation that they're an active participant in that session. And then I think it's important to set the expectations of what can be done over telehealth and how that will be implemented. So it really helps to set those expectations ahead of time.
Preparing for distractions at home is really important here. So even doing in-home parent coaching physically has an extra special element to it when the provider is physically not there. So there is a difference between when you're a provider in the home, doing some coaching, versus when you're on telehealth, totally virtual. So it's easier for there to be distractions in the home for the caregiver when you're not physically present there, if that makes sense.
We always want to make sure to really simplify the topic, so when you're learning things virtually versus in person, it's very helpful to streamline everything and send anything you want ahead of time to give the caregiver a chance to look at it, while not requiring that, recognizing that you may just look at those things together at your next telehealth session, but simplifying everything really helps.
You have to think kind of hard about your scheduling policy and telehealth allows for a lot of easier scheduling and rescheduling. You don't have to think about space or materials as much, but it just helps to have a clear policy about how you're going to do these sessions and then once you're in the session, what the structure will be.
So it's very easy to sort of, you know -- you have a very short period of time for a telehealth visit and you want to make sure you and the caregiver covered all of your wanted and needed requirements for that session.
And it can be easier to be unproductive in a telehealth session. So you have to make sure there's structure to the session and the scheduling works out that way.
One thing that's great about telehealth that's a nice adjustment is you really can record things quite easily. So caregivers will always report that having video of things or getting video feedback is really helpful, and so if you are comfortable with it as a provider, you can just record the session and then the caregiver has access to that session wherever they want. They can go back to it, they can show it to other family members that they are finding it's hard for them to communicate what had happened in the session or sometimes, just having that video really helps to work with other people in the home, if that makes sense.
So we're going to take a step back a little bit and talk about this intervention that we're going to

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describe. Aubyn is going to talk about the early start Denver Model and how caregiver coaching fits in there.
The examples we're about to give come from a more NDBI approach, NDBIs are naturalistic developmental behavioral interventions, and they were designed -- they're an ABA-based approach, but they're designed to combine the behavioral approach with the developmental approach together, and this gray area are these interventions we consider NDBIs. These naturalistic developmental behavioral interventions and they lend quite well to the caregiver coaching piece, because a lot of the common NDBI strategies are really more appropriate and developmentally appropriate for young kids and for caregivers.
So, for example, some of these common NDBI strategies are that a lot of the teaching episodes are child initiated. There's a big emphasis on environmental arrangement for learning. The reinforcement is delivered naturally, so naturally in the environment, the reinforcement is usually related to the behavior the child is doing, directly and contingently.
There's a lot of prompting in context, so we make sure that the prompts make sense for the natural environment, and they happen right away and gradually shape the behaviors that you want to see.
There's a lot of shared control, so we consider that turn taking or whatever you would call it, there's a lot of different words for this, depending on the model that you're using. Having balanced terms or reciprocal interactions between the child and the caregiver. We have quite a bit of modeling where the caregiver is modeling behaviors for the child to do, and then the adult is often asked to imitate the child's language, play or body movements in order to facilitate teaching.
So a lot of these strategies work very well, as you can see in the context of caregiver coaching, and we're often coaching the occurring caregiver to use these strategies, and then we can do that easily via telehealth.
So and then next, so Aubyn is going to talk a bit about the Early Start Denver Model in particular, and then we'll come back to some of the telehealth elements. Take it away, Aubyn.
>> AUBYN STAHMER: All right. I'm Aubyn Stahmer and I am also from the Mind Institute. I'm the director of our university's Center on Developmental Disabilities and I'm so excited to see so many people from all across the country. It's really one of the benefits of us being so comfortable in telehealth is that we can share information and chat with people all over in our AUCD network especially.
So I'm going to talk a little bit about the Early Start Denver Model, which is one of the NDBIs and it is compromised of three sort of treatment packages, and the first is the Denver Model, which is developmental-based for everything we did in the Early Start Denver Model and it is really compromised of information from developmental science, developmental principles, science of communication development, with a real emphasis on interaction with the adult and teaching within that interaction, and like Sarah said, daily routines. You'll hear me say daily routines about a thousand times.
The second major influence comes from pivotal response treatment, which is a naturalistic behavioral intervention with more of a behavioral focus so we're marrying these developmental science principles with behavioral analysis.
And then the general principles of behavior to think about challenging behavior and other antecedent and consequence-based strategies.
And so in this developmental framework, we are looking at curriculum that follows a typical developmental trajectory across all domains of development so that we try to set goals in the daily routines in the contexts that are relevant for the child and the family to help format the

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teaching so the child with autism or a high likelihood of autism can learn more quickly and get those communication and play skills to where they need to be to learn from their environment throughout the day.
Go ahead, Sarah. Thanks.
And so for airport coaching, what ESDM has done is take those million strategies and those different formats and boil them down to the key elements in a way that is hopefully easier for parents to digest and integrate into their routines, in that one or two hours a week of coaching sessions that they have to really learn the strategies.
And so you can see the topics are similar to the topics you saw in the NDBI, capturing attention, finding the smile, getting that interaction going, the dyadic play, it's a collaboration between the parent-coach and the caregiver, this is a collaboration between the child and the parent or whatever adult is doing the intervention. We want this to be something that is teaching, but also fun and engaging, because that's how children learn better.
You see there's information about imitation, about learning, and then a lot of focus on both verbal and nonverbal communication, because we know as kids learn to communicate, they're much less frustrated.
Those are the strategies that we teach during parent coaching and we teach those in the context of what we call joint activity routines, which are activity or play with an object or laundry or food or anything like that, and then sensory social routines, which are really non-object-based play. A song or something like that.
And so these four stages really help frame whatever activity the parent is working on, and so that setup is really, we're following that child into whatever activity or thing that they want to be doing. They've shown interest in a toy or in cooking something or a song, and the parent or the caregiver is going to follow them right into that and join and set up a scene, and that's really the action. It could be singing. It could be playing with a train. It could be jumping up and down. And that gets that back-and-forth going where everyone is having fun, and then the caregiver uses variation to vary what they're doing on their own terms, and to teach within that fun context, using those behavioral strategies.
And then we really help caregivers learn when to be done, right? So kids want to do activities, but they don't always want to do them forever, and so we want to make sure that before the child is bored our upset, we've closed down that activity, cleaned up together, finished together and help them go to the next thing or finish. That's the context with which we use all of those teaching strategies we just talked about.
And so caregiver-implemented ESDM has a strong evidence base and we know that in the context of this once or twice a week interactive and partnership-based parent coaching, that works better, parents can learn to use the strategies as well as providers can, and we see increases in children's communication and play and other skills, and it relates to the parent strategies.
We feel pretty good about ESDM and other NDBIs have other similar outcomes. I'm not trying to tell you on ESDM, we just have a lot of information from our side about that, and so that is why we're using that as our example today.
And so one of these things we've done to support use of ESDM is built this program called Help Is in Your Hands and it's an online version of those topics that parents, that we teach parents in parent coaching. When I'm done, I will put the link to these materials in the chat because they are freely available. They can be watched on a computer or a cell phone, and they don't use the word "autism" because we find that parents of young kids really might not be ready to hear that yet, their child might not have autism and have social communication challenges.

 Downloaded on: 28 Apr 2021 11:04 AM

And so these videos introduce the topics, the content, and so providers can use that, even if they don't know a lot about NDBI, to help explain it to the parents.
And then there are also videos -- in the next slide -- of real-life examples of parents using the strategies, and then explanations about what you saw and why it was happening.
Remember, Sarah was saying oftentimes, we use modeling in parent coaching and we can't really do that via telehealth, and these videos of particular topics are one way to use that and parents have found them relatively helpful, and sometimes, to even watch together with the provider.
And so I just want to talk a little bit about some of our service modifications that we've done during COVID-19. We have a program where we see children in ESDM. They are receiving typically therapist-implemented ESDM along with parent coaching and we'll hear from one of our families about how this went later, but these data are more of an overall finding that we really had some nice benefits of moving to telehealth.
So parent coaching was much easier to move to telehealth than therapist-implemented interventions for most kids, although some did pretty well with it. We saw that the increased flexibility of the scheduling and the ease of telehealth really reduced our cancellations for families, who might be canceling because someone was sick in the house and the therapist couldn't come over, but telehealth is okay because there was no risk, or any other million things.
And scheduling was easier because we didn't have to schedule for driving in between.
We also saw increased interaction between the parent and the child during coaching because kids are pretty darn cute, and so it's hard sometimes to give up that modeling and have parents work with their kids, but over telehealth, we don't have any choice, and so that has really increased interaction.
And it allowed many cases for us both parents to participate. That could be pandemic related because more people are working at home, but it was a nice opportunity for that.
And like Sarah said, also for recording.
There were technology challenges, Wi-Fi challenges and those are things we need to consider as we move to telehealth, especially for families who don't have access to good Wi-Fi, rural areas, things like that.
During this pandemic, we have lots of kids at home and parents working at home and other people all trying to use the Internet and the tech at the same time, so that was also a challenge that hopefully, won't be as difficult when we are not using telehealth.
Now, I am going to show you a little example of another NDBI. So remember our list of NDBIs. We love them all. And we have another project that uses Project ImPACT and one of our parents and providers graciously said we could show you an example from their parent coaching session, and so you'll see some of the things that Sarah talked about. It's a little long, but we wanted you to get a chance to see it.
So I will be quiet and let you watch. And then which strategy -- I'm sorry did you say you wanted to try?
>> I think I'm going to go see -- if you want me to open it up.
>> Sounds good.
>> If it's okay with you, I'm going to try to give you some feedback while you're doing it with him just to process. Is that okay?
>> Yes, that's fine.
>> Okay.
>> Look! See? Open. Open! (Singing) Open! Open! Do you want to try again, do you want to get it?

Downloaded on: 28 Apr 2021 11:04 AM

>> You can let him have it now that it's open. And then you can put the lid on the other stuff.
>> Ball! Ball! Ball! Open. Tap! Say open, Mom! Open!
>> So it's okay, it's great that you noticed the hand slap, you can go ahead and open it as soon as he does that.
>> Okay.
>> Zoom! Your turn. Zoom! Yay! Good job!
>> Great!
>> So overall, how did that practice session feel to you when we're thinking about the temptation -- the communication of temptation?
>> I think it felt pretty good. I was nervous about how do I get him to ask me to do something, so that kind of gave me more of like okay this isn't as hard as I thought. So I want to try to maybe expand on it by doing like with the applesauce, see if I can do that with him.
So I'll be strategic, you know, placing it where I know he'll want that and maybe see if I can get him to ask me or bring it to me like he did with that.
>> I really felt like your language was really simple. You weren't asking questions. You really labeled whatever he decided to do with bang, bang, you did open, ball, car, zoom, zoom.
You had a lot of great language in there. Did you notice -- this isn't related to the communicative temptation but did you notice what he did when you did a different activity with the car?
>> He imitated me. I thought that was cute. And then I don't know if you saw him, he gave me the ball.
>> Yeah.
>> At the end there, that was cool.
>> That was great. One thing I'm wondering, if you added a little more animation to the game of inside for him to open, because you got that great tap a couple of times. And so for that, which you did great, afterwards you just accepted it. You're like open! As soon as he tapped it right. And as he gets that, you might wait for him to kind of move it towards you and tap it or something, whatever that looks like next.
>> Definitely.
>> But you can definitely keep that simple, like oh, yeah! Open. And then when he plays, if you put it in the thing, like really close it up and go uh-oh! And set it next to him, right, you might have him --
>> That's a good idea.
>> See this as kind of like -- he grabs it. You modeled so greatly, we haven't talked about prompts, but that prompt, he immediately copied you, when you tapped it. And then you waited and then you did it, so I thought that was a really great example -- it was clear what you wanted him to do.
Once you decided what you were going to accept right, as that communication, and that's really part of the process. You might start with one idea and then go oh, you know what, this is what I'm -- this is what I'm going to do.
>> This is working, let's do this.
>> Yes.
>> SARAH DUFEK: Great, so obviously, this is a session that would happen over an hour and I went through and picked certain sections of it. Anything else you wanted to say about that, Aubyn?
>> AUBYN STAHMER: I just -- we did a really truncated goal-setting and things like that in the beginning that would obviously take longer, but just a nice example of how you can really see a lot of what's happening. And this was play, but doing telehealth also allows you to think about

Downloaded on: 28 Apr 2021 11:04 AM

what you might do, you see things in the home in the regular activities that you might not be able to see during a particular parent coaching session.
So we have some other telehealth stuff to talk about later, but we thought it would be more fun to start with talking with a parent, Otome Lindsey. So Sarah, I'll let you start.
>> SARAH DUFEK: Hi, Otome. You can unmute yourself, and then so we had some questions, but we also can take questions in the chat. So we were hoping, Otome, for you to tell us what did the coaching feel like when you did this yourself? Do you have any feedback for the providers?
So we'll have providers and parents really listening probably to what you have to say.
>> OTOME LINDSEY: So when we started, we had in-person sessions where we were actually going to the Mind Institute about once a week, and then working with I think it was Sally and it was a group of people. And that's when we were really learning. We did the ESDM, the Early Start Denver Model. We were really learning about that process.
>> SARAH DUFEK: You're okay. I minimized the slides so we can see your face while you talk.
>> OTOME LINDSEY: I was like what happened! And I would say in the beginning, it was really hands-on. It was very -- I remember being very nervous about how you interact -- how to interact with my son and my husband and I would attend. But it was, like, that in-person, you got that instant feedback.
So I thought it was really great, just learning how to take what we would naturally do with our son, and then to apply it to a more educational base, and to really have themes and know how to limit toys, because put everything in front of him and let him decide! And then it was like no, let's try to focus it in on one thing, and then that whole team spirit of okay let's just focus here, and then he and I were engaging with each other instead of having a whole bunch of stuff and that was really fun having that direct interaction.
When we switched over -- speaking of!
>> SARAH DUFEK: Hello!
>> OTOME LINDSEY: This is our star. And then when we switched over to the telehealth, we were working with Rachel and a lot of the times, it was different because we were -- you are now on a Zoom call and it was like okay, do you see what I'm doing? Do you see how I'm trying to model this behavior? And is this okay? It was a lot of that like, I had way too many questions. But it was a little bit different, going from like the in-person to the telehealth, especially when you're learning how to do the actual -- the sessions themselves, when you're learning how to model the behavior and then implement -- oh, boy!
>> SARAH DUFEK: He's going to show us! Great example.
>> OTOME LINDSEY: A toy.
>> SARAH DUFEK: Fire truck there, I love that.
>> OTOME LINDSEY: Thank you. And so I would say like that was a little bit challenging to go from in-person to the actual -- to go through the Zoom call and then, like, okay this is me looking at my son and trying to stay in that spotlight but also trying to make sure you got the right camera angle. That was a little bit hard.
One of the things I really did like about telehealth was the relationship I was able to build with my lead, and it was Rachel. And it was just everything that I had a question on, we planned it out.
She was always right there with me, and when we were talking about behavioral issues, such as his sleeping or his eating, his potty training, hitting. Like just those types of things, we would be able to like plan it out. He really validated my feelings, my husband's feelings, Nobu's feelings, my son's feelings, and then we would be able to, like, implement different strategies on how we

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could correct the behavior without, you know -- without it being very emotionally detrimental.
And she really listened to all my crazy ideas. Like anything that popped in my head, I was like I'm worried about when he has to go to sleep every night. Cry it out is an approach, but if you want to do a slow approach to get him to sleep in his own room, that's okay, too.
And my husband in the background is like yay! I want him out! He sleeps in our room.
So it was very I think for us and our family, it worked very well to have -- for us to have the beginning part where we learned how to learn -- learned about the ESDM in person, and then to have that parent coaching as a once a month, hour check-in. These are your goals, this is how we are going to achieve them.
Here's your plan sheets. She would make me, like, little sheets to check in for potty training. How many attempts did he do? Let's collect all the data and I was like okay, you know!
Or it was strategies on how to get him to eat his food, and we had a little star chart and she was like how did it go? What type of toys did he get? I found it to be very empowering, like both my husband and I were like this is what we did! (Laughs)
And so we really enjoyed it. Like we liked talking to her, it was very personal and fun. It was like our family. I was pregnant also during the pandemic, and so she would be checking in on like, how are you doing? And I was like oh, we're doing fine. It was like another family member, just another Zoom call with a family member, but this time she would be asking us and how did he do on this? Did this strategy work well? If not, let's try another approach. It was constant like that.
So I don't know, that's just a rambly mess of a compliment, but that's how we honestly felt.
>> SARAH DUFEK: Thank you so much, Otome. That was a very great explanation of what happened. And it sounds like to me like you noted these sort of technological shift issues of like how are we going to do this virtually versus the in-person? And then the other piece -- it sounds like having this ongoing support in this way, virtually. We worked the tech issues out, and then it really was a more individualized experience, it sounds like, and that sounds great.
Does anybody have any questions? If it's okay with you, we'll keep you here with us as we go through the rest of it, anything you wanted to add, Aubyn?
>> AUBYN STAHMER: I just wanted to thank you for that great mention of the shift and the challenges, and someone said in the chat that she was glad to hear the check-ins not related to treatment are helpful. I think that rapport building is so important over telehealth, because it's the only time you see the person, you know. You haven't even met them in person.
I know you had a lot going on during the pandemic.
>> SARAH DUFEK: And I think when thinking about telehealth technology, I know a lot of providers and even myself I felt like that in the beginning, we had this feeling, how could we possibly connect with the family through Zoom, and it's so nice to hear that you felt also like it does happen. In fact, it sounds like it might happen better than if you have to come into the clinic, because we're -- in this way we're able to be in your home, and connecting on the regular. It's great to hear.
>> OTOME LINDSEY: It was great. I mean, both ways I think would work. I don't know. For us, it worked very well having that extra support and having -- and the other thing is sometimes e-mailing her was a little bit easier than to actually schedule an appointment, so we could just quickly check in and send an e-mail and she would be -- Rachel would respond like, okay, she would give us like a general synopsis of what we could do, what would work best, or she would give us an option of like you want to have a quick meeting so that we can talk about it, so that we can get on the Zoom.
And then even for times where she needed to see Nobu model the behavior, she was able to

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see it, as well. So for us, telehealth worked. I still liked the in-person. I would opt for both, personally. That's what I would do.
>> SARAH DUFEK: That's a great point about using all the elements of technology to communicate. It does open us up to more, let's meet next week for an hour and you have to wait for that appointment.
>> AUBYN STAHMER: Brian, did you have a question? I saw your hand up. Great use of technology. Go for it.
>> BRIAN: Well, technically speaking a comment, not a question. Thank you, each for presenting and being here today. We had rapport, we had relationships, and then we converted it to online. Beautiful souls like Nobu are going to tell us in years to come how they built a rapport with people online and then met them in person. And I find that fun. Both in the autism dynamics as well as all telehealth. I just wanted to share that.
>> AUBYN STAHMER: Yeah, go ahead Sarah.
>> SARAH DUFEK: I actually do have an example of families we saw only via telehealth too, actually. Should we talk about -- do we have time for that, Laura?
>> LAURA CARPENTER: Yes, we have time.
>> SARAH DUFEK: Why don't we... I have to think about my -- my technology here.
>> AUBYN STAHMER: Otome, I really appreciated how you really articulated the partnership and the importance of the partnership and not just saying, you know, let him cry it out, but really working with your family and sometimes, differences of opinion in your family to figure out the best strategy for you and for him, for Nobu. Thank you for sharing that so wonderfully.
>> SARAH DUFEK: That is the most important part is this idea about thinking about caregiver coaching as a partnership rather than what we traditionally were doing before, many of us, where we were doing -- it was a lot less partnership and a lot more teaching.
Okay. So one example we have here that we wanted to bring is something we call TeleBaby, which is doing caregiver coaching via telehealth with families who are concerned about infants. As we know more and more about early red flags for ASD in the first year and this has been really a push of community awareness about these early red flags, we started to have, especially at the Mind, we got a lot of inquiries from families who were concerned about infants. And so we had to make a plan for what do we do when concerned families come to us with their infants who may be showing some of these early red flags for ASD? And we had these intervention techniques, and can we do it?
So even before the pandemic, we had started thinking about how to do this because we really didn't want families with infants to have to travel all the way to the Mind for sessions, and it was way more developmentally appropriate for the caregivers themselves to be -- to work with their child instead of having an outside intervention come in, and so it lended to telehealth very well. And so what we did was developed this approach for TeleBaby, which is pulled from some of the ESDM and other NDBI approaches, they overlap quite nicely.
And in this, we did a little pilot study to pilot this program and we're doing some of it clinically through our program, and this approach is really designed for infants 6 to 12 months and their primary caregivers. So the only inclusion criteria is that you have a caregiver who's concerned about their baby's development. And so we picked three streamlined topics.
Step into the spotlight, which is directly from ESDM and making yourself the focus of the baby's attention. Looking at what the baby's interested in and making it become an activity between the two of you. And then we also incorporated imitate your baby, which is essentially what it sounds like, where you imitate everything the baby does, and then talking to Baby is basically focused on language that you're using that's consistent and simple for a baby to follow in narrating things

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the baby is doing and you're doing.
And essentially, we thought we probably do these intervention sessions about half an hour, 45 minutes. We book for an hour because sometimes, with technology, complications and things, it's nice to have that, but essentially, you can cover these topics and get some nice practice in, in about 30 to 40 minutes.
And we, in our initial design of this, we did three times per week per month, and so it's kind of higher intensive, but shorter period of time because caregivers can get -- can pick up these techniques pretty easily during that time, but it can be adjusted in any way that would work.
We did do those telehealth specific adjustments that we talked about.
And this is essentially a session plan, how it looks. We do an additional chat, we would say how did to work since we last saw you? And then we go straight into warmup where we have the caregiver practicing whatever strategy they're working on, and then we do essentially do two or three activities, whatever we have time for.
Remember, these are infants, so you can't engage an infant in activities for longer than three or four minutes before they bail, most of the time.
So we would do an activity and say how did that go? What do you think? And then we would do sort of reflection and shared planning. So if the caregiver were to identify this didn't go as well as I wanted to, we would say okay what should we do? Let's think about some options of what we could do to help it go more smoothly next time, and then the caregiver would give us -- we would come up with solutions together.
And then we would say do you want to try it? And then say yeah, let's try it in the next activity.
Sore we would say are we done with this activity, do we want to move on? And then the caregiver would say yeah, we're done, and we would move on to the next thing. So it's very flexible based on caregiver and child needs.
And we would always end with planning for next week in terms of closing.
So in terms of the TeleBaby, we asked the families for feedback after. This is sort of a pilot, we just wanted to get information and we found unanimously, the caregivers felt this was very easy and convenient. We had families actually internationally. The most challenging part was scheduling, as you can imagine, for places across the world, that the timing may not have worked out well.
But for the most part, the technology made things very easy and convenient. Caregivers reported that the intervention strategies themselves and the immediate feedback, they liked.
Obviously, that's universally the caregiver-identified benefit of sessions like this. Their only suggestion was that they wanted a longer course, so they wanted to keep going after that initial month, and they were preferring sort of a booster, check-in, feedback thing happening.
So we sort of added that where we do some booster sessions. We may not need that initial intensive time, but the caregivers liked the handouts, found it was easy to follow. They also found that that also helped others in the home because they had that brief handout they could refer to and show it to other people who were interacting with the child.
They didn't feelCaregivers also gave us some feedback, things to look at in between might be helpful, especially video, which is why I think Help Is in Your Hands would be a nice addition to a program like this, but it would be great to have video of babies. You want to get as close to the interactions the caregivers are trying to do.
And we did a little graphic here, like -- we asked the caregivers what was the hardest thing and easiest thing to learn? And step into your spotlight was the easiest and some families thought it was easiest, some families thought it was the most difficult.
We got sort of a little bit more consensus that imitation was the most difficult versus something

 Downloaded on: 28 Apr 2021 11:04 AM

like step into the spotlight, but you can see there's not really one size fits all in terms of this for families so some caregivers would report very differently than another caregiver about what the strategies are in particular and that has a lot to do with individual caregivers, but also the children and the infants and how much they were responding to a particular intervention technique.
We asked about helpfulness and it was really reassuring to report that none of the caregivers reported that the techniques were not helpful. We couldn't even get them to identify least helpful technique so we thought that was nice to have there because we didn't -- again, we want to streamline these approaches, to only teach the things we think the caregiver will want to know or are the most important.
I would say -- I just wanted to note here we have some quotes here from families who participated in this pilot, and one thing that we would always hear is it was really nice to do it at home and be in the normal environment where the child is most comfortable, especially with babies, right? Because they're wary of outsiders.
And then the other piece that kept coming up was caregivers would report in their local community setting, having a lot of trouble getting assistance. So they felt that their concerns about their child may have been minimized a bit by providers or the providers could see that there were concerns and they would validate that, but then say your infant is too young, there's nothing we can do. Let's just wait until they get a little bit older to serve him.
So this option of the caregiver coaching through telehealth can be a really nice addition I think in the community setting to serve families at this point in time.
And then we just wanted to end with some tips for trying it. So hopefully, we sold you on caregiver coaching and doing it via telehealth. But there are some things to consider.
So really think about fit for you as a provider or for the families that you're serving. Again as Aubyn mentioned, there may be families that this is just not the best fit for.
The hybrid approach we find is really helpful, especially easing into it. So maybe having some in-person sessions at first and then doing some telehealth sessions in addition or every other week, or as an additional support until you get more comfortable.
And then we always recommend an initial orientation session. So the technology, difficulties and challenges of navigating technology can be very frustrating. For you and the caregiver. And so having just an initial orientation session like let's make sure all of our technology works, or planning on how to manipulate it with the child there, because sometimes, we'll do that and the child won't be there, but there's a whole other set of challenges of navigating the virtual with the child present. So we often recommend this orientation session that is as close to what a session would be like as possible.
Make sure to really set expectations for you as a provider and a caregiver. So you know, talk through what the plan is for each session, what you're going to be able to do virtually. Really don't be afraid to create a script or detailed session structure for yourself. This is a new skill for you as a provider to do often, and so it really helps to just write yourself a script, telehealth is really conducive to that.
Making a consistent session space for yourself as the provider. It can help you sort of get your mind into the mode of being the provider, but, you know, as we've all learned from working at home, this can be a challenge.
So having a consistent space really helps, because any of these extra things that can happen can take the telehealth interaction session more frustrating, and then maybe abandoned over time.
You want to maintain open communication over time. So I think there's a tendency for us as

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providers to sort of say oh, yeah, how's it going in the first session, but then never check in again. This requires a lot of ongoing check-in over time, just to make sure it's still working, it's still working for the family.
And then make sure to send any documents ahead of time, but again, don't require families to really look at those things. Sometimes, it's nice to look at them together via telehealth rather than creating sort of homework situations.
That was our discussion, and then we just want to say thank you so much, Otome, for coming. It was very helpful to have you here, and to all our families who volunteered their time to give us this information. It's so valuable. And then our faculty, staff and training for the Mind Institute really make this happen on our end. Aubyn and I are very grateful for that piece.
I don't know, we may have time for one or two questions.
I went through that end kind of quickly.
>> MAUREEN JOHNSON: Yes, thank you so much Sarah and also, Aubyn and Otome. Please, if you have any questions for our presenters, you can put them in the chat. I haven't seen any questions so far, but Kristin wants to say thank you for sharing your experiences with us.
>> Thanks, Kristin.
>> AUBYN STAHMER: Feel free to e-mail us if questions come up later for sure.
>> SARAH DUFEK: Any time.
>> AUBYN STAHMER: Depending on your time zone, you may be hungry.
>> SARAH DUFEK: (Laughs) Right!
>> MAUREEN JOHNSON: Please feel free to provide feedback on this webinar. I have placed the link to provide feedback. It's really helpful for us to create more webinars like this.
>> BRIAN: Thank you, all that put this together and present, as well as those listening. Brian Be from the special interest group for autism with AUCD. Please consider joining us for Thursday's open house. The link is in the chat. You want to grab that real quick before we close off the Zoom. Thanks, again, to our presenters. If you can click on your reactions and you want to give them a clap, thank you very much. As well as my cochair for helping put this together and AUCD for hosting. Captioner for giving us more access.
MAUREEN JOHNSON: Thank you to all and I do see one last question before we conclude. It's from Aida. It said we did the ESDM as a family when our child was younger. Now, that he is 8, what is recommended since we followed this model and ESDM is until 5 years old?
>> AUBYN STAHMER: It's very hard to give specific recommendations for a specific child, of course, because I'm sure he has unique needs, but several of those NDBIs that were listed have curricula that go older than 5, so Project ImPACT, the response training, those have strategies that you can use to much older ages. And ESDM's strategies also can be used. The curriculum just ends at 5. So I think you can still incorporate what you learned and maybe it can also be helpful to have some additional parent coaching as your child grows so that you can fit with his new skills and goals for your family and for him.
Is that all right, Sarah?
>> SARAH DUFEK: I think so. I think also it does require, especially around 5, starting to partner with the school and thinking about the education setting that you're going to be in and never too early to start doing that and thinking about the right fit. I think it's so hard to know without really coordinating -- and Otome has something to say, too.
>> AUBYN STAHMER: Go ahead, Otome.
>> OTOME LINDSEY: One of the things I just wanted to say real quick was working with the parent coaching, they helped us with getting our son set up with his EIP, and just working with the school district and then going through his evaluation form, and then talking with the school

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so that he would have appropriate goals. So it was like -- that was another piece about the parent coaching that was really helpful, is that they helped us along with transitioning from ESDM to school setting, and then hopefully, we can all come back and check in.
>> AUBYN STAHMER: Really great point.
>> MAUREEN JOHNSON: Thank you. I do want to point out that AUCD did do a webinar on Project ImPACT for last year's Autism Acceptance Month webinar series. I placed a link there in the chat for those that want to view the recording. We're going to conclude our webinar here. Thank you so much to Aubyn, Sarah and Otome. Thank you, again, for this lovely presentation. This webinar has been recorded and will be available shortly, as well as a written transcript.
So again, please if you can provide your feedback in that survey link, that will also be sent to all attendees after this webinar via e-mail.
So thank you and have a wonderful afternoon.
>> SARAH DUFEK: Bye.
>> Bye.

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