>> Hi, everybody. Thank you so much for being here. My name is Mary Ann Stefko. And I'm an Earl interventionist for Choices For Children at The Scranton School for Deaf & Hard-of-Hearing Children. I'm thrilled to be here today to talk to you about some work that I have done, and Jacqueline Bailey Busch has done with our local medical college. Today we are joined. We are very blessed to be joined by medical students who participated in this project. And it's really their project. So I'm going to keep my comments short, as well as Jackie, and then we'll let them have the time to be able to present the work that they have done, which is special and that can be helpful to deaf and hard-of-hearing be families all over the country. So my work as an early interventionist really comes from a long standing desire to help our kiddos and our families navigate the systems out there that they have to interact with as they're going through their hearing loss journey.

And as was mentioned by Miranda in the presentation before this, most of our kiddos spend more time in doctor's offices. I'm sorry. There we go. Thank you.

Most of our kiddos spend most of their time in doctor's offices in their very early years. And it was important to me and to some folks at the medical school I connected very early on to make sure that those interactions were as positive and as productive as they possibly be. So we forged a relationship with the medical school under the pretense that we wanted to make sure that future physicians knew about deaf and hard-of-hearing children, their families, their needs, and we also then, when Jackie joined our team, as our school counselor, we wanted to make sure we were giving the children the voice to be able to really make that connection with their medical provider.

So through a collaboration with Geisinger School of Medicine with the Scranton school as well as with the professional learning community, that we have in our region, thanks to our cooperative agreement with the Department of Health, we were able to all come together and we were able to produce something that really would make a difference in the lives of our kiddos. So the choices for children is an exponent of this. This is the early intervention branch The Scranton School for Deaf & Hard-of-Hearing Children, and you will see my little friend who is in her bow in this picture way over there with her mom and dad. And we're excited to have them here today as well.

Again, as I said, the program started through a collaboration between one of the professors at the school of medicine and myself where we got together and said, how can we do a better job at preparing future physicians? And so we put together a program called support for the journey. And we also included future physicians in our professional learning community so they were learning with us, with the families as they were going through medical school.

So we have this support for the journey, we had the partnerships that we were creating and then last year, we began a community collaboration and emergent program which these students are part of and this tool will become a part of after today, I guess. Making it very official. So we have a huge Deaf Community involvement. So we always try to include as many member from our Deaf Community to provide input, to provide insight so that, again, not only the families, but future physicians have that opportunity to become well-rounded as they finish their medical education.

And for this project, we added a counseling component. Because, again, we're looking at the social-emotional well-being of children as they grow, and we wanted to make sure that was addressed as well. So I will turn it to Jacqueline Bailey Busch. Jackie is our school counselor and she was instrumental in this part of the program.

>> JACQUELINE BAILEY-BUSCH: Thank you, Mary Ann. I'm the school counselor for The Scranton School for Deaf & Hard-of-Hearing Children, and I work with kids from ages 3 to 21. And as we know, especially, these kiddos, this have so many doctor's appointments, so after a kid would be out for a doctor's appointment, I would say how did your appointment go? Almost every time whether they were 3, 15, 21 years old, I would get, I don't know. [Laughter] And I say, well, you know, what did you talk to the doctor about? Nothing. And I say, well, what's your doctor's name? I don't know. And so I ask the kid, you know, tell me about that appointment. And they say my mom talked to the doctor. Or my grandpa talked to the doctor. And I had a bellyache, and the dad told the doctor if now I feel better. And it's clear, like, we expect these kids one day to just grow up and feel like they're in control of their medical life, and they're in control of their appointments. And we never give those opportunities for kids to practice that when they're babies and when they're toddlers and when they're kids so, I was so excited about this opportunity to have our medical students come first because we put them in front of our students and for the first time, they were able to talk to their future doctors about who they were and what they liked and their favorite video games and through that, I saw comfort levels changing which was so cool to see. So I think this tool is just very, very important. And I was excited about it, because kids don't realize that they are "the" most important player on their medical team. And none of it exists without them. And through a tool that, not only covers why they're there for that appointment today, but who they are as a person and what they like, they're able to have that voice and set the tone for self-advocacy for the rest of their lives. So with that, I will turn it over to the medical students who developed this whole thing. And we're super proud of them.

>> Hello, my name is Melissa Indy and I'm one of the medical students. I'm going to speak a bit about the perspective and how our perspectives have changed because of this project. That we've been very fortunate to be part of. So I feel like my biggest change has just been that I feel very empowered with this tool. A lot of the times, our biggest hurdle is just a problem seems really huge. How am I supposed to make a change? I don't know where to start. I don't understand the root of the problem. What am I supposed to do? And thanks to Mary Ann and Jackie, we were able to discuss very finite thing that we could actually do, a single step that we can make that could actually have an improvement. It does not have to be a huge step or have to be perfect, but something we can take action on to really help this problem.

So our card is not perfect. This communication tool is something that will need to be changed and adapted to each individual. But it is something that will help our little kiddos to bond with their providers and help them self-advocate. Now on to the next.

>> Hello, my name is Hayden Swakame are medical student. Something I really enjoyed for the past year-and-a-half were the holiday lessons. I thought the signs and just the whole getting in the holiday spirit was so much fun. But I didn't realize how important those signs were until Mary Ann taught us about incidental learning. Children hear the word Jack lantern all throughout October. And hard-of-hearing and Deaf children does not get the exposure of over hearing it from school bus, or the neighbors, or on TV. And that's what makes repeating the signs over and over again so crucial. And on top of that, there's such a small window of opportunity for learning, because jack-o lantern only comes once a year. And the same concept can be applied to the healthcare for kids. Doctor's office is scary for most kids and they don't understand that they get shots, their ears are checked, their heart is left hand to, and they get their temperature taken to either keep them healthy or to get them healthy. And this scary environment can be made even worse when doctors don't use the same language as the patients they treat.

And hard-of-hearing and Deaf children may miss out on the kind words that a provider might say to make them feel more comfortable facilitating that incidental learning that they care about these kids. Things like, oh, I really like those shoes. Or, I'm going to give you medicine to help your tummy ache. And that's kind of where our card comes in. Kids have the opportunity to tell their providers things about them, like, their favorite color. Giving the provider an opportunity to react in a positive way and start forming that bond.

And it also allows the kid to tell the provider things about them on their own. Which is very important and we'll hopefully start paving the way for self-advocacy. And overtime, our hope is that my favorite color is green can evolve to, I don't think this medication is working for me. I want to try something else. And more hard-of-hearing and deaf Charen may not get the incidental learning that providers care for them, these cards can form those trusting relationships and lead to better value care.

>> Next slide again? Okay. Sorry. It happened anyways. So, now I'm going to transition talking little bit more about how we developed the tool. So Mary Ann and Jackie came to us about this idea about having a tool for kids and their parents and caregivers to try to communicate with the healthcare team. And actually, I also wanted to highlight somebody who is not here today, Thomas Riley Potter and he did a ton of work wrangling the software involved trying to make this tool. And a lot of what we talked about was what everyone has already been mentioning where we wanted to be also about these children as children, not just their healthcare needs.

And that we wanted them to also be able to talk about their healthcare needs as a dual edge sword. And while we were doing that, we also recognize that not everyone using this tool has spoken English as a first language or general English when they're reading or they may not be able to read English as well as what they need to do in order to effectively communicate with their healthcare providers. So we wanted to come up with visual representations of the questions we were asking, which took a little bit of creativity sometimes, and was a very fun part of the process for me. And I enjoyed getting to do that. And then once we had come up with some of these ideas, we got to interact with some of the kids at the Scranton school and got the understanding of these symbols and going to the doctors and answering questions like what is your medicine that you take every day look like? So that was cool to see the different levels of where each child is at, and obviously, that's a personal thing because different kids have different ability to communicate that information. And then we did an iteration of that and did another round of editing and where we spoke to parents who had kids with specific needs, because a lot of them experienced additional stressors and expressed some frustration that when they go to the doctor, they're explaining the same things over and over, which can be really taking away the limited time you have with your care provider. So they wanted something that sticks with their child sork we wanted to create hopefully an aspect of the tool where it could be scanned in and kept with a software itself in medical software so it could really follow the child throughout time and then we also were hoping that actually, Alice came up with the idea of laminating the sheet and using it with an expo marker so every time the child goes to the doctors, they can update the information. Because their favorite color isn't purple forever. So that's something cool about this tool that can be used widely and it doesn't have to be just at the doctor's office necessarily, but it can help students become, patients become advocates for themselves. And it also enables the healthcare providers to be advocates for them, because that is part of the job, especially when you're first getting the diagnoses that can be scary for families that don't flow what to do or where to turn. So you need an advocate both in the healthcare system and outside of it.

>> Okay, my name is Benjamin Krause and we're going to talk about the tool hopefully everybody has. Next slide. Okay. Okay. So the first part of the tool, if we can all follow along contains basic information like name if birthday, and also as Hayden with us discussing, favorite color, or toys, or certain activities to help the kids connect more with their physicians. This presentation is called learn about me, which is more about us than just medical diagnoses. So we were hoping that patients and kids using this tool would be able to fill out as much as they can by themselves before having help from a parent or a guardian and as lots of us have touched upon to really work on this self advocacy component of being with a medical provider.

So the second sort of section or part of the tool does get more into the medicine aspect of it. It talks about medications and allergies, hearing device use and communication. And these things can get a lot more intimidating for everybody. So it's important to write these things down and as Marisa was saying, lots of times, these things can get buried in paperwork and documents, and it's frustrating to have to bring these up over and over again. So that's why we included lots of these things that are very important. And the last sort of section is talking about why the patient, why the child is in today. And I think in this tool, it's something we can all take away from this in that we often forget things that we want to talk to our physicians about. So it's important to write them down ahead of time and, especially, this is just amplified even more if there's a communication difference between the provider and the patient. So overall, we hope that the tool would be an aspect of this relationship, and it would help improve communication and help teach self-advocacy.

>> Hi, everyone. I'm Alice. I'm the last medical student. In terms of future directions of the tool, we see it going a variety of ways. Of course, on the individual level, we hope that the tool will be able to grow with the child alongside the child until this child eventually out grows the tool, sort to speak. So while a toddler might be able to look at the sphincter say this is my favorite color. Maybe as a teenager, there's room to expand in the tool to use it kind of as a bit of a stepping stone to be able to communicate with their provider. They can elaborate in the sections that say other. They can specify. They can, you know, use this as a bit of a trigger to remind them, oh, right, I need to check in about this. And eventually, we've all talked about the advocacy that someone developed, eventually, they won't need the tool anymore and they will move on and will be able to talk to their providers as most adults can. And that will be at a different stage for each person, but hopefully, this can be used for them to grow.

Little bit broader, we hope this tool can be expanded to help children that are not just deaf and hard-of-hearing. You know, children that have learning disabilities, or other sensory challenges that might make communication with their physician a little bit more challenging. And require a little bit more care and understanding, and this would be able to be changed, modified slightly, adapted to suit whatever needs of whatever place it's used in. And, finally, we hope to spread the tool as much as possible, because the tool will only work if it's used and if it is changed and tested. This tool works in theory and we talked to a lot of people and it's a great idea. But only way to make its mark is to be tried and tested. And for us to receive some feedback and make change, adapted to whatever a child needs, and go from there. And so I think the only way we can do that is if you all take it with you, and you all share it widely. We have electronic copies as well. And we're happy to send it out, all of our contact information is here. So we would love your input. And we welcome any questions. And I just want to thank other medical students involved in this project. So I want to give a little shout-out to them at Geisinger and for their support for us being here today. And especially, Mary Ann and Jackie who made this project possible.

(Applauds)

>> And so now do you see why we're so proud of them? And we are very, very proud. So we absolutely will answer some questions as best we can. For those of you out there that know me, there's a QR Code right now, you know, Amy, I know. You're like going, Mary Ann, radio really? I didn't do it. I didn't do it. So anybody who needs to know about the QR Code, Jackie or one of them would be happy to answer those questions for you. But we are certainly open to answering any questions and sharing any information or feedback. So, Michelle.

>> First of all, I think this tool is wonderful. I'm so excited about it. I think it would be great for children who have significant speech delays without hearing loss. I could totally foresee, we have a whole classroom of students like that at our school. And I have two suggestions for adding if you're ever wanting to add, on the communication type, we have a lot of children that use AAC devices. I don't know, like a little icon, or mini iPad type look or little grid with pictures or something like that would be a great thing to add. And probably about 25 to 30% of our students in our preschool, their favorite color is pink and it's not on your choice. [Laughter]

>> MARY ANN STEFKO: Well, we will absolutely add those two things. Thank you so much. That's actually the reason we're doing this is because we would love the feedback. We love to modify it and get it out and have people using it. So, yes, I see another hand?

>> I stole the microphone on its way.

>> MARY ANN STEFKO: I'm sorry, Mark.

>> One quickly. I just want to note. I know one of you and I forgot who mentioned, you put a lot of thought and effort into visually representing some of these things. And I just want to say thank you for the work on the representation, especially, around the I describe myself section. It's thoughtful and cool of you guys. Secondarily, just piggyback on what Michelle said, my wife works at a grade school with kids who have ISP and IFSP and those sorts of things. And it's in a rural setting where there's limited healthcare access where a lot of kids see a dentist, an eye doctor, even a PCP as they come through the school. The school has things set up where they monthly where a dentist comes in and options like that. And it's only time some of these kids see those healthcare specialists. And my wife is always talking about how it's a struggling get some of her kids with language issues, or kids who have communication difficulty to engage with the doctors in a meaningful way and I'm looking at this thinking, I'm going to take it home and show it to her. She's going to love this where they rotate in those medical practitioners might be a good target for this tool.

>> MARY ANN STEFKO: Thank you, Mark. Please take it home and share.

>> I'm a mom of a 2-year-old who's deaf and hard-of-hearing. So thank you for doing this. My husband is also a medical resident. So he was doing things very similar to this not too long ago. So I feel your pain or your blessings. Couple of things. The captioning is covering the QR Code so I can't access it. So if there's a way we can get that information later, I just can't see it with the accessibility for the captioning.

Has this been used in any sort of application or clinical setting so far?

>> MARY ANN STEFKO: Not yet. No. Not yet.

>> Have you used physicians as advisors into how they would see this? Have you had any pushback?

>> MARY ANN STEFKO: No.

>> Because I know you have a 15-minute appointment, boom, boom, boom, we've got to get in and out, and we have to talk about this stuff and then they have to go, so I want make sure they're not getting pushback taking the time to meet the kid where they're at.

>> MARY ANN STEFKO: I can share with you, this was shared with our professional learning community, which does include a good number of folks in the medical community. And they vary very readily received it and were excited. We also -- I also shared it with our school physician. And she was very excited to have it. Yes. So I appreciate that. But so far, the folks that have seen it really like it. Yeah.

>> So my husband is also a medical resident. He's a pediatrician. And I think he gave some input on this. And he's the one who said get that in the EMR, get that in the medical chart. Because he's taking time to talk to every kid and put a little bit in. Hey, this kid likes soccer and ask that about him. And that's the trend, trying to get something in that medical record that builds a relationship and this takes the pressure off the physician who never learned how to talk to a kid with communication difference. And it's automatically in there. And it bridge that gap. So I think as medicine is becoming a lot more patient-focused and person-centered, which is so cool, this is going to be really well-received. So huge.

>> As marking the mic, if you stand up and get the QR Code to work.

>> Great presentation. And a new novel way to communicate with young kids who are hard-of-hearing. My question is how I'm trying to see how this will fit into the office schedule. And I was wondering, do they fill it out in the waiting room? And how about responses from all the parts of the team? The medical assistant, the nurse practitioner, the physician, so as they come in they say, ooh, your favorite color is pink and blah, blah, blah, and have where they hear some of this and positive feedback and guidance to the providers also on how to respond to this.

>> I think we have couple of different ideas about how this would work in an office setting. And I think the short answer to your question is it will depend on what office. You know, is it at the audiologist? Is it at the dentist or physician? How is that office functioning? What is the workflow, sort of speak. I think our idea is if people can take it home if fill it out at home if their child would benefit from having a little bit more time going through it and sit down with their family member and get help filling it out, we considered having a laminated copy with a marker and photo could be taken so we remember for next time. Hopefully, it would be able to go with the child and kind of go person-to-person so that everyone has the benefit of having this information. But I think part of that will come with time and implementation.

>> I will say I also shadowed a pediatrician this summer who was talking about how when they had information about a kid, they would also just hang it on the door outside side so each person going to through that door could look at it. Some offices might be possible and some may not be, it's a big system in PA so it might not work in larger settings, but in some settings, that could be an option too.

>> I was thinking under the why am I here today? The big question mark. I don't know kind of a response would be really appropriate. Because I think very many times, children don't know. And that can indicate to you, oh, I'm this kind of a doctor. This is the kind of thing. Don't worry, I'm not the blood taking doctor. I'm the doctor who does this kind of work. That might be another area of clarification. Along with the AAC, there could be other photos. If you have some icons that can get at pictures, because if you're serving perhaps an autistic kind of group of children, they might use the way picture is communicated. That's just another thought too.

>> Any other thoughts? If not, thank you so very much. Thank you so very much for being here. Thank you so very much for sharing your ideas with us. We certainly are available if there's anything that you want to talk about, we are here. Thank you so much for your time today. Have a wonderful afternoon.

>> Thank you, all, so much.

(Applauds)