>>: Hello, my name is Regina Meyer's. This is a EHDI MAID: A Deaf and Hard of Hearing Journey in a Mobile Application. I will hand it over to Brian to introduce himself.

BRIAN SHAKESPEARE: Hi, everyone, my name is Brian Shakespeare I am the Idaho EHDI coordinator. I guess that is my introduction. I've been around since 2011 became a coordinator in 2014. What we have found in our state is that when parents children get diagnosed with hearing loss, they get to meet all these people, newborn screeners, audiologists, pediatrician, deaf educators, Part C early intervention provider, speech-language pathologist, deaf mentor, are there any parents in the room we probably more, right.

Anyway what they told us is that they had all these people who are helping their kid out, but they did not know who they were. They had somebody coming to their house on Thursdays at 3:00 p.m. and had no idea who these people were.

What we did was try to build a care coordination app and in it we had some tracking options, but the real need was for her parents. Or part want to walk you through the app. I wanted to do it live for you, but it turns out even in 2023, we can have live stream and cart at the same time. So I took some screenshots for you all. This is the starting screen. The idea is when the child does the hearing screening, either in the hospital or with a midwife, anywhere they are screened, that screener will be directed at least in Idaho to have the parent download the app and you hit the get started button of course.

This is when you put in the demographic information as the parent. Name, last name, birthday. Then this is a scroll down of that same screen. Scroll down, enter your address and ZIP Code.

Then enter the information about your child. So their name. This is my brand-new granddaughter. Actually not brand-new anymore, but she was born late November so I use her for the demonstration. Her name is Eleanor. Her birthday was November 1st. I'm going to hit continue. To ask if your child has been screened for hearing loss.

If you're downloading this, the answer is usually, yes.

We had some parents do focus groups. At they basically approved all the language on this. We did not come up with that. We came up with terms that we and the EHDI programs use like did your child pass the hearing screening and things like that, but they wanted us to use please select the ears that failed the screening, left right or both. All those options are okay. A lot of our job is to report statistics to the CDC. We have a disclaimer that is pretty small but I consent to share information and I record about my child's information for recording purposes. They can click, yes, or no. Regardless of what they pick, we did not want to exclude anybody so the app will be completely functional even if they do not want to share information with us. If they want to check out the blue down there is our terms of use and privacy. It will click them down over to Department of Health and welfares' privacy policy two is for them to decide whether they do or don't want to share information with us.

Then it takes over here she can build your team. I expect they will do this in stages. At the first person they will probably add as the audiologist or maybe they were screener. Who pulls up a list of all the providers in Idaho. We are slowly populating this list and changing it all the time. Audiologist are moving in and out we have primary care providers in their ear nose and throat physicians. All of our teachers for the deaf, all of our early intervention providers, basically everybody who is going to help the family out with who has a child with hearing loss.

You can scroll through this I think there are several hundred in here already. Right now you can search it for an alphabetical order or by ZIP Code. We are just at the beginning stages of this. There'll be more functionality planned for the app that I will talk to about at the end.

 when you select a provider, this is the screen you'll see. If we have their picture you'll see we will be able to put the face of the name for the person who comes to the house at Thursdays at 3:00 p.m. We're having technical issues with the app right now. We do actually have Amber's picture. The app developers had some sort of glitch they are fixing. Anyway normally we have Amber's picture here. Assess where they work. Amber, audiologist, and she works at Star's pediatric facility and if you click that phone button, it will automatically dial, it will use the phone's native app to dial the phone number the clinic's phone number. And you can add them to the child's care team. There are appointment notes, which I will go over in a minute.

If you hit the get directions button it will pull whatever your phone uses for the maps and you'll be able to find their office. Just under that as whatever biography they sent to us or we pull from their website and they will tell you whatever they want you to know about their education and experience.

Okay,, this is where we create a no. I just picked one, but there are several different note and they will change by provider. There are a million notes you can put in there and that is up to the parent. Whatever makes sense to them. We put in an evaluation note, and the location was at the office, appointment date, one of the reasons we are building this app is because when a parent is in a medical environment, they only remember 50% of what is said, and 50% of that they remember incorrectly. We were trying to create a way for parents to be able to share the information from one of their providers with the other one accurately.

This will always live in their phone, and when they're in the next appointment they can pull it up and we are in the ENTs office and say what did the audiologist say and you can pull out the meeting notes from the last exam in the audiogram which I will show as well. Anyway the parent does not have to try to remember all that because most of it is like Greek to them anyway. At least at the beginning. I am sure you guys develop a vocabulary. But at the beginning you don't know what sensorineural neural hearing loss is. Then you put in the appointment time and date. Then you can organize your notes and go back to that appointment date and find the note you are trying to show your next provider.

Then you can attach it to a care provider so in the end you can look at all notes or maybe you only went to see Amber's notes of the notes I took from my audiologist to basically. This does the note require follow-up inquiry does the audiologist tell you to go see the ENT? Or to make sure you talk to your teacher of the deaf and for this week make sure your SLP knows this so they can do certain exercises. That is where the follow-up is. I got a little ahead of myself.

You can choose which provider, let's say you are in an audiologist's office for the situation. Whatever provider the audiologist to follow up with click this button and when you are home and got groceries, you can go back to the app and remember who you are supposed to schedule with..

If you need to enroll with a certain program, you need to enroll in early intervention or with your Idaho educational services for the deaf and blind, those are deaf educators in our state. Need to make sure to do that this will remind you of what your audiologist told you to do in our two after your appointment.

Then if you're already taking those therapies, this will tell you their advice on what to do.

I just wanted to get to the bottom of this screen there. I took another screenshot. So you can see at the bottom that I have added in audiogram. That will always live in their pocket. If the pediatrician or antique wants to see it, that is where we would put that. This is what it looks like when you have an upcoming when you have you that know you are created and you look back and can't remember what I was supposed to do next week, you pull it up and it tells you everything in a quick snapshot. Was a note that I took with my audiologist, Amber, it requires follow-up, I need to follow up with the ENT and I need to register with my educators for the deaf and continue my speech-language therapy. Basically we are trying to put all, we are trying to build them a notebook, but in an app that stays in their pocket all the time.

We you click on the GIF at the bottom it will get bigger on your phone and you can put anything you want on their. You can get these e-mailed to you as a PDF and upload PDFs, you can take a picture with your phone and start that way eventually video options, which I will go over in a minute because right now does not have that. And this will be your care team. You can look at everybody on your team all at once.

I feel like I am going really fast. This might be a shorter presentation then I planned.

You can look at your notes or attachments and just have all this organized in one spot. Then you can look at your child's, both ears, eventually the developers don't know anything about hearing loss so they do not listen to me very well. This is supposed to say what degree of hearing loss in each year but right now just as both ears and a gives you access to all the notes or attachments that you have added to the child's card.

What are the challenges? I have been working on this conceptually since 2016. I got approval from my department to start working on it in 2019, and I got a working demo of it about one year ago. So I was able to start presenting on it just like I showed you. Then we had to get approval after we did all this and that we had to have a go to the legal department. I think that took seven months through our legal department to submit it to the Apple Store. We submitted it to the Apple Store in November and the Google Play store so it would be available on both platforms.

They have been telling me for the past month that it'll be ready next week. They promised me it would be ready for today. It is not. Anyway. For anybody who was to do something like this, it takes way longer than you would think. I think we are going on seven years now from concept to demo that is not even in the Apple Store.

Addressing HIPAA concerns was a major thing. They're going to be sending HIPAA protected information through us to the state. That is exactly why we built at the way we did so that we have that approval button at the very beginning, which tells us we can or cannot transfer that information. If the plant if the parent clicks know, all this information lives on your phone and never gets exported anywhere. They are in complete charge of all their HIPAA protected information and other personal health information.

It just that concept, all my deputy attorney general, it took me about three months to convince her that this was okay. Even after I convinced her, she had to convince our director. It was a major deal that we finally found a way that all of our lawyers agreed was HIPAA compliant.

Maintaining a provider list is a huge headache. Just getting them in, getting a list of all the pediatricians. We created a list of every pediatrician the earlier, detection intervention information system so EHDI use the from screening from entry to early intervention to family support and then to deaf mentor snapshots program. Anyway we printed all of the physicians that were entered in our system over 10 years and did the same thing with audiologists, speech-language pathologist's, we worked with our state's speech and hearing Association to get their current list. We consulted our board of occupational licenses to make sure that we knew who was licensed in our state and that we had to weed out the duplicates. Now we have a reasonable list going on.

Of course, we are never going to stop with that. We are always going to have to update that list. Audiologists, primary care providers, teachers for the deaf, are always going to be changing. We will have to be deleting and adding all the time. Those of the challenges that we have identified.

I want to tell you want we're working on next. We had I think 10 focus groups with different groups of parents to figure out what they wanted. We build the first thing they wanted, the thing that came up in every single focus group is I have all of these people and it is my job to keep track of and I'm not qualified for this.

We build them a way to organize their providers and have a way to remember what happened and each appointment and be able to show that information with the other providers. For part, which is built the bare-bones right now. The next thing we're going to work on is enhancing our search feature so it is easier to find the providers. We have several harder providers in that list. Even if you know the name, if it starts with a Z., you will be scrolling for a while. You can search by location for a while it'll go by location and then alphabetical so that will make it a little easier. There is a search option so if you know who the provider is, it is pretty easy to find.

If you're like I don't know, I don't have an audiologist, I don't have one. We will make it easier by letting you search by ZIP Code and just basically refined that search engine so it works better..

One thing I forgot to mention is that on one of the first screens assess find a provider. That will link directly to EHDI Powell's. It is a national website that parents can use to find a provider. They enter their ZIP Code and age of their child's name and it will pull up all the providers that are qualified to test a child in that age range that are close to you anyway that is an easy way to find an audiologist but not an easy way to find an SOP or pediatrician or teachers for the death or perceived program and all that.

Getting those photos into the provider card is the next most important thing that parents wanted. Again, this is most of the reason we made the app so parents could match faces to names. We are having some pushback from providers. I don't want you to use my picture.

It is for your patience. We are working on selling that to all of our providers. Most are okay with that, but we are receiving some pushback on that.

Originally the way this idea came up is EHDI PALS used to have an app that would track a child from when they got screened and they woods it would say I need an audiologist and click okay, and make it a point with an audiologist and would put that date in your phone whenever your diagnostic appointment was in after you attended your diagnostic appointment than I need to enroll in early intervention. And basically basically do all those little things that parents need to do to help their child develop language.

We are going to build a calendar app that will send reminders to the parent so they have a diagnostic appointment I will send a reminder the day before to not forget. We have not figured out the timing with this because all the parents have disagreed on it, but after they go to the audiology appointment, when they are ready to get that notification about the diagnosis, some parents say they want it immediately and some parents alike I will don't want to see it for at least a week but it will pop up with the notification this essay how did your appointment go queen to the abnormal hearing, hearing loss, what is their hearing loss. The timing on that we are wavering on. Like I said almost every single one of our focus groups came up with a different timeline in which to put that. I'm not really sure what we are going to do, but we are trying to be emotionally supportive with parents with this.

Where developing resources section. I am hoping to pack on tag on to PALS EHDI PALS and it is really comprehensive. For professionals and families if you are professional in this room, I believe Randy is on the back over here. I believe you presented on that already, or is it tomorrow? Tomorrow at 4:15 p.m. in what room we okay. If you are are interested in learning more about EHDI PALS, if a parent or professional, there are fantastic resources and she will walk you through what those look like.

Anyway, we're going to link to them in the app and also going to have a way for providers to endorse specific resources. My audiologist thinks these things our apartment are important or that these things are important. Rather than having to picture this enormous resource list, it is conference of, then go to just once at their particular private provider thinks are important for them.

Then we're going to have a button like I said physicians move in and out of the state, change cities practices et cetera. We will have a button that has either a my provider is not listed, or my provider's information is incorrect. So parents can actively report to us when something is not right. I went to the wrong place. Sorry and that we can update the app and the next person will have the issue.

Capturing video. The parents really asked for this with early intervention providers. Excuse me. They wanted to record whatever exercise that their provider wants them to work on because they only go in once or twice per month or maybe twice every two weeks but in the meantime they want to be working with their child and want to be able to do it accurately.

I saw my provider do that, but I am not sure I'm doing it correctly. They can pull her phone out and open the video and do it exactly the way the provider did it in the office.

In the end, will have both professional to professional messaging and the family to professional messaging. Of the family can e-mail the provider. We will obviously, collaborate with the providers to make sure it is not going to their personal e-mail, but to their office over they wanted to go. But still to get in the list and they can send that directly from the app. They can hit the provider e-mail my provider and whatever e-mail that the provider gave us in the app is where we'll go. They can send any time through the app.

For the professional-professional messaging say the physician was to send them as a message to the audiologist, they'll have to know who the audiologist is. They it will be in the record and send over the report.

Those of the things we're going to work on. I imagine I will still probably be working on this when I retire.

(Laughter)

But again we are doing this completely for families. We are doing what they asked us for every wanted to show you guys what we have been working on in Idaho. I think that is all I got. Yet, I am happy to answer any questions or address any concerns.

(Applause)

>>: Ginger wants to know how we steal shamelessly. I am not really sure yet ginger to be honest. Once I get into the Apple Store, then I will talk to the providers about how other states can use this. Obviously, I've already talked to you about this, but I will say it to the room. You have to come up with your own provider list and resource list. Any national resources obviously, we can take from the database. You want your parents to go to Idaho Hands and Voices, for instance. Or the Idaho services for the deaf and blind. You want them to go to your people. Those two things would be necessary for your staff to complete, but the framework, one other thing that we have been careful to create properly is that you would not even have to use it for hearing loss. You can use it for any developmental disability. For autism or whatever. A variety of development of disabilities, sickle-cell. You can use the same framework. You might have to change the timing and follow-up procedures that we will build and for hearing loss because not everybody uses 1-3-6. But you can customize it to whatever disability you specialize in. Go ahead and I will repeat your question.

She was to know if we're using a contractor to create the app. Yes, we are. I don't want to mention that front of everyone because I did not really talk to them about doing this, but I can talk to you after and let you know who we are using. It was a little bit of a challenge. Are used actually somebody I knew who was a developer to do the design to get it approved to go forward and then my state has a contract with a particular company so I was required to use them. They have done a reasonable job so I am not terribly upset. I would have preferred to use my person, but, yes, we are using a contractor.

There is no way. I can't do any of that.

>>: Thanks. I am wondering I hate updating contact information. Obviously, of probably thought about this do they have their own ad providers --

(Off mic)

BRIAN SHAKESPEARE: Bradley wants to know about the provider list management and how we would complete that and specifically if we are going to let parents just update the contact information on their own. That last part is where I may have misspoke. Parents will not be able to update the list on their own, but they can e-mail that information and we would verify it and update the provider list in the app.

>>:

BRIAN SHAKESPEARE: What if parents added their own provider? We will not create the ability for them to do that. The only ability for that is to report incorrect information or when the provider is not listed. All right. Anybody else.

I know we met earlier, but I met 100 people today. Tina from Louisiana. I think I have four minutes so we will see how much I can cover.

The initial cost I believe was right about $80,000. I can't really tell you how much the enhancements are going to cost. I my budget is a certain amount and we are funding this through our HRSA grant. I am basically budgeting $20,000 per year and whatever we get done, we get done. And whenever will run out we are out.

>>: Does it accommodate multiple children in the same family?

BRIAN SHAKESPEARE: Of course, unless they name on the same and they have the same birthday. If any of their twins the exact same name than we are in trouble. Right now we only have the ability for one kid in the app I should have mentioned it and what we are planning going forward.

Gotta make a quick.

>>: Is it possible to connect providers to the app so they have to update it to update their information?

BRIAN SHAKESPEARE: The question is can we connect the providers to the app so they are responsible for updating their own information when they move our change of phone numbers, that type of thing. But I would love to do that. First, we are going to have a problem selling the use of it to the professionals. I don't think they're going to use it until the patient start going to them and say I want them to use this and that is an easy way for me to do things.

I agree. That is the idea. Again, if I take this to a PCP he would be like cool, I guess. What am I going to do with that? None of my patients use it.

We would have to get it pretty widely spread for that to be functional I believe. I think my time is up so thank you guys so much. I will be here until Wednesday. I'm going to plan a rate so if you just catch me, I am happy to answer any other questions for you.

(Applause)