>> Topical Sessions 3&4

03/18/2024

>> Welcome, everyone. I'm Jodi, and I'm moderating the room today. I'm here to keep you on track with time and to let you know to remember to fill out the evaluation after the presentation.

>> I'm a parent of a kiddo who is deaf. He's six and wears cochlear implants in both ears and I have a colleague that is going to introduce herself.

>> Hi, I'm Tamera.

>> We are excited to be here with you today and share the thinks we have worked on in Wisconsin and started work in the department of health in 2023 and tam started in December of 2023 and we're fresh meat, so we tried to come up fresh ideas on how to make newborn screening better in Wisconsin. So as EHDI staff we're responsible for tracking which babies have been screened and have referred or follow up screening. We work with a specialist that helps us to report out on how we're doing on these measures and working with audiologists and sometimes the family on follow up. So we're going to start there. Order to do our follow up work we had to learn our database system quickly it's a system called home track.

We have both of the hearing and heart screening results. It's a web-based platform so hospitals and midwives and audiologists have access to it. We don't do long‑term follow up for hearing and heart in Wisconsin. We realized that is was out of date and for example the organizations did not reflect who is practicing in the state. I activated 18 birth units. 36 of them are out of hospitals and those were midwives that were retired and not catching babies anymore. Same thing for our contact people for those organizations we have 75 user accounts that are not activated they were staff left or moved to another job. So we had to replace that contact information as well so we activated 62 user accounts in the last year.

So of course, we're here at the EHDI conference, and I'm sure we're familiar with the goals. We want infants screened by one month and we are able to document cases that have timed out. So have surpassed those timelines and that is reflected for us at the state department how to follow up with and how behind organizations are getting. We found that healthcare staff are often changing jobs so this has to be an ongoing activity and once we see timed out cases going up we can guarantee that they moved and told nobody about the responsibility of documenting hearing screenings in We Track.

The other thing that we're doing our data reporting specialist is tracking the volume of the cue in a spread sheet so we can see how things are improving or not improving. We do batch updates, so if I reach out to a NICU, I can document on all of the babies at one time, and we talked about updating the cases in a week's time or whatever deadline we set up. We decreasing overall volume of cases so that we have strategies in place that continue to work and not focus our time on things that don't have the same effects. So this is what it looks like at the beginning of 2023 we have 1,800 hearing cases and 1,200 of these are timed out. So you see big jumps total hearing cases and timed out cases in the graph.

So those efforts like setting up a meeting in person with an organization or midwife and sending out reports to organizations that have timed out cases. Those are over e‑mail but we do snail mail still for midwives or those that don't have a solid Internet connection. So we have 1,400 cases and 800 of these are timed out. So this work is not done but the attention that tam and I have been able to provide on this work has been important to keep organizations accountable. One more slide I think. So starting in September of last we're we started monthly reports of birth units and that is hospitals and midwives. So we have a third colleague her name is Susan and works in the southeast of Wisconsin in the Milwaukee area so it's that reminder that if you're not logging in every other day it's that I have work to take care of. These are mock up reports but it tells them what action is required at the bottom of the table and gives contact information with e‑mails and phone numbers so there is no excuse if they have a question, that they didn't know how to reach out to us.

We also provide quarterly reports to the organizations, previously the CCHD team was doing that. But it was only for organizations that opted in to receive the information so we flipped that and said that everyone is going to get a quarterly report and that is including heart screening and hearing so it if they want to opt out they have to let us know. So that is a great way to keep an updated contact list because that goes to folks that are not the day-to-day people so it gives oversight in the organization. So we have five regions and Susan is over at the Milwaukee area and I cover the southern, northern and western regions. That's a huge population, and I do the hospitals in the area, which in the western and northern section there is few hospitals.

In the northern section, I think we're talking about maybe six or eight hospitals, so that is a huge geographic area but the population is sparse. So we let the organizations know how they are doing individually and compared to their peers in the region. So in the Milwaukee and Madison region it's easier to hire healthcare staff and harder in the northern and western regions of the state. So we give a metric and I'm sorry this is small. But we're letting them know how many babies have passed the screening and have not and why and maybe they are within normal limits and have confirmed permanent hearing loss and if there is conductive transient hearing loss we let them know. On the blood card, they can document heart and hearing screening. There is boxes so if the family refuses the screening or the baby passes away or the baby moves and that is not on the blood card but we're able to close cases if they move out of state we pass on the information that we have to the EHDI program next door.

And then we let them know how many babies with partial data have been recorded. Those are considered missing results so we get left ear passed and right nothing, so we need to follow up. That's our report for our hospitals. Tams is going to share about how we customize for out of hospital providers.

>> So as Mandy mentioned, I started in December of 2022. I am a midwife and I understand the unique needs that parents have when birthing out of hospital and also as a student midwife I'm embedded in the state. I'm a member of the Wisconsin Gilded Midwives. So when these reports come out, it looks different because the right column is not populated so we're not giving them comparisons with other midwives and this relates to independent practice and teams where there is two midwives that work closely and some are mother and daughter and that covers a freed‑standing birth center so they don't have a sole job of doing data entry.

But after the baby is born, the midwife comes and does the blood card, and they do the hearing screening and if not they do that after two weeks. So they have been able to be a fly on the wall and taught by an experienced midwife. So I reach out and offer support and that looks like we coming to their practice or home and meeting at a community meeting and we're getting together and I bring my laptop and tell them what kind of support I can offer. One of the incentives is baking really good bread. I get my skillet out, and bake some banana bread. I'm doing these things and I'm able to form relationships for the midwives that don't use We Track and two have access to electronic databases. They are getting snail mail and we have paper copies for the Amish and Mennonite families, so we have our quarterly meetings and offer greetings and support. This is an example of what that paper copy looks like and child's name and asking for results in the different fields.

There is the center for special children that offers free hearing clinics three times a year through the students that are going into the community. Anyone that has a baby born that might have missed the hearing screen they can come and gets their kids seen. If they is a toddler they can have that child seen as well. We see a baby that is transferred to the hospital and sometimes the parent says we'll have the midwife do the screening and they are thought aware of that so we meet them where they are and offering for me or Susan to go in the home and offer that screening for the infant.

I think for quality improvement we covered that because I'm a chatty Cathy. So this is the dedicated positions for us to follow up. If we're having a bit of a challenge getting ahold of somebody we call her Elizabeth. Susan is the outreach specialists for Milwaukee that Mandy mentioned earlier. Weekly meetings help us to know how things are going and if we know that a midwife has retired and moved how do we close those cases? So being able to communicate with the Wisconsin Gilded Midwives what are the things we're seeing as a trend we Track has a nice bulletin if we're holding a familiar events they can see that if they sign in.

>> So things we're looking forward to this year, we want to do more education and training. I heard groups talk about how do we provide parent education about the prenatal phase and newborn screening we make sure they are accessible and have inclusive language so that is reviewing blood and hearing and heart screening information. On Tuesday, I was in central Wisconsin to meet with the birth attendant and it's a quarterly meeting where the traditional birth attendants and they bring a dish to pass for lunch and we have education topics it's a 9 to 3:00 p.m. day and those have been great.

I think we're able to provide talking points for families about the need for understanding hearing loss in the community it's a safety issue and they live on farms and there is horses and large animals. If they are in a buggy being pulled by horses they need to hear a car coming on. It's the information to provide a consistent message about newborn screening. We have a grants that is going to have an effort to train in the Amish community to use a battery operated OAEs. And the families that have trust are able to accept the hearing screening and not decline that service. We're going to track outcomes from the early intervention that we provide and we're really excited about that. Our contact information is in the slides and that's all we have. Any questions?

>> Hi. I was wondering if you get pushback from midwives when communicating? And if they give reasons for not wanting to be trained on equipment and give out hearing screenings?

>> I have not had ‑‑ I'm sorry. The pushback is not necessarily performing the screening but the barrier is that the equipment is very expensive. So midwives there is equipment sharing and they have been able to obtain a grant and there is a coordinated efforts to share the equipment. If they are not part of the guild we see they are writing down declined or refused when it's a matter of them not having that equipment so it's building that relationship with a midwife and educating it's not a refusing if there is no equipment. As far as push back it's not from midwives but people are concerned like people having an ultrasound and might be radiating something to their belly. Thank you.

(End of session).

>> Welcome. I'm Jodi, and I'm moderating the room today. My job is to keep the presenters on time and remind you to fill out the survey at the end of the presentation.

>> I'm Sherry Nievers at the Department of Education DHH family engage program and this is the director stormy cone.

>> Good afternoon. There is a lot of things in Georgia that we're known for like our southern hospitality. And we have a southern draw. I don't know if you heard it from Sherry, but we're southern. So way back in 2019, Georgia Mobile Audiology was started. We have one director and two pediatric audiologists. We have a fully functioning clinic on wheels. We are safety net program and we work with families that lib in rural areas and work with families that speak other languages other than English and work with low socioeconomic. We are funded through the Georgia legislation. We prepare for increasing the program to a larger state scale. Sorry.

>> So now we're going to talk about what is a parent navigator that starts with the first initial call and that is helping them understand the why and why the urgency. We are a sole resource to help navigate them through the hearing loss we are a master hub person of that area so all our parent navigators master the areas and know the resources so they can be experts and connect them with programs and have family engagement opportunities and connect them with other families and we're not an advocacy service. We don't show up to IDP meetings and we help them with their medical appointments and don’t attend them but we prepare them for everything. So that is a big summary.

>> So back in 2020, when COVID hit, we were a mobile clinic. So what we were able to do is say that we know that 14% of the DHH students are reading on grade level and we found out what was going on. So we noticed that 35% of the children were enrolling in early intervention services so we said why is that? We went and took a look at the state of Georgia. Now in the purple circle is the Atlanta area and those are the areas where they get the diagnostic testing and we partnered with EHDI and we're blessed and fortunate to have 18 EHDI coordinators in the state so it's a wonderful relationship and collaboration because the goal is to increase the literacy rates. We have two EHDI coordinators and we have Phyllis and Alice and Pamela and Latoya.

So we set up these teleaudiology clinics and I live down there where the circle is went to had the health departments and connected the electrodes and I was able to do that with our audiologists that Zoomed in and begin the parent navigation services. So we wanted to know what the data was. So we had data from October of 2020 to September of 2022. We had 11% to follow up and 10% no show rate and when you compare that with otolaryngology, we want these rates to increase so we developed a plan. Sherry and sat down and developed an action plan.

>> I know that lack of service is outside of Metro, and they did not have a place to sends them so we did this strong partnership. Fearing and unknowing they wanted to go back to the hospitals where they were comfortable. Lack of personal connection about us connecting with them so they were comfortable going to the appointment. Postpartum. Scheduling conflicts. Oh, right. So in Atlanta it's hard to get an appointment it's like six months sometimes so we connected with facilities so it's quicker and we are able to increase the amount of times. Socioeconomic factors. Transportation we created that and provided services for the family to get to their appointment. Uninformed sense of urgency and the importance of getting the next appointment and getting a hearing test.

>> So, in collaboration with our local EHDI coordinators we developed scripts and made sure we used text reminders with the families.

>> So we created a protocol, and this is the beginning of the parent navigation. This is most important. So if we called three to five days before the appointment, we used local numbers. And we found that they would most likely answer. If we called and didn't answer and called back immediately majority of the time they answered because they are curious and thought is was not a scam. If they did not answer, we leave a detailed message and do a follow up text as well. We use their home language with an interpreter. So with text, they are comfortable with the service.

>> So when we have that initial phone call, we want to make sure we're getting the most bang for our buck. We wanted to call when it's good for mom and making sure we connect with our families and want to ease their fears and how the test is going to run. We connect that back to language and why it's important to have this test for your baby. If your baby has hearing loss what those next steps are going to be. We offer transportation, and it's big deal to have this test done for you are baby. So here we go.

 Ring. Ring. I'm trying to reach Sherry. This is her. I'm Stormy with Georgia Mobile Audiologists. Is now a good time to talk? Yes. So what is going on with you and Taylor and how did we got to this point? Taylor was born at the hospital and didn't pass the hearing test and we heard about Georgia mobile audiologist. Do you know tell me about Taylor not passing the hearing test. Was is one or both ears? It was both. So I need Taylor to be really sleepy and hungry. So when she comes in, we need to know that she's going to be asleep. When you get there, I'm going to clean her and put electrodes in her ears.

And the audiologist is going to be on the Zoom and they are going to play frequencies and so that allows them to see what her brain is hearing. We know that babies need language in their brains to be a good reader. So we need her to have access to language and babies with hearing loss they don't have access to language and are not able to read on grade level. I know you're about 35 minutes from the clinic site. Do you need help with transportation? No, I'm good thank you. I know there is a lot going on in your life so if you have questions, you can call or text me. Thank you. That is how our conversations go and we're making those connections with families, so they understand the why behind it and they show up.

>> And we follow up with a text and that is how they come back, and this is pretty much what a text looks like. We do that the day before the appointment, so they have the address. So the most important question, did our intervention work? If we look at the data collected, we had 199 appointments and 15 appointments canceled and have 6 to follow up and 4% of the families that we work with requested an interpreter 2% requested transportation. There was a 50% decrease in no shows and cancellation is a 58% decrease. And the loss to follow up was a 38% decrease overall. And this is the true life story of a family that lives in rural Georgia and receive Medicaid. At 25 days old, this baby was diagnosed with profound hearing loss.

At 60 days old, we had virtual appointments their initial appointments and 61 we provided virtual meet and greets with the schools and at 62 days old they were enrolled with the auditory verbal center. So we met the one, two, three benchmarks. So Georgia Mobile Audiologists is a sister program because we're growing and we have six parent navigators and these are people that are involved in the journey with us. We feel like we're moving the needle in our state. This is the contact information I encourage you to scan the QR code and we're finished with the presentation. Are there questions that you may have?

>> Let's see if I click on it if it's going to work. It does. We want to show you something that got created on the web sites it's called find your audiologist. So this is where I live down here. It tells you who they are and their address and the insurance and the ages they provide services for. All of the good information that you need about finding an audiologist in our state. No questions? Y'all are quiet. Yes, ma'am.

>> My question is about transportation you said that 2% that needed it do you provide it and get them an Uber or are you assisting with buses how does that go.

>> So it depends we work with a charitable organization that provides the funding, so we connect the family with that organization and do the Uber/Lyft thing and we don't don't have it where I live so it's providing gas cards and make a better transition for families that way.

>> I believe you said that is funded by state law what does the sustainability look like going forward. Have you been contacted by organizations outside of the State of Georgia?

>> Yes, all of the above. With the new parent navigators, we're using a parent navigation curriculum that can be replicated. And that is there so that the current one that we work under is expanding so there is no issues with that. We have a good connection with state legislators and they support with that local kinds of connection. We have done hearing screening days at the University of Georgia and they support us, so I don't see this going away any time soon.

>> Thank you. If you diagnose there is a hearing loss, and the wait time is long, does your team fill in the gap with those as well?

>> We don't because we're not in the area frequently enough to be the primary care provider. So we can move up the board quicker and we work with different hospitals that are in neighboring states that we're making connections with them as well.

>> Do you do the same thing for ENT appointments?

>> Yes, ma'am.

>> Do you do private pay insured Medicaid babies?

>> We don't ask for insurance. If you have it, good. If you don't, we don't ask that the parents have it.

>> Last question.

>> With your audiologists that run that, is it people that are employed for the project.

>> We have people that are on site and we have contracted before. Thank you your time if you have questions we will be hanging around. It was nice meeting y'all.

(End of session).

>> Okay. It's really nice to see so many faces in the room. I'm Debbie Mood. I'm a psychologist here in Colorado. I'm going to go ahead and introduce the presenters. These are co‑organizers so Brenda Elliot, Shandel, Robin Getz and Jen Hill. We would be remiss if we did not acknowledge Sarah Kennedy, Jessica Dolman and Ashley Renslow from the College of the Deaf and Blind who are planners of this amazing day. Our objectives are to summarize three key elements and list three strategies that you can use planning a similar day in your area and identifying how we identified three resources to build this amazing collaborative day.

So we hope to give you a bit of a taste of what deaf autism day is about. It was started in recognition of us who work with deaf children that have autism. And there is many children in our state that are autistic and deaf and interacting with the family they reported they felt like there was no place for them and the resources that were designed for the children that were deaf and hard of hearing are not meeting their child's needs and did not feel inclusive or welcoming because of the communication access so this is a place of belonging. So a lovely quote that explains our why from one of the surveys that we asked families to complete of the three kids.

The oldest is deaf and has autism, so it rarely happens that we have something that all three will enjoy. We can feel left out of events that are not sign or autism friendly. We're in the process of planning our seventh deaf/autism day. We have grown and grown. So in the first event, we have 12 really dedicated volunteers and 10 parents and 12 children that attend and we have 34 volunteers at the last event. It's not hard for us to get volunteers and they keep coming back. 21 are care givers and 20 children. So we developed this day around a few key principals with Jessica Dolman's insight and relationship with Happy Dog Ranch, a nature‑based therapy.

It's important to have the event in an environment in nature we can demonstrate the effects of children being in nature. We committed to making the day fully accessible and we're used to talking about accessibility and we're considering communication as well as all of the child's developmental needs. I'm very proud to be part of this amazing group of collaborators from so many systems within the state who have come together to support children and family in this way. We very intentionally tried to make the day child and family centered. We have nature‑based activity and caregivers have the opportunity to meet one another and the experience of having time to connect with shared experiences is so impactful for families and they return year after year. Our goal to is foster inclusiveness and belonging, and we're going to talk to the different components of the day. And we're going to share a QR code of the resources if you want to try to build something similar in your area.

Hi there. It's our favorite day of the year. I'm going to talk about accessibility. So as a teacher of the deaf accessibility is always the issue. So one thing that we found is that when families come to the deaf autism day they are comfortable knowing that everything is going to be okay for their kids to get involved and we make sure we have interpreters and there are people that volunteer with the kids that communicate can them and we make sure they are developmentally appropriate and make sure that they get involved in something that is at their developmental level. Everything is accessible with a wheelchair and there is that access.

And kids are able to get on the horses because there are ways and steps to use and things to get them up and finally, dietary needs we have a dietary need and we have been able to partner with a restaurant nearby that is able to meet the needs of everyone. So it's really a great day. So the important thing is the kids know watt what is going to be next. So if I can show them a picture and help them understand what is coming next, this helps our volunteers as well. So this helps them be able to know what is next and how can I prepare the child that I'm working with.

>> Hello, this is Robin. What you see is a different organizations that have come together because they have demonstrated an interest in supporting this awesome cause and working together for the past 7 years now in making this event a reality. That is the spring learning community in Colorado springs and one of the restaurants, Santiago's, who donated their time and resources to make help make our event successful. Oh, and then one more organization that is not up there, that is the Denver Deaf Dove. Any other organizations? And another organization through the Colorado School for the Deaf and Blind is called ascend which is where we have our deaf hard of hearing role models that come J join us for the event supporting our families. Thank you so now our volunteers they make up an integral part of our day in helping make sure that things go smoothly.

So as we are planning for the year, we start recruiting volunteers and we have questions that we ask them to make sure they have expertise in working with hard or hearing children and ask about if they have expertise in supporting young children that may be on the autism spectrum and inquire about that modalities that they are able to use because the families use a wide variety of communication modalities and we want to be sure that our volunteers are comfortable being matched 1 on 1 with a child because they are paired with a child based on their background and their expertise.

Not only the volunteers but the child and their families as well. We do our best to match the volunteer with a child and that has gone pretty well for the most part. Sometimes we need to have two volunteers to one child. So and the way we determine that is when families register for the event, they have to answer some questions about their child and their child's needs and if we determine that their child needs additional support we make sure that that happens. We communicate with the volunteers in advance of the event and have a list of expectations. What we can expect throughout the day at the event. We cover safety information and we always identify the volunteers as a runner or go to person.

>> Good afternoon. I'm Sean Delisa. I'm a mom of six including a six plus deaf son. I'm happy to be here and talk about the things we have prepared for you today. If you have the QR code you have resources. And the fliers are available in the resource drive and a look at the YouTube video that I'm going to show about 45 seconds into what our day looks like.

 (YouTube video clip playing).

>> This fills a need in me personally and in our organization to serve a group of families that are underserved. How that works together and how a family cannot live through it but thrive. I love seeing the families see their kids in the new light and seeing the gifts that that child brings to the family.

>> This is a couple of years old, but gives a look at the fun that is happening throughout the day. I also wanted to ‑‑ okay. Let me get through it. Give you a look at another section of the day that allows us to have parents meet each other. It's one of my favorite parts of the day. Thank you. Okay. Thank you. One of my favorite parts of the day is the child and parent support time. Some‑years we have guest speakers and we reserve about an hour and we have times where we pose a question and allow parents to share out time. So we found that for all oaf the community members and parents there is a sense of community. I know having a deaf child how isolating that can be at times so it's a rewarding time and our parents give great feedback.

So what works well? We talk about the routines of the days and their love for being outdoors and following the child's lead and giver visual schedules and choose our battles and these are topics that we talk about during that parent support time.

>> Hi, I'm Brenda Elliot. And I'm going to talk about the sensory activities that we do. We do our best to create activity in terms of age, skill and enjoyment and these are few examples of things that we do and it's a nice to bond and parents to see what their children can do. One of the popular activities is a noodle shaped like a horse and it's an opportunity to engage with things around you and what you're seeing and incorporate opportunities to model calm and enjoyment and we have samples of these an that shared drive.

>> Okay. I get to talk about the nitty‑gritty details I'm Jen Hill. So we have the different things over the years because where does the money come from for this? Everything costs something. So we get real creative and have had small grants from the Colorado fund for the deaf and blind. Our state school for the deaf has paid the ranch fee and sent us interpreters and deaf adult role models. We have volunteers that coordinates different things and the local restaurant donates food and they take care of the dietary restrictions and I work for springs learning community so we donate art supplies and we send volunteers that are registered behavior technicians to help with the kids with autism.

I don't know all of the weather contingency plans but we have a huge garage if it rains and we learned instead of going in one group gob from one place to the next we split it into three groups. And everyone knows this is your time to ride the horses or this is your time to do the petting zoo. We have had to be flexible especially the repeat kid they know they are going to get to ride horses so it's like it's these kids turn now. So it helps to bring back that sense of regulation for the kids because it's about keeping everyone enjoying it and having that wonderful experience that they may not get anywhere else we have bubbles and sensory bins and scavenger hunts.

>> And just like that I'm back, part two. So one of the things that we do with this presentation is put deaf autism day in a box April is around the corner, so we put those things together and get that information out so that gives time to market to the families and when school resumes we get that out and we have the amazing event typically in September and we meet again after the event and we try really hard to have someone from the community a young adult who is deaf and autistic to come and we had them come from another place in Colorado. It makes a huge impact for the parents and children to see their own role model.

We have resources here this is the famous QR code and we have fliers and forms we have created so craft ideas that video worth the time to watch. We are down to our one-minute warning, so we hope that you can take this deaf autism day in a box and we'll leave you this quote from Walt Disney. There is our volunteers. There we go, the way to get started is to quit talking and begin doing.

>> Thank you. I don't know are we out of time or do we have time for questions? Five minutes. Okay, we have five minutes for questions. We need too bring you a mic. Are you asking for the QR code? Okay.

>> Is there anyone in the audience that has a similar event and maybe the activities look different but is there a similar event in their area? The summer camp. Is that designed for families to come? Okay. Kids and their siblings can go to summer camp called Rosie's Ranch. We love it. Is anyone in the audience hoping to plan a similar event in your area? We would love to hear your experiences and happy to answer your questions. We did not put e‑mail addresses on this but you can contact us.

Yeah. Come get our contact information if you're planning an event like this. We're happy to give that contact information and happy to reach out with questions. We hope you will go look at the video. That gives a sense of the joy of the day. We emphasize that idea of trying our best. We put a lot of thought into the structure of the day so the theme is structure and flexibility and we're intentional of the being structured and flexible to meet the child's needs. Other questions? Thank you.

(End of session).