>> SPEAKER: If you're here for the journey to universal parent support, you're in the right place. We'll go ahead and get started. So, for those that don't know me, my name is hadey Klomhaus. I am the Executive Director for Arizona Hands & Voices, and I'm also our Guide By Your Side program coordinator. You'll notice that I am missing one. So, um, my co-presenter was not able to make it to the conference this year, and that would be Cynthia Miller, and she is with the Arizona Department of Health Services Office of Newborn Screening. So, I'll be taking this alone, so, bear with me. I am the parent of three children, ages 26, 13, and 9. My youngest was born hard of hearing, like myself, kind of what brings me to the table. As I mentioned, I'm the Executive Director and a coordinator. Cynthia's background, she has 20 years as a social worker for various parts of state agencies within family assistance, division of developmental disabilities. She now holds a position of the follow-up program coordinator for the hearing case management of office of newborn screening. Going to, kind of, get into a little bit of the history here. So, Hands & Voices was established as a chapter in 2007, and the Guide By Your Side program was established in 2010. So, a little over 15 years as an organization, 13 years as program services and, over the years, um, we've had a lot of support from our Arizona EHDI coordinator. We've been very lucky and blessed to have her in our corner, and she has always tried to ensure that there was some component of parent support in the HRSA grant that she's written over the years. She's been writing that grant for more than 20 years for this HRSA EHDI grant and, way before it was even integrated and within the actual requirements of HRSA. So, prior to 2017, the Department of Health used to send Guide By Your Side letters that would offer parent support enrollment. However, that was always met with really low responses. We know that, if you're a parent in the audience, that, oftentimes, we don't respond or make cold-calls or take that initiative ourselves. We have to, kind of, have that reach-out and that one-on-one initial contact with somebody to talk about what those services are before we're willing to, kind of, take advantage of those things. Then, also, prior to 2017, audiologists and early interventionists were encouraged to make those referrals, if they could, to parent support and, when we got the, excuse me. So, when we would get those referrals, they were very few and far between. So, over the years, we really worked hard on trying to get more of a systematic way of getting referrals and reaching families and being able to offer parent support. So, another nonprofit in Arizona and the Department of Health entered into a contract in 2017. The Department of Health outsourced their newborn hearing follow-up and, so, EFAD applied for that, and part of setting up their staffing was to require parents, um, to be on that staff as well and, so, that's how I came to be a part of all this and worked within the system, was I was hired on as a follow-up specialist, and I met the previous Executive Director for Hands & Voices in Arizona. We worked on that follow-up team and, one of the things that we did was we integrated parent support into the follow-up process. So, when we were following up with families and ensuring that they had their first screening or making sure that they were going back for their outpatient screening and, then, through the process of diagnosis and, then, entering into the early intervention system, we were also establishing that parent support piece at the end of that. So, we like to call it the one-three-six plus model, with the plus being that parent support. So, within that, we really worked hard to make that a routine part of the process, and we were able to get that enrollment up to 85 percent. So, 85 percent of the families reached were being enrolled into Guide By Your Side parent support services, and I think one of the main reasons that that was so successful is because we were, as parents, a part of the follow-up process. So, we've established a relationship with some of those parents from the very beginning of their journey of even just having not passed the newborn hearing screening. So, we followed them and got them back in for outpatient, back in for audiology diagnosis, ensured that they got enrolled in early intervention. So, it was an actual thing, for us to get them enrolled into our parent support services. I think that's one of the main reasons why that was so successful. So, then, in 2019, August of 2019, the contract ended with the foundation, and the Department of Health Services took the newborn screening for the hearing case management back in-house, which was right. It belonged in the Department of Health, it should be housed there. However, what that meant was that they reverted to the prior protocols, which meant that it was simply a letter that was being sent or it was a verbal recommendation of their staff, if they remembered it. It wasn't necessarily a part of their actual protocol to integrate that parent support connection within their follow-up steps. Then, I actually, um, made a mistake and put that 85 percent enrolled there, so, let me clarify. It's not 85 percent. That was when we were doing it within the follow-up protocols. What Department of Health does, they were ensuring that all the HIPAA regulations, things like that, which we were also doing when we had it as well, but their main thing was they had to have written consent. The way they were requiring that was requesting parents to download a form, physically sign it, scan it, then send it back in. That's a huge barrier. Parents were most likely not going to do that, and we actually were going from seeing anywhere from 10 to 15 families enrolled per month prior to giving it back to them, then we were starting to see one, maybe, three, and the most that we saw in one month was five and, so, that was from August 19 until June of 2020. During that timeframe, we made some quality improvement efforts with Department of Health to really work together to try to see how we can improve that system. So, in doing that, we established a contract. No cost data sharing agreement, andit allowed us, Arizona Hands & Voices, access to their database, which is their database that houses all the information, and the way it works is that, when there's confirmation of a hearing loss, somebody on the DHS side, usually, it's the follow-up coordinator, will assign it to GBYS. So, when we access the database, we have access to whatever's been assigned to us and, then, we go in and make those calls, and we offer them enrollment to parent support. We do still have to receive written consent, and it did prove to be a little bit of a barrier in the beginning, when we were trying to figure out our new method of getting those enrollments, because it wasn't apart of the actual follow-up process. We were new people that were calling them again, on top of all the people that we know typically call parents. So, we really had to think about what, how can we make this process simpler, and it took some time with COVID, um, there wasn't a lot of us that could get into the office, we couldn't have more than one in the office at one time, things like that, so, it was kind of slow-going that first year in 2020, but, then, in 2021, we really did a lot of changes and made some QI efforts, which I'll get into, but, next, I want to give you some numbers of what we've established for 21. So, for the year 2021, there were 192 infants that were born and identified in Arizona. However, only 173 of those were assigned to us, which means that we only had access to 173. So, obviously, the system's a little skewed of how we're getting those families, and we're working on, hopefully, improving that. We were able to successfully contact 88 families and offer them Guide By Your Side parent support, which is just over 50 percent success rate of contact and, then, we have 66 that, of those 88 that provided verbal and written consent, which includes three of them that happened to already be enrolled by other measures, whether they found us on their own or they were already referred by their EI provider. So, essentially, that's approximately three out of four parents that were saying yes to parent support. So, that's huge. So, we knew that this is essential, um, but we needed to look at how, what about all of those families that we're not reaching? So, the second graph shows all the ones that we were not able to reach and, so, 15 of them did refuse, and the most, the largest response was they didn't quite believe that their child had a hearing loss, so they were still in that denial phase. There were four that were contacted but unresponsive, which means that we made contact, but they were still on the fence and didn't respond to the written portion of a consent that's needed, because while we might get verbal from every single parent, we still have to have that written piece, giving permission. Then there were 20 families that had incorrect information in the, um, database or there was no contact information. Since we are not fully accessed in their database, we are not able to access other methods of contact information or even the notes of each family. So, within the database, there's notes that you can see and, in our own sharing agreement, we don't have access to those notes, to see if there might be an alternative number. Then, at the time that this was captured, um, there were three families that were not contacted. Data shows that two of them had normal hearing, and one was a recent

referral, so, they hadn't been contacted just yet. So, some of the QI improvements. We knew, so, the challenge, you know, was we knew we had to have a written consent. However, we know that asking parents to download a form, sign it, and return, we're just not going to get the return rate that we need, and that means that the parents are going to lose out on what, you know, the support that they potentially could use throughout their journey. So, what we did was we implemented the use of Google Voice. It's HIPAA-compliant, and we established that as part of our protocol and our policies and, so, every conversation that we have with a parent, we are sending a text as well. So, if we're leaving a voice message, we're also sending a text, saying who we are and, then, when we're on the phone with the parents, we are offering them Guide By Your Side, we are also able to accept a text message as a written consent. So, I will, while I have them on the phone, we started this differently, so, we send out this message that says thank you for talking to us about the program, before making the referral, we need your consent to share, and we have what demographic information we need permission for. So, it would be name, e-mail, date of birth, diagnoses, all of those things that are needed, and please respond yes for that referral. So, then, the parent would have to respond yes and, then, we take a snapshot of that and, then, we send it in a secure e-mail back to Department of Health, and they will upload it on their end to the demographic of that child in the database. So, there's a lot of pieces in this. So, one of the barriers was, in the beginning, we were doing that with the text messages, but, then, parents weren't following through with the yes. So, they would get it, we had their e-mail, we're sending the same message that we sent in that text, but also sending it in e-mail. So, then, we kind of changed it up a little bit and found that, in that moment, when you have the parent and they're willing to accept it, you, kind of, you might not talk to them again, so, you've got to grasp every opportunity. So, we changed it to where, while I, I'm usually the one that makes the call, so, I say I, so, while I'm on the phone with that family, I tell you just a moment while I send you a text, and I send that text over, and I say while that text is going through, I'll take down your e-mail, so, then, I'm not having them wait for any period of time, it's kind of this flow. So, while that text is going through, I'm writing down their e-mail and, then, I'll say, okay, you should have gotten that text, if you'd like to look at that, that's giving you, you know, us permission to share your name, date of birth, and I verbally say all of the things that are in the text, and they say sure and, so, then, while they're on there with me, they'll respond yes. So, before I'm closing out the phone call, I've got that yes, that consent. I say great, I'm sending a response, a referral will be made and, then, I'm able to close that out, make the referral over to the organizational level and then carry that forward to the parent guide and get that started appropriately. So, some of the challenges, as I mentioned, were, you know, the written consent, so, we've made some improvements on that, and that seems to be working very well. Um, of course, you know, ongoing, there's always challenges, right? We're still trying to figure out, how do we reach families? We change up the time of days that we might call. Maybe, we'll call on a weekend instead of during the weekday. Then, you know, mind you, we all have lives, so, sometimes, my weekends aren't available, so, it's not consistent, but it's always, you know, trying those small changes. So, it might be once a month that I'll do Saturday calls or one of my staff will do Saturday calls. We continue to send those secured e-mails back and forth to Department of Health and ask them if they have other contact info. However, this isn't their scope of work. They still have their follow-up to do, so, it is a timely process, because we have to wait until they're able to respond or give us further information, if it's there. Then, of course, every time we access the Department of Health database, we have to match it to the list that we've got. We want to ensure that we're not missing any babies or any babies that might have been assigned to us don't accidentally get taken off of the assignment of Guide By Your Side on their end, and we've had that happen, where we've had a baby that we're following, and we've called, mom said, you know, call me back in a couple weeks, then go back into the system, it's on my list, but it's not in the database, so I have to reach out and say what happened to this family, and they'll either respond, oh, not sure what happened, it's re-assigned now, or we've had instances where they say it turned out the child had normal hearing, and that's okay, but just ensuring that we're matching those lists, to maintain that consistency and ensure that we're not missing any babies. So, that requires consistent communication and constant updating. So, it is a timely process, and we are looking to continuously make improvements. The data sharing agreement that we have in place is very restrictive, so, we're looking at some of those changes in our future. So, some things, as far as quality improvement on Department of Health side is that we were seeing, for awhile, the re-assigning of babies to GBYS and, so, because there's only myself and one other that does these calls, we're pretty good at remembering the names. So, when a name pops up on the list, we go, wait a minute, I remember that one, because we connect so well with our families and, so, then, we'll go back through and look and say this one's already enrolled and, so, we started noticing that we were getting some re-assignments and, so, we reached out to Department of Health and said, hey, this is what's going on, we've had a pattern, not sure why and, it turned out that there was something, when there was this, um, turnover from the previous follow-up coordinator to the new one, she was having some issues with her access within high track and, so, there was something on her end, for some reason, that was, I'm not sure of the details, and I wish she was here to speak on it, but it wasn't assigning correctly, when she was trying to assign the one that she meant to assign to us. So, we haven't had that issue in a few months now, so, we've seen improvement on that, so, we think we might have overcome that, but there was also, you know, another challenge is, also, timely assignment. So, as you know, with this HRSA EHDI grant, you know, we were trying to get babies enrolled with parent support by the age of 6 months, but we have seen a few infants end up on our list a year after diagnosis, and that's troublesome, and that's worrisome. So, we, which is another one of the reasons why we're really trying to see about the future of tracking, to ensure that we just have direct access, so we're not missing any of those babies along the way or that there's timely access to parent support and deaf and hard of hearing adult support. Then, another, of course, I think everybody, everywhere's having these issues, staffing challenges, that's ongoing and, then, um, another issue was, um, staff understanding on Department of Health side. So, one of the things that the new coordinator did ask her staff was to, maybe, attend an event or two of ours, to kind of see what we actually do for families. Though they attended one of our panels, which it was a deaf/hard of hearing/deaf-blind panel, so we had several individuals that talked about their journey and their experiences, and parents got to interact and ask questions and, from that point, Department of Health, their staff for follow-up was all in. So, it was, essentially, kind of creating that buy-in, if you will. So, now, where we are. So, we're continuing to work on deliberate communication, sharing data with each other, and providing data for the CDC report. We have ongoing regular meetings with our Arizona EHDI HRSA team. We meet on a weekly basis and, so, now, Department of Health joins us on a monthly basis, just to, kind of, ensure that we're all on the same page and we know what's needed moving forward. As I mentioned, our data sharing agreement, it does expire in May, and we are working really hard on getting the next agreement in place, but, also, with some improvements. So, some of the things we would like to see is, maybe, some direct access to the demographics of the babies and, also, to the notes and, then, some access to EHDI-related data for quality improvement efforts. Right now, we are doing some hospital quality improvement, um, projects that would be beneficial for us to have as direct access to screener information, hospital referral rates and things like that. So, we're reviewing and attempting to expand that DSA. With that, I'll end it and, if anybody has any questions, be happy to take those.

>> SPEAKER: Thank you. For families that speak different languages, what is your process? Do you work with interpreters for families that speak, um, other than in Spanish?

>> SPEAKER: Okay, perfect. So, the question is, if they speak a different language, how are we getting those families? Perfect. So, my, the other person that makes the initial call is a bilingual parent guide, so, she speaks Spanish and English, and we have had some instances where, um, we've had some families that speak Russian or some other languages. Um, we will ask Department of Health what their protocol is, and the last time we've had, it was a Russian-speaking one, family, and the mom wasn't comfortable using an interpreter, because that's what we find oftentimes, they're not comfortable using interpreters, so they'll ask their adult children to interpret for them and, so, it's not the ideal way, but we have done it that way as well. Any other questions or comments? All right, well, with that, you guys are free. Thank you so much. I appreciate it.