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TOPICAL SESSION 3& 4: Granite A-C

March 18, 2024  
9:40 AM – 11:55 AM (MST)  
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START TIME: 10:05 AM

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>> Good morning, everybody. My name is Angela. I'm the moderator for today. This is the first time so if I mess up I'm sorry. Welcome you to the What's In and Out for Outreach Programs? It's going to be presented by Tony Holmes, and I'll leave it to you. We're going to try to stay on time so I'll be flashing cards in the back when it's two and 5 minutes up. Thank you, enjoy the presentation.

>> Good morning. Is it better if I stand over here or? Okay. We'll make it very visual and no distractions. Which is better for me to stand ‑‑ is it okay here? Do I have X marks the spot and I stay right here? Can I move a little left or right? If I was taller. That's not going to happen. The only way I would be able to do this is by breaking my legs and doing something else. No. As I was just introduced, I'm Toni Lynn ‑‑ sorry the interpreter had to move so we can see and the title is on the slides.

How many of you know about that organization? Maybe half of you. Okay, that's great. That guides me how we're going to presented to. Let me talk a little bit before we jump in the outreach programs and he survey results, and we just got the information back.

Outreach programs are happenings all over the United States. If you have any questions or clarification or anything you need please feel free, raise your hand and let's make interactive so we're having a conversation. If we have a lot of questions we might have to postpone until the end but let's see how this goes.

Once again, CEASD. Professional development advocacy organization for school administrators for residential schools, residential day schools, charter schools, deaf and hard of hearing programs, the school districts who provide services, the ‑‑ it was established in 1868. This is the oldest organization for school administrators in the United States period. And our goal really is to promote interaction and conversation throughout the United States supporting each other, advocating for each other. We talked to the top administrators. We talked to the middle administrators. Our goal is to have that conversation with everyone. Our real goal is to make sure every deaf child thrives and succeeds X. that's what our organization is for.

We have 65 schools for the deaf in the United States and of that 65 our main membership is where we have the collaboration with the university, we have the college campuses, we have commissions for the deaf. We are growing exponentially as we go along. Right now our headquarters are in Washington, D.C. I live in that area so it's quite easy for me to be there. Our strategic plan for 2022 to 2025 as you can see our goal is building cultural competence, responding to outreach and intervention and having the language access necessary in promoting that.

Also goal and what we're focusing on is diversity, equity, inclusion that is happening in the schools and address the least restrictive environment. What the meaning of that is what can you do, there are so many misunderstanding so our goal is make sure that is clear. We acknowledge and address there are language deprivations. We've seen with deaf children as they come through the schools and we see it every day and it is a variety of levels of deprivation but it is there.

Also, we're talking about retaining deaf educators and leaders and advocating and supporting them and making sure they are staying within the field and not leaving. Today we're focusing on B, which is outreach and early intervention. Also, I would like to add our board is truly amazing. Our board is leaders in throughout the United States. We have 16 people on the board. And they are committed to our strategic plan. They each are serving on committee, within the leadership groups. They provide interaction, they provide information for us. The outreach that we do, they helped us with the survey for that so our board is amazing is and responsive to our needs.

You said 16 people? Yes, 16 people on the board. How many of those are deaf? The last count, we have more here in people than we did before. We have four hearing people on the board. That's different than we had before. We were very, very strongly represented with women, but again focusing on DEIA, we have three BIPOC and I think we're about half and half men and women right now.

The reason for the survey really was to collect information about what was happening within the schools. What were they doing for outreach? Because really we need to expand that realm. And it's a very broad term so we want to make sure when we're talking about that that we're talking about programs or we're talking about advocacy, and specifically when we're dealing with the school districts, who are we talking to and what are we saying? So when we say an outreach the committee felt it was important to have that survey so we would understand from those result where is we're proceeding thereon and use the data to make sure to guide us what we're doing in the future.

As I said 65 schools and other collaborations and partners that we work with. Fourteen schools responded, and they have an outreach program. Three schools that respond said they do not have an outreach program. We're trying to figure out, again, we're talking about the division between those that have it and those that don't, and the number of people that responded are number of schools that responded.

Prior to the survey we estimated 30 schools would have outreach programs. Now, remember we sent it out to 65 and we had the schools that responded was not all 65, but from the survey when you're looking at it that we had a 60 be response rate, which is pretty good when we talk about a survey, when we talk about the effectiveness of the programs 57% of the schools responded that they thought were effective, but there were some barriers, some instances that needed adjustment. They were people that needed, you know, everyone involved has financial difficulties or goals they want to reach or other things they are trying to do, but at this point they are still trying to make the program and the outreach as effective for everyone there.

I said CEASD, I said, I ‑‑ CEASD I did not do that. Our president elect right now will become the president in April. And she is the co‑chair of the outreach program. I wish she could have been here to talk about that but budget restraints and out of state conferences we were not able to have her here today so that's why I'm presenting the result from the research. But data is so important when we are talking about services and programs and providing those services it's nice to have that data to inform us on how do we improve the program? Which school districts need help? Which school districts are doing a great job? 40% of the schools are tally the number of participants in this activity. That means talking about the number of students they have. The parents that are involved. We got that information as well because we wanted that part of our data so we would understand who we were talking about and who was involved. The Sawyer was just late last spring, 2023 we gathered all the data, collaborate ‑‑ we analyzed the data with the school. I'm going to give a quick snapshot of the survey results when we're talking about the services, when we're talking about are they government funded, are they not, are there laws, legislation that goes along with it?

The first part are they supported by any specific legislation. We're talking about each state, do they provide access to the services do they provide support for outreach? So, when we say outreach there is a plethora of things that can be when you're talking about outreach. As you can see, from the slide, 43% said that they are providing direct services to Deaf and Hard of Hearing students through IEP, IFSP services, the agencies, you know, that's talking about giving transportation to the students that are going outside of their district. Making sure that the services they need at those schools are being provided because remember we're talking 504 schools a lot of them are coming from a different district coming into the school that is a 504 school. We're also talking about professional development, if they are providing interpreters, if they are providing staffing.

And then the 7.1% is where we're talking about the statewide services and, again, that's the professional development the technical assistance in special programs. The other category basically is providing mentors to parents, to providing sign language classes, giving support to the individuals involved, having mentors, having a connection if there's some ‑‑ a gap or something that's missing is being able to help individuals that the need those services to be introduced to them and who is providing them.

We know when you're talking about on staff any school anywhere you don't just wear one that you have to make sure you're working with everyone. You can be advocate can one point, another point you can be providing mentor services so understanding that our audience is not just one category or one specific thing we're talking about students, teachers, parents, so you can see some of this looks like this is just this part. We're only talking about the parents, but there are two sides to it when you're talking about providing a service so we need to make sure those are included. We want to make sure we see where the gaps are.

When you're talking about needs, providing services, again, we're talking very broadly providing services. If we're talking about state funding or federal funding or anything that goes along with that, then we know that that means that the states need to agree to make sure they are providing this, and they are investing in those services, they are paying if you the services agree to by legislation and making sure that's happening.

We have as I said, a slew of outreach that occurs and the data shows that. We also talk about if the outreach data is a mandated activity. We the green represents the yes and that helps us to understand some of the schools, yes, have collected their own data because it's mandated. They have it. They were easily able to provide the information to us as opposed to the schools that may not have been mandated and do not have that information and data easily accessible.

And, again, we're talking about types of outreach and how we tracked it, and keep in mind that there is more than one, you know, if we're talking about the number referrals or applications, we're talking about the number of presentations. We had 24% we talked about the participates and programs and services. Some could be providing service to five hundred students, providing services to one family, but we're talking about also how is the service being provided? In the post COVID are we doing it via zoom, virtual, in‑person? How many people are participating can depend on how the services being provided.

The number of presentations we had was 14%. The onsite support that is provided was 14 % as well. And then how do you see collect that information? What do you do to be able to get the data that you have provided to us. . It's very important that we get input from individuals. We're asking, you know, what is your feedback? What do you believe is good with this? What is happening? What improvements do we need? And it's really asking for their knowledge and once you get feedback from someone it's not just okay we're done it's making sure you stay involved with them, it's and it's a collaborative process, and we're talking about how many services you provided? Are you talking about how many videos distributed how many programs do you have, how many brochures did you make? How many sign language classes were provided? And some of the information is the demographic information as well. The families of origin, the school of origin, where they are coming from, what they are doing and that takes time because if we're talking about being able to provide stories to us and it's not just numbers. We're collecting information.

We're doing qualitative instead of quantitative research. So qualitative means taking the time to listen when someone is providing the information and the stories that are matching the questions that we're asking. And with the outreach program sits 57% I feel confident and then you can see the variety of others, the green is the second lowest. It's very difficult ‑‑ I'm trying to look at the screens seeing the colors and I'm looking on the computer seeing the colors. But it's like a sliding scale it's one to ten. You know, one is ‑‑ ten is fantastic. Ten is oh we're not doing too good.

Some examples of outreach services are here on my slide. It's impossible to document all of them. We reached out and looked at some of the once but understand there are so many examples out there of outreach programs depends on the state, the region, the location, asking what are deaf schools providing, maybe realizing there are more things out there.

We got some examples here. Some of it includes things like summer camp programs, workshops for families, weekend retreats, deaf mentor support, literacy support, shared programs, and other things like that. Videos ins ASL, professional development, analyzation service, meetings the list goes on and on so these are some examples of what we're doing for outreach even including online school. This is not only in the U.S. but also the global world. Some schools don't have the kind of access. They don't have access to interpreters. People don't know sign language, so they struggle using that approach.

They use distance services online as well with. They may reach out in individual districts or other countries as well so that was neat information we collected. There are things like family fun day as well. Events for families to gather. Some are programs for students, some statewide programs that run year‑round and have everyday availability. Some things, you know, are not accessible online to everyone. Some are kind of limited DCMP, for example, description media program that is through the national association through the deaf and they have a whole catalog of captions media and that's part of outreach services as well.

Story time in sign language in captions and ASL doing things did you know and fun facts, some weird or unusual facts, that seems to be a favorite. Children just love to discuss those did you know facts they relate to science and other things and spawn other conversations.

We'll have the interpreter interpret it. It doesn't have captions. Strange nonfiction but true. Did you know that octopus can squeeze through the opening of a size of a quarter. They are 600 pounds and still squeeze through an opening the size of a quarter. Even if it's only the size of a quarter, a 600‑pound octopus can squeeze through. That's incredible. How many of you knew that, right? That's pretty neat.

I got to turn this off. One second. So that's one example of something that gets people's attention and is very interesting so in noninformation cases staff are looking for those things to be able to provide and often there aren't enough videos. There's out there explaining things relating to learning. There are performative videos. There is so much rich literature out there, literature tends to support student learning and family engagement as well. The families can sign along with those videos, for example, the ones we just watched now the family learns the sign for octopus and able to discuss that with children. And so much available. You can even look on Instagram, for example. You can find ASL specific channels online.

There are tons of things available out there as well. The national deaf education center from Lauren Claire, the clerk center. There is a portal with tons of resources so accessing that is one way to get access to all of these wonderful tools. There's also a partner with the Alabama institute with the deaf and blind and that is with the real group, regional acquisition of language. They are developing lots of documents and resources on their Website with the partnership of the clerk center so feel free to use that as well.

Now, we have an opportunity to take questions, comments, what do you got? Okay, sure.

The data that you have collected, where would be the best place? Okay you got an interpreter voicing me. You have data to collect so what are you doing now? Are you looking for a specific kind of data? What's the key you're working on now? Great question. Now, CEASD we're working on publishing models. We've got two or three models of outreach programs, what has been effective what hasn't been, and we're trying to establish some models and what kind of specific outreach services are working? What do they look like? We're working on a goal to publish model that is other states can look at to be able to provide those effective services and that's our next step so if you have any information you want to be involved, let me know.

Should I stand? You said that you have 65 schools that identify as deaf schools. Does that also include mainstream? Did you include that in your data? 65 schools for the deaf and numbers of mainstream programs vary so much so we haven't been able to document and collect data from the mainstream programs yet.

All 17 schools that responded to the survey, do you know who they were or was it anonymous? I do not know, the committee does, but I do not. Outside of that it was anonymous and that's how we collect good data. One question. So we used to have outreach conferences. We have EDHI, which is great, we have CEASD, and there are many others; however, what about an outreach conference? Has that stopped ? We are talking about it. The national outreach services have been working hoard in the Gallaudet University region center there and so due to funding, budget cuts, prioritization, staffing but yeah, if there is a real desire to have those conferences. We should talk about. Who would be interested? You can talk to those folks there. Thank you for talking with me about it. If you have any real questions please feel free to come up and chat with me about it. Thank you so much.

Angela. Oh, wrong one. Oh, clear back there.

>> There's a switch. It's booted up. Just in the middle.

>> Hello, everybody, my name is Angela, I'm the moderator for here. We're going to be presenting introduction to cued American language from a native cuer perspective. Thank you so much. I'll leave it to Hillary.

>> Good morning, everyone. I'm going to ask those of you in the back to move up if you don't mind. I like to see people. Not at a distance. My name is Hillary Franklin. I'm a deaf cuer. I've been queueing for a long time. As people move up, I'm going to ‑‑ today we'll be talking about queueing, what it is, why it was developed, and I will also demonstrate the principles of queueing so that you can ‑‑ demonstrate those principles to other people.

A little bit about me first. My name is Hillary Franklin. I'm a deaf cuer. I was born deaf. My parents are hearing. I was the first deaf person in the family. So when I was three, my language was identified as a little bit delayed by a few months. So my parents started cue can with me because they knew they didn't know ASL would be appropriate language models for ASL so when I was three, three and a half we started queueing. My language took off. I'll talk more about that. I was mainstreamed in public schools medicine Maryland with cued language translators. Throughout my elementary, middle school, and high school career. I also had translators in college. And I went to the University of North Carolina at chaplain hill. Very happy and our basketball team is Number 1 seed in the west region. That is good news for me yesterday. I got my master's of teaching ASL in foreign language from Columbia university in New York so I cue and sign.

I currently work for the deaf defense and I'm a certified instructor of cued speech for American English I'm also the vice president of outreach of the national cued speech association.

A little bit more about my background with education. My elementary school had a cued speech program. In any given year there were about 20 to 25 of us throughout the school that cued. In my grade alone my cohort, there are four of us who cued. A few of us were fully mainstreamed. A few had learning disabilities and self‑contained classes for academic. Mainstreamed nonacademic classes so we could all eel reach full language potential. When I was in middle school my elementary school was two other elementary schools. One had the oral, well, now call LSL program. And another had a signing program. All three elementary schools fed into the same middle school.

That middle school is write learn today sign from the exposure watching the deaf people who signed. I asked them so many questions. How do you sign this word? What does that sign mean? So I became dually bilingual and I consider myself bilingual so I learned around ten, 12 years of age. How did my parents choose cue?

First and foremost they wanted me to be able to read and write English. They told me if I did not learn how to talk. Surprise I learned how to talk. But their goal was for me to be DIT rat. To be able to read and write anything.

They met families who were queueing even though they were no long‑term outcomes at that time, they thought it sounded like a perfect fit. So they started queueing with me, and when my language took off they never looked back. Both parents cue.

We lived in Connecticut at that time and then we moved to Maryland which already had a queueing program in existence so I was able to grow up in a queueing rich environment. So I became literate, I was in a gifted and talented classes, and I had deaf and hearing friends. I had a good social educational balance. I took foreign language classes in high school, Spanish in college. The nice thing about queueing it's a consonant vowel base which we'll talk about more in a minute. There was no translation needed with the interpreters in the classroom it was just consonant vowel in and out. I learned Latino the CLT translators did not learn Latin.

Let's talk about more about spoken languages. One of the reasons so many deaf kids struggle is that it's just not visually clear. So up here, we have three consonant. They look the same on the lips. What's the difference? You can't tell, right? So let's take these six words. Which one did I say in which order? You don't know, right? But if I add queues, you get mat, met, bat, bet, hat, pat. You can see the difference without sound. This hand shape is for em, bah, and we'll talk about that in a minute. All consonants so you combine the hand shape with the placement to make a cue. The reason queueing was developed was to make those faux names that you just saw clearly visible.

Not just English, Spanish, Arabic, Chinese, Spanish, Hebrew, all those languages can be made visually clear through queues. And another thing is that lit enable real‑time communication between parents and their children or educators and the students. That real‑time communication is how we as children acquire language. I don't remember learning to cue. I've also been cueing. I have no recollection of being taught to cue. I was just exposed to it. Just as any hearing child is exposed to spoken language or sign language. Queueing also enables native language literacy for the spoken language of the home.

This is an image of an educator reading a book with queueing to a deaf child. This is the system in a nutshell. And on the left‑hand side of are the faux names on the right‑hand side are the vowel faux names. Excuse me. We have groups of consonant. The groups are because those consonants look different on the mouth. The first one, for example, if you look at my mouth, you can ' see the difference so they can have the same hand shape so what happened next do groups. That helps simplify the system.

Vowels same reason. The first one, E and er, you can see the difference. So there's eight hand shapes for the consonant, four placements for the vowels. There's also vowel movements but those are the same placements. For example, long vowels like A, oy, are two short vowels strung together, so you move from one vowel to the second vowel is kind of how that works.

So it's compare modalities. Signing exact English purports to show English. But if you look up here you see very little actual English faux names. If you sign I you have the letter I. Okay, that can be English. For am, you have the first letter, A, but you don't see the M. So no one watching will know that there's an M of the second letter of that word. Going, all you see is the I in going. To. There's nothing English in that. It's just a sign. The, you see the T. But it doesn't actually show that the consonant is. Store. No English in there. The so the reality is in order for people to understand English, in signing exact English you have to already know the English first. It doesn't really make sense if you want to show English.

For PSE, you lose even more language, so PSE can be a good modality for people that already know English and can use it to communicate with others, but it should not be used to teach English in my opinion. Now, we have ASL. As you can see there's no English. And there shouldn't be any. ASL is a separate language from English. Then cue to American English, it shows all the faux side names of English. Take a look and tell me what you think is missing. E the letter E. Why is it missing ? There's no sound, right? It's silent. So queueing falling the faux names of the phonics, not the spelling. That would be cued as I am going to the store. A cue is a hand shape or hand someplace placement with corresponding with the corresponding mouth shape that visually represents a consonant or vowel so I can cue without my voice. The Voice is not required but I do need to move my mouth. So the mouth and the hand need to be there. The Voice is optional. If you have children who have visible hearing you can add The Voice. If there's no visible hearing or not wearing hearing aids or implants you can drop the voice and, for example, the language is the same.

We're going to do a really quick lesson here. I do not expected you to remember this when you leave the room so don't worry. I have two columns. They all have the same vowel. We're just going to go through different hand shapes so you can see how it works. The first one is P as you can see it can be the vegetable P or I have to go P or the letter P all the same thing, P. Second word key. Third word, see. See. So it can be C, the letter C. B, it can be B, the letter B. T. T‑shirt, the letter T. She. Then the. T's. I added something there. So cheese. This is the Z sound. So, again, we do not follow the spelling of. We follow the sound which is zzzz. Cheese. So those were all eight hand shapes. That's it.

So we'll do the same eight hand shape with a different vowel. Ew, like blue, first word, do. Second word, zoo. Third word, sue. Boo. Expression. Awesome. What does a cow say? Moo. Shoe. Goo. And then you. That's it. That's how queueing works. You combine the hand shape with the placement and it's all interchangeable.

So I mentioned before queueing doesn't require speech. The name cued speech is a bit of a misnomer because it was developed back in the 1960s. Just before ASL was recognized as a language. And up until the mid-1960s, the prevailing thought was that language needed speech. You had to have speech to have language. We now know that's not true. As I said before, The Voice is optional. But queueing also does not teach speech. What it can show is pronunciation. So for myself, I had to go to speech therapy to learn speech. .

Learn the mechanics of how to talk. Queueing by itself does not show all the articulation, how to move your tongue, whether my mouth should be open or flat, all of that stuff. That doesn't happen. What it can do is show the target pronunciation. For example, when I was a child I was in the car with my mother. And we passed a new big box store. I said, oh, look, mom. Home depot. I was ten. 11. My mother said, actually, it's pronounced depot. But there's a T at the end of the word?

Yes, but the word comes from French, French words that end in a consonant are not pronounced. But we're not French, we're American. I was ten. But because my mother not only taught me how to say depot, but she also explained the rule to me, which meant later as I got older I could accurately say important words like merlot, pinot, cabernet. So that's my home depot story.

We now refer to queueing, not as cued speech but as cued languages because language requires more than just utterances. I babble. E I E I O that's not a language so we can babble, cue babble but the sounds, queues by themselves are not language. To have language you have to have meaning tone, stress, inflexion, whether it's a question, statement, all of that is language. With queueing just as we do with signing we show that. Eyebrow up and down we show questions, we show stress, we show excitement, eh all of that happens visually. Cued languages are cued with all the grammatical indicators that can happen visually.

Cued American English is how we refer to queueing in the U.S. Because of time I'm not going to show this video but this PowerPoint should be available to the download after the conference. If it's not you can reach out to me to get it. This is also in YouTube. You can Google Jabberwocking and cued American language and find it. Can we combine cueing and signing and LSL? Yes, because queueing preserves the integrity of English and you can use signing to preserve the ASL. It more appropriately separates the two languages. Deaf cuers are able to decode written English through phonics. Even if they have no useable hearing. Queueing fills in the blanks of what children don't hear or mishear. Even if kids do well with hearing aids or implants they still miss auditory information. We know that.

A lot of them will miss the S, plural S at the end of the word, queues can show that. So queues provide that complete visual access with or without hearing devices. If you're working with a deaf family and their first language is ASL, you can introduce queues to benefit learning English as a second languages. And keep the signing for ASL.

Illinois school for the deaf has a bilingual program where students cue and sign. How much queueing they get depends on their IEP. Some are through reading only, some have it part of the day depends on parents and kids goals there are many deaf families queueing with and have asset at home so they get the best of both.

Quick over review of research. This is older research. There's a research packet available at the NCSA exhibit booth if you want to grab a copy of the reach, but real quick this research one hundred 20 kids, 30 hearing, 0990 deaf, 30 deaf who cued, 30 deaf who sign, 30 deaf who use neither.

Based on all the testing in comparison with hearing control group, the deaf queueing group performed the same as the hearing control group. The LSL group didn't do quite as well and the signing group performed less well than both groups. It's important to note that all of these deaf kids had hearing parents. There were no deaf on deaf signers in this group looking at English being the language of the home.

One thing that's interesting the group of deaf kids were broken into 15 with severe deafness, and 15 with profound deafness, the cuers with profound deafness did better probably because they got more consistent queueing because the assumption was they are doing well with hearing aids, cochlear implant, so we don't need to cue as much. Turns out that's not the case. There are multiple resources available for families and educators. The cue college, they have a booth here. They have both self‑paced and instructor based classes. You can also request a cue with me, seasonal activity kit. They were made by a woman in this room. I'll point her out in a minute. The ‑‑ new to queueing can request free one year kit with information about queueing. All I need to do is go to the Website and register. And you can get that information from the NCSA booth in the exhibit hall we're all the way to the left in the exhibit hall. We provide support for families, educators, reach out to us at any time. Again, multiple resources available. You should be able to download this. If not, take a picture. We have been one minute left for questions, so if you have any am I'm willing to take them or find me in the exhibit hall. You can find me later and follow‑up with me. Any questions?

>> (Away from mic).

>> I can. You can cue with any hand. The nice thing about queueing it requires only one hand but I can cue with both if I really want to emphasize something. It's whichever hand you feel most comfortable with. In the back.

>> (Away from mic).

>> I have many cards available. They are in the back by the water cooler if you want to grab one on your way out. We have more at the booth. You want to also sign up for the virtual class on zoom, you can come find me at the exhibit booth. We have both. Twice a week, virtual available starting end of April or also two hours a week, once a week for six weeks starting early April. So both are available and coming up soon. And research findings are available. The exhibit booth flyer for parents available exhibit booth. Thank you very much.

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>> Hello, everybody, my name is Melissa, and I'm the senior follow‑up specialist at the Arizona state lab. I've been at the lab for two and a half years. I started in Bloodspot, and I been transitioning to the senior position and learning about hearing. Next up is our learning objectives we will be reviewing the history and screening and learn how screening follow‑up and drive blood spot follow‑up really are, explore data system collaboration for families and understanding the importance of newborn screening follow‑up and collaboration.

>> What is newborn screening? Who is from blood spot? Who here is from hearing? Who does both? We got lots of people that do both and work together. We're going to start off talk history of newborn screening. Every state has a program. All states are the screening panel. It was established in 2010 and there were back then 29 core conditions and in 2012 point of car testing was added. A strict nomination process for adding test. The advisory committee meets quarterly every year, reviews nominations and recommendations and goes over and then nominates conditions to be added to that panel. Some of the things this that they consider are the best outcomes are arrived before symptoms are evident in the babies. All things have some sort of treatment available. Some are simple as a diet change, a pill, complex treatments, gene therapy, support for language acquisition, so there's lots of things that can happen for babies identified. There are currently 37 position on the national recommended panel and hearing is one of them.

A little bit about history. I said every state has a program, every state is independence how they run it, how conditions they screen for. 2023 actually celebrated 60 years of newborn screening so it's been around for a really long time. It started by Dr. Robert G.; people call it the PAQ test. He was the one that developed the test. He was a parent like a lot of people here, parents trying to find answers. He had a son that had a cognitive impairment and he used his skills to help figure out what was going on with his son. They developed this paper filter test and were able to screen babies and found out if they have this PAQ and put them on a diet these babies had much better outcomes.

The test expanded and 29 states were interested in piloting the test on their babies. He with his passion as a parent and working with the children with disabilities and within two years infants tested and they identified and 39 with PAQ. Newborn screening for PAQ was mandatory in every state. We see advancement of testing, so the 80s brought on looking at mutation analyst, different laboratory test to find these diseases. The 1990s added testing high throughput model test. Lots of babies fast. And the interesting the Doctor died 1995 never saw where this was going to go, and newborn hearing screening legislation was passed to begin to fund hearing screening that we all know today. Prior to then less % received a screening and re. The.

>> The Arizona screening panel 33 include dry Bloodspot test and two point of care test which include the hearing and con general heart disease. Arizona is a (?) State we add any condition within three year to the (?) And every baby screened twice. The first screen screened at 24 to 48 hours and the second screen collected at five to 10 days of age. There are many components to the newborn screening system. The point of care test. Point of care test at hospitals is where the initial newborn screen is collected. The laboratory where we run these tests, and then demographics. Who linked the sampled to ensure critical information like the date of collection which can impact the follow‑up. Education, which provides family, outreach, education to medical staff to improve sample quality and awareness for families and providers.

We have follow‑up, which is what I've been working for two and a half years and short term follow‑up, providing next step social security, providing referrals as well. And we have been working on the long‑term follow‑up. It's currently in the works for Bloodspot. We are working on providing follow‑up and support to families after a diagnosis is made. We have a short video we wanted to show.

(Video).

>> Do we have an AV person, does anyone know how to get it back? Control tap. Oh, here comes somebody. Here you go.

Awesome our hero for the day. Thank you.

>> Wait. Don't thank me yet.

>> Okay. Well, no pressure. Right there. The oh, it is captions. Oh, there they are. Yes, thank you. Our hero. So it's really interesting if you have only been in the EDHI of the newborn screening to see ‑‑ it's a different type of testing but it's really part of the same system of care, so newborn screening follow‑up, collaboration it helps us locate beaks. We provide the same notification to the pediatrician that is something is needed for another test for this baby, whether it's a repeat newborn Bloodspot screening, whether repeat screening referral to audiology, we're making that same connection to a pediatrician. Hearing is one of those conditions that we provide follow‑up for so we have people assigned today each one.

Everybody's cross trained we share data systems for doing this, we have the same way of locating babies, and the cross training happened to really benefit us. One day several of us were away at the conference and somebody called out sick and somebody was on vacation and we have one Bloodspot and two hearing. The hearing people help identify where babies, call pediatricians confirm that they were there and the Bloodspot person was able to provide the technically on the next steps had the roles reversed could we do the same thing and that's the beauty combined together you can collaborate and work together.

>> Sharing workflows and processes. While I've been in training I come to realize it's very similar workflows. It's practically just reviewing screening results, locating the pediatrician can be tricky reporting results and requesting a referral. Also faxing to the pediatricians or audiologist. We contact parents to review and assist family with next steps which is unique to hearing in Arizona, follow‑up on status of diagnostic testing results and referring parents for parent support and early interventions if needed.

>> We're able to learn from each other like Melissa mentioned we're going to use some of the process we have in place for parent support for the hearing program to develop ‑‑ having a voice at the table those types of things so ensuring that's happening new for families identified through Bloodspot testing as well. We have universal systems. We have different data systems for hearing we use high track and we reference both for both sides of follow‑up. A hearing data system we merge that with vital records so when Bloodspot needs to find baby updated name, no longer baby girl or boy or whatever, they can go into the hearing data system and see what's their new name. You can see each other notes in the two systems.

If somebody already touch add baby case and was able to find all this information saves time on the other side like I said the notes are helpful in locating babies. We get calls all the time from pediatrician for a baby that ‑‑ guess what? We're looking for them on hearing. We have been chasing them trying to find them but now we know they moved out of state. Same thing question get vital record information in birth and death and able to find out babies sadly expired for Bloodspot as well. It's really helpful. The other big thing is the health information exchange. Some of the test we do for Bloodspot screening is critical.

Before a metabolic crisis or emergency happens so that gave us the impetus to ask for access to every record of every baby in the health systems that report to the health information exchange in Arizona so that helps both systems again. Perhaps if we didn't have the time impetus critical to ask but benefits both systems. We're able to see a baby had an audiology. We can see if the hospital system has reported it to the health information exchange where that result lives so that helps. We have our immunization data system that helps us where pediatrician are receiving follow‑up care.

You can see we're more alike than different in what we do. Take home ideas. If you're not already connect today your Bloodspot team find them and reach out to them. Find that conversation. Schedule regular meetings. Share ideas. They may have things that they are doing that you want to learn more about and vice versa remove the mystery of it all. Discuss ways to collaborate on follow‑up initiatives. There's things we're both doing and can do together and make it work well. Share resources, phone lists, process, everything you can do custom mise. Explore sharing access to data systems, piggyback on each other. Use what the other one has. There's no need to be separate so if you consider yourself newborn screening then you should have access to all things newborn screening. Just remember we are all here for newborn screening. Do we have any questions?

Do we have another mic? No.

>> On your metabolic screen card, do you have ones we can see? Do you include hearing and CCHD on that card?

>> I do not have one but if you go to babies first test and click on Arizona there's a link to the image of our screening card and it's same for other states babies first test will have resource for all the states including a snapshot of Bloodspot card so in Arizona the results are report odd on the Bloodspot but response for the learning response.

>> I just had a quick question. More out of curiosity. Why high track metrics instead of doing neometrics for both hearing and blood. That decision was made before I started so I'm not for sure why did two systems. And I think there's process and cons. I think both systems have strengths and their weaknesses. But I think we find different benefits be it. And some of it may have been the ability to receive those screening results electronically.

Like I said, when I started 12 years ago they were just transitioning from nay tell us for the hearing and left it for the Bloodspot.

>> I have a couple questions so I will blurt out and if you don't have time that's fine. I'm wondering if you have any collaboration between Bloodspot and hearing in terms of prenatal and in terms of training for hospital staff just so you kind of get a one shot deal? My other question is tracking of risk factors conditions identified Bloodspot like bio deficiency and at least somewhat associated with hearing loss and how those systems interplay the flag conditions that you need to watch for in the other database?

>> Those are really good questions. For the risk factor monitoring we do not currently do that, but that is potentially something we will be exploring with long‑term follow‑up program as more of these conditions are added more of them have a likelihood of having some sort of a hearing loss so we will be tracking some of these things. It may not be risk monitoring in the traditional sense but it will be tracking those individuals longer term. And the other question was related to ‑‑ oh, the education. We do education for both. If we go out and do a site visit she will talk about both hearing and Bloodspot in her education. We provide scorecards for Bloodspot and for hearing.

>> Hi, just ‑‑ I'm actually in support of having the follow‑up together because I really think through some similarities and some things that it belongs with the Department of Health services however can you address some of the issues how you prioritize hearing when dealing with reduced staffing, funding and impact loss given Arizona lost follow‑up numbers going up?

>> Sure. So, you know, all of our conditions receive similar priority. We triage sometimes what we need to do when we're short staffed I think most people can relate sometimes there's not enough hours in the day and you triage how you do and what you do but they all receive the same sense of urgency we need to do follow‑up. I talked from several people from other states the pandemic had huge impact not on just hearing screen, well baby care, vaccination all of those things so you have to factor while staffing numbers remain constant demands increased and keeping up with demands of increased workloads.

>> Hi, do you have any existing sharing agreements and MOUs between the EDHI program and the newborn screening program?

>> We do not necessarily need a data sharing agreement because we're all one program so we can share data internally on hearing Bloodspot screening we do not need any data sharing. We are able to we have electronic data transfer so able to capture from part C and reconcile baby by baby for early intervention program.

>> Is there a place where it's tracked which states have these kind of collaborative agreements collaborated and where it's still being built?

>> I do not think so and I think sometime department on the Department of Health instructors so some of them instructor them differently some hearing programs are under title five or health care and not integrated with a lab and that's write say start those course. Talk about, you know, what we are newborn screening. Why is there a difference how we share data, how we look at things, it's all the same program, it's another one of those rough conditions we're testing and use those for your conversation to be able to strength your argument that this is why we do not need a data share. It's public health, newborn screening, let's talk about 34 of them but not the other one, you can't so maybe just starting those conversation and knocking on those doors. No ones is no once sometimes you have to leave it for a little bit and then come back to the conversation and start again. I would ‑‑ what was that? The squeaky wheel. But yeah, in a good way. It's just the conversation. Keeping them going.

>> I just wanted to piggyback I think on Allison's question earl about education, prenatal education. What is provided to parents and how is that provided? Neighbor through pregnancy and then through birth, discharge, etcetera.

>> So prenatal education is something we haven't done a whole lot of but a lot of states haven't done a whole lot on prenatal education prenatal education and that's another piggyback on Bloodspot. It's one of our projects for this summer to start developing our prenatal education program to pilot with some of OBGYN in the valley to start that conversation because that's a tough one and really where it needs to begin.

>> Speaking to prenatal education in Wisconsin we're having initiative to get consent or occupant in I was wondering and there's discussion over Bloodspot cards and how long you keep them, I'm wondering where Arizona is on that?

>> That is controversial everywhere. We destroy all cards after 90 days so we don't keep any of our cards after that. Some states it's a very big deal. Yeah, years, yeah. So thank you so much. We can stick around if anyone else has any questions.

[Session concluded]

END TIME IN YOUR TIME ZONE – 11:51 AM (MT)

START TIME: 9:40 AM

END TIME: 11:51 AM