>> Hello, everybody. My name is Taylor, I'm going to be the room moderator for this session. So if you have any questions, let me know, I'll be sitting in the back. This is a presentation called Supporting Parents-Same Needs, New Normal .

>> MEREDITH BERGER: Thank you. Welcome everybody. My name is Meredith Berger I'm here with Jrk ackie Garcia today. We have a nice amount of time compared to the other sessions so there'll be points where we ask for feedback. But if people have comments or questions whatever, feel free to join us, jump in.

Are we not going to -- here we go. Now to the good stuff. So when a parent finds out their baby is deaf or Hard of Hearing, there are a couple of simultaneous paths they end up traveling. The medical path, which is about the child, the intervention path, which is also about the child. And the other path is their journey. But there isn't really a clear path for them to follow.

And so one of the things we wanted to talk about is how we work to address some of that need, particularly around COVID. So I'm assuming that people in the room work with families, particularly with young children. And so asking you and if you are signing a response, I'll move over for the interpreter to grab the mic. If you are saying a response, I'll repeat it.

So what are the reactions you've experienced from parents when they find out their baby is Deaf and Hard of Hearing? Anyone? Scared. Denial. Shock.

>> [off microphone] as a parent you feel like oh no, what are the next steps? In your head you are trying to plan ahead.

>> MEREDITH BERGER: So as a parent she felt all of those things but also thinking about, how do I plan ahead? And what am I going to do? Did I capture it? I wanted to make sure we got it.

>> The unknown, is there more coming up?

>> MEREDITH BERGER: Right, the unknown, what else is coming? What other surprises are out there? And we experienced the same thing. Surprise, shock, stress, confusion. And we also talk a lot about isolation. Stepping out of COVID times. There's a point where when you're pregnant you are meeting other pregnant people, either it's your friends or you end up ponding at a waiting room in the doctor's office or a prenatal yoga class. When your baby has something unexpected when they are born you are isolated from those people you thought of as your safety net and your support system. But you are also isolated because you are not supposed to be going out with a baby who doesn't have a robust immune system. So it can be a very isolating -- very isolating time.

And there are also, unfortunately, I'm sure many of you hear it as well. Way too many parents who come in and say, I was even more surprised because the person who gave me the newborn hearing screening results said don't worry, this happens a lot. It's probably nothing.

So that's a problem for another discussion. And it's also with these multiple systems are hard to navigate when you know how they work, let alone when you are dealing with a new baby and trying to meet their needs. And recovering from pregnancy. And all of those things it's a really rough time.

So we know that parents benefit from a number of supports. But particularly from parent-to-parent. And there's a lot of research that supports this. And reasons why. And I'll give you a second to read the comments.

Really at the heart of what we do, we try to use a family-centered approach to early intervention. And at the heart of that is parents feelings of self-efficacy. The feelings they have the skill and the knowledge and the, um, resources to meet their child's needs. And as a new parent, regardless of whether they are Deaf and Hard of Hearing, you don't feel confident, you don't know why anyone let you leave the hospital with a baby. And now you are struggling with these other things as well. And parent's self-efficacy is strongly tied not just for Deaf and Hard of Hearing hearing but children in general, parent's self-efficacy is tied to a number of outcomes for children.

And so what happens with parents self-efficacy? And it's kind of a self-feeding cycle. That if parents believe in their own ability to meet their child's needs, typically those positive feelings support them in increasing their involvement in intervention or education. But in those things that support the child that are unfamiliar to the parent. And then the child's outcomes are positive.

Which when parents see their children responding positively to something they are doing, they then feel more confident and they become even more involved. So the cycle continues. And so -- and so for us, before COVID, um, we had things that were virtual and different ways of supporting parents. But from a birth to 3 perspective as an EI service provider most of the in-person support most of the support was in person. It was related to Early Intervention, families came to us. They got to meet each other. The babies were present because they were in parent infant groups often. And they were layered with supports for the parents and they were effect when we were doing them. And then COVID hit.

And like most of you if not all of you, when COVID hit things shutdown. There was a little bit of a gap before New York State Early Intervention gave the approval for telehealth models. They had not provide groups to be virtually to provide reimbursement.

They had bigger fish to fry at the time since they are under the Department of Public Health. And I think they equate groups with ABA-related services with children with autism. And not understanding how pivotal the work that we do with the parents supporting them in those early stages are.

So we were in crisis as professionals as I'm sure you were. And in the beginning we were working just to survive. And then as we were talking to our therapists and reaching out to families we had a bunch of babies that were identified just before COVID. Or just after COVID started. And we knew the families were in crisis because they were further isolated not only all it have normal isolation but they couldn't have family support. Nobody couldn't come over, they couldn't go to mommy and me groups. It's important to keep in mind how that -- oops -- what that might have been like for them. For some of the families at this time, they didn't have a partner in the room. They might have been discharged the day after but it was as soon as after to get them out out of the hospital for their own safety. Their experience was traumatic. There's no other way to put it.

My sister gave birth during this time and I think she's still dealing with the emotional effect of being a first time new parent without any support. That isolation is something that is really -- we can't really imagine it from their perspective.

And so we knew we had to do something and Jackie will tell you what it was.

>> Hello. Okay. My voice doesn't normally need amplification so I'm not used to this. Okay, so we had all these babies that we knew. And their families that really needed support. They were super isolated. Because they were newborns and their families had no support. But in addition to that, they had this new diagnosis they were dealing with. And they had no idea what to do with it. Most of their audiology appointments were pushed back and they had very furorses.

So we started out talking about virtual parent groups which we had been talking about but really never had done.

So in addition to all the craziness of figuring out virtual services in general during COVID we were then trying to figure out, how do we do a group? That seems crazy. But we needed to do it.

And we started to kick things off.

So we started out by sending out an email to all of our families. Oh, I didn't realize we didn't do that. There we go. So the first meeting. So before the actual meeting I sent out an email to all our families with babies that were under 1-year-old. All of these families were families that hasn't been in one of our in-person parent groups so they really hadn't met other families in the same boat as them. And just choose an initial date and time. I feel like if I tried to send out a survey to see what would work for everybody, we wouldn't really get anything.

So I said okay, I'm having a meeting Wednesday at 2:00 and come if you can, I would love to see you.

It's a baby optional meeting and it was Zoom. And I knew newborns weren't going to interact with us via Zoom. I said if your baby is sleeping ing or in the other room or whatever, you don't have to bring them, we would love to see them but you don't have to bring them with you.

And I said I choose this initial time to get things started but if you have feedback for better dates and times you can email me and let me know or you can join the group and we can talk about it during that time. And that was a pay major point we wanted to talk about then. The group was for the parents and not me. So we wanted to make sure we were reaching as many as possible. So the group got started.

I signed on and had no idea who was going to show up. Maybe I one looking at myself for an hour. But four families came to that first group.

All of their babies were under 6 months. They were all born just before New York State went into COVID lockdown. And so it was kind of crazy. It was a really emotional session just being able to connect with other people that were dealing with the same raw emotion they were dealing with.

And for many of them they hadn't even seen their own families in several months let alone people that were really in the same boat with them. With a newborn and with a baby with a hearing loss. What I said when we started the session was, I don't have a plan for today. I think we are going to figure this out together.

Usually when I start groups I know exactly what I'm going to do, right? I'm willing to be flexible and go where the parents lead me. But with this one I had no idea what I was doing and I was really up front with the families about it.

So I said let's figure out how this will work together this is a journey we are on together. And we did. We started the session in the same way I start my in.

Person groups which is with introductions.

So for the first session it was about introducing themselves and I'll talk more about how that progressed through the group in the next slide. But we -- they introduced themselves and their babies and they talked about they stated their baby's age their degree of hearing loss and their amplification if they knew at that that point. At this point in their journey they didn't know how to describe their child's hearing loss yet. And I reassured them that was fine. That's part of what was the group was for was to learn together. As the -- we talked about what was going on. And where they were. We talked about topics, things they wanted to talk about and learn about together.

And that's how we choose our topics for all of the future groups. At the end of the groups we said, okay, what do you want to learn more about?

In that first group, one of the biggest moments that still stands out to me about that, one of the dads said, you know, I would really love to hear more of everybody's stories. We did these introductions but I want to know how did you get here in what happened at the hoopt and where did you go after that? Because of COVID, I'm people feeling like I don't know what happens to everyone family with a baby. What happens to families with a baby with a hearing loss? And because of COVID all of this is so wonky. So he said I really want to know what everyone else's experience is like. And this was a powerful moment for me I think. Because in the in-person groups it takes us longer to get there for families to be willing to share or even be ready to hear each other's full stories and that was a big moment just on day one. Everybody agreed and I saw everyone's heads nods say I would love to hear about this.

And that's how we made the plan for the next group and. Of course we talked about days and times and all that not fun interesting stuff.

Okay. So then, it became a weekly thing. Everybody agreed we definitely want to do this, let's do it. And so we met at the same time every week during the day. And the really cool thing about this, nobody had anywhere to go. There was everything was closed in New York City. So you could barely go for a walk really at that point. So both parents joined because they could. And that was really cool.

And something we had never seen in in-person groups or rarely seen in in-person groups before. So that was pretty exciting. Both parents joined consistently. Every week both parents were showing up to this group.

Through the months that fold our group expanded from four families up to ten families, all with babies under a year, until they started hitting a year. But they were all around within 6 months of each other.

And then we had this consistent format that happened. We started out with that intro. Even we had been together for two years we were still starting with a intro. Which seems silly because the parents formed deep bonds with each other and they knew a lot about teach each other, probably more than their families knew about them. But the reason we did this was for a couple things.

First is to learn the information. Like I said, when you first started, many of the parents didn't know how to describe their baby's hearing loss or talk about the amp amplification they were using. So they needed to practice saying it and using the words so they were confident in that.

On the other side of that, the emotional piece is deep. It's hard to say out loud my baby has a severe hearing loss. And being able to say it in this safe space every week over and over again helped them feel safer in doing that. In less safe situations. And so that was really important. And all of the families bought into it.

And did it every week without any complaints.

At least to me.

And then the last thing that everybody was required to say was a celebration. This was super important because I think we often get hung up on how difficult this journey is. Right? And we lose sight of how magical the first few years of a baby's life are. And I really wanted families to hold onto that. And see the magic of their babies.

And so their celebration didn't have to be related to developing language or their hearing loss or anything like that. It could be anything like, oh, one of my favorite celebrations was, he kept his socks on for 15 minute today, both of them, can you believe it? That's a celebration when you have a 6 month old. It's a big deal. And is like it could be anything. And sometimes it was a little hard you had to really dig for a celebration. But it's important. It's really important to hold onto those wins. Even more so in a time when the world is in such a crisis mode. And so we celebrated together. And that was really sweet.

From the intros that took up a solid amount of time. There were 10 families doing that introduction took a lot of time. And going from there we talked about a recap. And we said last week we talked about this. How did that go? This was a really good time for me to be able to assess their knowledge and kind of have a feeling for what they held onto, what they took away from the week before.

Sometimes it wasn't at all what I thought they took away. So I made a note to myself like we are going to revisit this and get back to this conversation again. And sometimes they went even further than I thought they would and they held onto more.

And sometimes the conversation ended up continuing and we continued that same group from last week to the following week as they tried different things and they wanted to talk about it. So this was a really important, it was important to start with what we finished or we thought we finished the week before. And then when we could we moved onto the current topic. When we did the current topic, I always started out with tell me what you want to know, tell me what you want to know, tell me what you are thinking about with this. That's usually how I started, what are you thinking about this topic? Sometimes they were just stories to share, and that's okay. And sometimes there were real questions, and that was okay too.

What usually happened is most of the families weighed in and talked for a little while first. And once everybody lulled down, I gave whatever information was relevant to it and we went from there. I didn't interrupt the families. I like to let meme say what they needed to say. In the way they needed to say it. Even when -- I found -- this was harder initially, but I got better at it it. It was hard work. Even when they said something I knew was wrong, if I waited an extra second, usually it was another parent that said you know, I heard something different than that. And they didn't need me to say it. And that's okay that's the point of a group is to be able to learn with your peers. So that was really important.

And then we ended the session with topics for the following week. So we talked through a lot of times this happened really naturally. We were talking about something and other questions came up and I said this is a really good thing I think we can to a whole group on this. Why don't we talk about that next week?

Sometimes it was out of left field where a parent would say I had the craziest interaction and I want to talk about this. So that is how these things evolved.

This is a big slide, do you have questions or anything about this? [Laughter]

Before I move on? Okay. This is a very, very short list of topics. We've done a few years of these so there are more topics we covered uh but these are the big ones. And the parents choose this. I didn't say I think we should talk about different types of amplification. This is an earlier group. A parent said when we went to the audiologist, they said your child is going to be fitted with hs and that was the end of the discussion and but I've heard of a cochlear implant or a BAHA and I don't know what those are. so we talked about what the different kinds of amplifications are. retention is probably the most revisited topic we have. If we didn't talk about it every week it was a miracle because what parent isn't constantly dealing with how to figure out how to keep these devices on a tiny human. It's nearly impossible. Even when I didn't have anything new to say, just them being able to say I can't get them on out loud to people like, man, I've been there, it's meaningful, it's really meaningful. So we talked about it over and over and over again.

Audiological testing I remember a parent saying my audiologist said we were doing something called RVAs and I was VRAs, let's talk about what that means so we talked about the difference between an ABR and VRA and play audiometry and behavioral testing and what all of those words mean and what to expect during that time.

And it was all a little bit different because of COVID again. But it was an important conversation. Reading all of the audiology reports the parents would say, you told me that he has a severe hearing loss but where does it say that? How do I know what that mean h we have this report and it has a bunch of numbers on it and I don't understand what that means. So we went through them and everybody brought their reports and we read through them together.

And talking about the diagnosis with family and friends was a huge one. And another one that was revisited over and over and over again. So in the beginning of this group, again remembering this was the beginning of the pandemic when everybody was in this lock-down period, many of these families weren't seeing their own families.

So they didn't have an opportunity to really talk about their child's diagnosis. As that time period progressed and they still didn't do it that conversation felt bigger and bigger and bigger to them. How are we going to say, my child is deaf? After all this time. And so and many of them were in that same boat, they didn't know how to have those conversations with their friends or family. So just talking that through together was so powerful for them. For them to be able to say, I'm really scared of what the reaction is. And I'm really scared of how -- what's going to happen next.

For all of them they of course said we love this baby so much and we are scared they won't love them like we do or they'll see them in a different way. And that's not something you can have a -- you can't have a conversation like that without people like you. And that's a meaningful one and big in group. And something that came over and over and over again. But we spoke with my parents and my best friend is coming in from wherever, how do I tell her about it? And it kept coming up.

And it modified into what do I say when people say stupid things to me? How do I have that conversation like no, you should talk to him, he can hear you. Those things that evolved through the years. Considerations for future children has been a complicated one also. Kind of thinking, well, if I have another baby, what if they also have a hearing loss and also what if they don't? Those are two really different things. And both are a big deal. And there are a lot of things to think about and unpack with that.

And self-advocacy. And of course it comes up a million and a one times in a million and one different ways. How to talk to your baby about their hearing loss. And how to teach them to be able to speak for themselves and advocate for themselves. Tobe their own people in this crazy world.

Okay, I think -- yeah, okay.

So um, with all of this, remember we were learning together, right? I'm a planner, I like to go in many with a plan, I like to know what I'm doing. I am a teacher. So I'm also flexible and okay with rolling with the punches. But the idea I went into this group and said I don't really know what I'm doing let's figure this out together was scary to me.

So you are probably wondering what does the parents actually get out of it? How did they feel about this afterwards? So I think the best way to get the answer to that is directly from them.

So we don't have videos but we do have votes.

So I'll play -- put up a few of those in a second and I'll give you time to read those on your own. But again hold onto this. I know we keep bringing this back up. But again hold onto the idea they were so isolated during this time.

These were our original parents that wrote these.

They had no support. Really at all. This group was their lifeline. And so holding onto that as you read through these I think would be helpful. So here we go.

 Next one.

Okay. Last one. Okay, pretty cool, right? That last line that prepared me to both answer calmly and confidently stands out to me and that's the whole idea with practicing these conversations with your peers in a safe space. And so it's a big deal to parents. All right. And then things calm down a little bit. [Laughter] the world was just a tiny bit less crazy, still crazy but a little less crazy. So we had our version 2.0 groups. We took a small break, mostly because funding had run out and we were starting fresh. And also because it's good to take a break over the summer and we kicked back up and said okay let's think about this more intentionally. We don't have to wing it anymore. We have all this information from what went well and didn't go so well.

So let's think about a plan, how can we attack this more thoughtfully this time around? So we made a couple changes.

First of all, we added a group. Which was pretty exciting. At this point, our original group was around two years old. So those babies born in COVID or at the height of COVID were a bit older now and now we have a new cohort of tiny babies whose parents were in the same boat where they didn't have the group supports.

So we said okay let's do a second group. We changed the timing of the meeting. So when everybody was working from home, everybody could meet in the middle of the day. And everybody want back to work at this point so that wasn't possible. So we moved the group from 2:00 p.m. to 8:00 p.m. Most of the babies if the parents lucky, I'll say. Most of the babies were asleep at this point and they could really focus on the conversation and have that conversation, which was how it was with the daytime groups too.

Um, we had -- well, and I should also say related to that with that timing the way we really thought about it strategically is because what I realized was that we were able to get so much further into the information that we were talking about parents were able to learn more and talk more and hold onto more because they were able to really listen and focus on the content of the group. Rather than in our in-person group when we are spending at least half the time chasing crawling babies around the room. There's only so much consistent conversation you can have when you are managing a baby at the same time. Does anyone finish a sentence when you have a infant around? I think no.

So that that 8:00 p.m. was important. It was important to give the parents the time to meet when they were able to focus fully. And the parents agreed on that. That wasn't just us. We had our older our original group the version 1 group, we weren't doing it weekly anymore. They didn't really needily weekly anymore. We met once a month and did check-ins and talked to each other consistently along the way. But we formally met once a month.

With our new families we felt like once a month was not enough to form the bond that you need that trust that you need to be able to run a group so well or to have an effective group. So we met twice a month with them. And I'll admit I had some hesitations about that. I didn't think it was going to work. I thought we need to do weekly. But I was super wrong, like totally wrong actually and quickly they were able to form the same bonds. So twice a month was just perfect. And other thing we did was using What's App, so we did -- I'll pause for a second. Our original group was using What's App informally like hey, a reminder we are doing group tonight or we have this ebbing speaker coming to talk to us. And sharing adorable pictures which probably was thebest part of it. But we weren't using it super intentionally back then. Meredith had a conversation with Uma how she was using What's's App with the groups she was working with and it sparked

ideas for us.

So we were using it a little differently and so I'll show you the ideas that came with that, it was too late for the first group, but the second group. Such is life. But the second group when I said let's use What's App together I had clear intention what we would use it for.

We used and Meredith will talk about this in a minute, we used the spice R to assess family knowledge and to help us decide what topics to cover during the group. That's not to say we didn't let the families have a say in it. We talked about it. And all the things they naturally decided on was already in there and so it was easily so work that way. So we knew the importance of parent self-efficacy and we wanted to make sure we were using the tools we had to help to increase that.

The families had homework. It's sort of a loose term. It was a super simple things and they usually talked about them and decided about them on their own. I would say at the end of the session, what is your plan? What are you going to do with all of this? And most of them had something in mind. I really want to work on this. I want practice this, I want to read more about this.

So than we used that in the following session when we did our recap. We would say last week we talked about this. Many of you had plans tell me how that went.

And then in person meet ups finally New York was open again. And families were able to do things together, isn't that crazy? So they weren't just faces on a screen they were able to have happy hour or to go to a playground and have a picnic in the park. And they did that. And that was super exciting.

So yeah. Okay. So with What's App this is version 2.0, our second group. And we used it for a bunch of different things. For one because we weren't meeting weekly I wanted to make sure we had time for the questions and support things that would have come up if we were seeing each other every week. We still wanted to do the celebrations. So this first one is a parent sharing a celebration. I'll stop talking so you can read that.

Oh, yeah, can everybody see it in the back? Is it too small? Yeah, okay, cool.

I can't play the video, it's just a screenshot, sorry, guys, but it's adorable.

Okay and then we always used it for resource shares and so talking about retention that worked or things that were cool about that you could add to your implants or hearing aids so again I'll give you a second with this.

With this, what it doesn't show is that the family that was asking questions about and getting excited about it, her son was about to get cochlear implants. So this was just another oh, this is kind of cool and exciting. Like a way to be excited about it. And help to manage some of the fears she was dealing with. And the last one is the support piece. And so questions you would have asked if you were seeing these people every day or at least once a week. This the first one of higher is the question from the parent. And then the smaller one over to the side is one of the many responses I had I think like 6 or 7 screenshots of responses just to this one question.

So this is just one small piece of it. But I think it shows how parents can connect in this way and support each other so powerfully through this also.

Okay.

>> MEREDITH BERGER: So we mention that had we used the spice, which is the scale of parental involvement and self-efficacy revised. I printed out a couple of copies to pass around in case people are curious about what it is. We didn't have a stapler so I used the old college fold over trick. But it's a couple pages so be careful when you pass it around you have all the pages. There's only three copies we didn't know how many people would be here. And I didn't want to waste too much paper. But it will give you a sense.

And it's actually the article that is referenced is in the EHDI journal, JEHDI and it's free and the tool is in the appendix of that article. So I know we all like free stuff so that's useful. For the second phase we received grant funding too cover the expenses which were largely related to staff. But we also wanted to collect data for people who know me, you know I like data. But we also wanted to learn from this. We wanted to get a sense of how effective it was. And we wanted to be able to report back to the donor on the effectiveness.

So we modified the spice-R for our purposes. And asked parents one of the things we asked was, what was are your goals for being in a parent group? What do they want to learn? And we created a survey using like Microsoft forms so parents could use that like almost the enrollment for the group. And we did that for the pre-test and adapted that form for the post-test.

And so these are the very basic results. The green are the pre-test. The purple is at the owned it have -- I guess it was almost a year. Almost a year. And obviously within this individual scores ranged a lot depending on the learning curve and the point the parent was in their journey. But we felt really positive at when we saw the results. Especially for the knowledge and confidence section. Knowledge is power, right? So but what did the parents say in there were a lot -- oh.

Oh, sure, the question was, what was the column headings for the graph? So the first one is beliefs. The second is knowledge. The third is confidence. And the fourth is actions. You're welcome, thank you for bringing that to my attention. There was also a lot of space within the survey the pre and post-surveys that parents filled out for them to make comments in on different sections. And we felt also really good when we read them. I didn't actually include all of it in here but there were some that gave feedback on why they felt a certain section didn't apply to them or what they felt they still needed to learn or wanted to do or something else we could do to further enhance the support.

Are people done reading it? Okay. And I think that just, you know, like nature's funny sense of humor is often we are working with families whose first child is Deaf and Hard of Hearing so they don't have a comparison for what the raising a child and language development and developmental milestones or any of those things are supposed to be. We always say language-wise there's a second child advantage, having that older sibling that you are chasing after is trying to keep up with is great for children's language development but it's also really helpful for parents and a lot of parents commented on their ability to understand where their child's development was in the range of child development. And that was helpful for them.

Has everyone had a chance to read it? When we were doing more in-person parent groups, I would often say the single most important thing that we did as professionals was provide an opportunity for parents to meet each other, especially in those early days following the identification of their child's hearing loss.

And I think the same thing with this. There's a lot professionals have to offer. But finding your new normal, finding your people and your safety net is really that will have ripple effects on that child's life in ways that we can't measure.

I think what we found is that for doing this virtually had some advantages to in person. But also was still as effective if not more in some ways in supporting parents during a critical period of time in their parenting life. I don't know if we ever had as good attendance for anything in person. We cover a large geographic area with public transportation and it's difficult for parents to come to us in person regardless of what they would like to do. They just have too many responsibilities. It's the distance is too great and the virtual group allowed parents to participate in a way that was not adding a burden to their lives. And adding to their feelings of guilt in meeting their child's needs. And consistently dads are involved and that's a big thing too. We always say dads are a parents too. Because we often talk about moms and the dads haven't the chance to be first-hand recipients of information and also to connect to other dads is incredibly

important. The WhatsApp use I think that's helpful and will continue to be. And we know some families they are like the they are in each other's lives now but they'll lose touch and others will be at each other's children's weddings. You can see the deep connections they have with each other are tangible. We loved using the spice-R and really getting a better sense of parental self-efficacy for these parents we were working with. And I meant to mention before that Sofie Ambrose the lead in developing the spice-R is presenting on March 23rd at the children's hearing institute's pediatric audiology conversation. It's virtual. You can go to children's hearing.org if you want to register. I get no financial compensation for that, although I'm in the conference co-chair this year.

And I wanted to hear her talk more about it so maybe I could have better fidelity to the tool she developed than I did the first time around.

The date Thursday March 23rd. And the website is childrens hearing.org and they have the brochure and enrollment information. So some of the things we thought about with our planning considerations was identifying that initial schedule that can be difficult.

Because we -- it wasn't necessarily the original plan for it to be without babies. It kind of worked out with that. And we found there were a lot of benefits to that. The parents being able to be present and not chase after a baby as Jac kie said, when my kids were young, I didn't think I ever finished a conversation I started. So they have to be themselves as a person and not mom or dad in that way. And we had to think about staff because we were doing this at night and people work ad full day. And we talked about the group being an hour. But what Jackie won't tell you is in that first year the groups went like 2.5 hours and she was like baby group hung over the next morning. And I had to be on top of her and other people involved for their emotional selves we had to structure it and stick to a schedule because it can be really easy to get burned out in a caregiver type of role.

Thinking about how many people are kind of too many people. And then how does that effect the conversation. The little green picture is the way normal communication goes. Like it's a little messy and we talk over each other. And virtual there's a default to like someone being in charge. And trying to like really having to think about how to allow that ease of communication in that virtual format with its limitations is something that is probably a little bit different with each group of parents because they develop kind of like a group personality. So figuring out the role that the professional plays in trying to moderate some of that. And we also wanted to be clear there were times that there were many times where there was someone the parents want to do hear from there was information they wanted to hear from and meet. There were speakers in the group. Even for our internal planning discussions and discussions with parents the distinction between whether you are offering

workshops, which to me are like one-off topics, even if they are a part of a series for your plans purposes. Versus a parent support group, which shouldn't be just like a drop-in class type thing because you want some consistency to the group so there is safety -- there's a safe space to be vulnerable. And sometimes parenting isn't pretty. And you need parents to feel they don't have to hold back because there's a new person who just showed up who might judge them.

One of the drawbacks that we had concerns about was parents not seeing other babies again that like what's typical? Whether it's about gross motor skills, fine motor skills, eye contact, social skills. And thinking about how to fill that need if parents aren't getting that exposure during a virtual support. That we realize that at some -- at the early stages, like a 2-month old and a 4 or 5-month old, they are not moving or they are not -- whatever developmentally they are closer alike in some ways than in others but when you get to a point where the child is starting to be mobile or interact more with language, the difference may feel bigger between a 6-month old and a 9-month old in terms of the parent discussing needs.

And then thinking about if you are going to have specific groups what the age ranges might be. We were able to integrate families -- new families into the group without it being a problem. The issue was more like if the families had been if you had a bunch of families that had children all IDed during newborn hearing screening and a family whose child was identified at 2.5. Age wise that kids might be the same but the early identified child might be hearing things that highlight for them what they weren't able to do for their child even though they didn't know but that feeling of guilt or feeling lost, you have to really think about who is in the group to make it work best.

So our next steps we attempted to start a Spanish group. And ran into some challenges in part because many of the families who were mono lingual Spanish speakers were also if areas hardest hit by COVID and had life survival priorities. And that they needed to attend to. And so trying to find a schedule and have the same consistency was challenging but that's next on our list, we have a large Spanish speaking population so it's something that weighs on it. And then thinking about us, targeted groups. Like the late ID'ed families. And also balancing that information versus support and how do we replicate this particularly for families with older children who didn't get the support in the birth to 3 time period you sigh the difference.

And for any of us who work with both age groups you can tell when a parent they are doing the right things but there isn't a deeper understanding or maybe an emotional kind of comfort level with some of the things we talked about because they haven't had a chance to deal with it in the same way yet. Oops.

I always push the wrong button. And we could not possibly have done any of this without the generosity and trust of the families that we work with. And we are forever grateful. These were children who were babies at the beginning of the pandemic and now preschoolers. So time continues to move forward. And hopefully with the support they'll do it with more healthy sense of their parenting ability for a child who is deaf or Hard of Hearing, thank you.

I'm sure we missed something. Are there any questions?

>> My question is, did you have families who had children who had multiple diagnosises? How did that fit into your first version of just going by when they were born?

>> Good question, I think there are kids who were part of the first and the second groups that do have other needs. Often if we are starting when they are infants some of the needs aren't known at that point and develop over time.

>> Yeah.

>> But we went by age of the babies.

>> The second group is I think we actually don't have anybody in the group that doesn't have something else. [Laughter]

But the -- yeah, yes is the answer. And it really didn't have a huge impact on how everything ran. I think they were working mostly through the same thing.

>> When we were doing more in-person groups we discussed because we had a way to transition a family from one age bracket group to another. And developmentally sometimes children with more complicated medical needs weren't developmentally ready to move to another group. And we talked about having groups for children who are Deaf and Hard of Hearing and have another developmental related diagnosis. We haven't done it yet. Sometimes it's sensitive and the parents aren't there yet. So we are still thinking about that.

>> I was wondering with the WhatsApp group if the professionals were on the WhatsApp.

>> Sure am.

>> You are, and do the parents feel that's as helpful? Or do they sometimes express they want a safe place without professionals monitoring it?

>> That's a good question. I set it up. The purpose of that WhatsApp group is? Immediate. I don't have much to say on it. I generally check if there's anything I need to add into.

Most of the families after a few weeks have each other's phone numbers and are separately texting and messaging which is obviously fine. And so this group is set up specifically as kind of related to this parent group. But they certainly fly with it on their own.

>> Jackie I had a question. Did you -- we have a very similar model. Did you set up rules of the group community sort of? Or did the families co-create it?

>> That's a good question, yeah, we did. We talked in the beginning of it being a safe place and everything we say stays here.

Meredith calls it the vault. We keep it in this place. And usually I mean they started sharing things that were pretty deep pretty early. But I think everybody quickly agreed to that. And said this is the place that I feel the safest. So they -- to my knowledge, how do I know if they shared elsewhere.

>> One of the things that happened with our groups was we weren't starting out with families at the same stage. So there was a lot of variation in ages. And then very quickly we started getting individual messages saying oh that kid is doing more and faster than mine. How can I do that? Or parents were starting to say to us, when I shared in group I got a call from this parent after saying, how are you doing so well and my kid isn't? Which we had to help the parents see that, these are good conversations and you want to share strategies. Or you know, wisdom, whatever you want to share, we don't tell you what to share or not. But it's not a competition. And that could have been a cultural piece of the puzzle for us. All of our families were in India.

>> I think -- eferl times I remember having to reach out to all the therapies and say, hey, heads up we tacked about this today and it was deep so expect that in your next sessions.

Often what would usually happen is they come to me or go to their therapist and say during group this week I heard every is doing this but he's not there yet. So I tried to give the rest of our staff a heads up.

We are fortunate enough to have most of them getting services through them too so we have a team there.

>> I was going to check, did you all just say, hey, we have this parent group, if you would like to join? I'm thinking of confidentiality. Like how you connect the families. Like obviously they sign up. But how did you introduce that so they -- that piece of it was respected as well?

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>> It was all totally optional. I sent emails to all the families and said this is what I'm doing if you would like to come on submit this like registration form of application or whatever it was.

And that was kind of that. So because it was voluntary they were deciding what they were going to do.

>> I'm wondering how you dealt with a technology piece of it? Did all the families have what they needed to get started with this?

>> For the most part, yes, there were a few families that were using -- for the most part the families already had it. But I think there were one of two families that had loaner equipment from Clark that they were using. But for the most part, they had their own.

>> This was on Zoom?

>> Yes.

>> They were doing it from phones or iPads? Or how --

>> Whatever they had. Some iPads, laptops, cell phones , whatever.

>> Any other questions before we get thrown out? [Laughter]

>> We had entire groups on phones and it works fine.

>> Yeah.

>> Yes, and we tested multiple platforms, Zoom is the lightest, most nibble platform to use on phones and thus Zoom.

>> And I think it's the easiest one for families who have low digital literacy tech skills because they can click the link they don't necessarily have to sign in or do something.

>> Sorry, it wins on the basis of end user use as well as bandwidth. Yeah. Or -- I mean, we have a lot of families in India on data plans and that's still works fine.

>> Thank you, everyone.

[applause]

>> Thank you.