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EHDI Conference 2024, Granite A-C Sessions 5 and 6

3/19/2024 9:10 a.m. - 11:55 p.m.

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**GRANITE A-C SESSION 5**

One Meeting, Two Stories: Parent-to-Parent Support from Two Perspectives

3/19/2024 9:40 a.m. - 10:05 a.m.

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Captioner standing by

>>: My name is Angela and I am the moderator for the morning. Welcome to One Meeting, Two Stories: Parent-to-Parent Support from Two Perspectives to raising thriving teens there is water in the back it's the first one all day. --

[Overlapping speakers]

[Laughter]

>>: No worries at all.

We are here today to talk about parent-to-parent support and how it is mutually beneficial to the supporting parent as well as the learning parent.

My name is Penni. This is my crew. Did you know that the Las Vegas Golden Knights won the Stanley Cup last year?

[Applause]

Surprise! I am the mother of six. My husband and I live in Las Vegas. We have five kids at home right now, one in college. There's 10 years between my oldest and youngest. Martha is our youngest. She was born in 2014 and took us on a wild ride. We knew before birth that she had a very complex congenital heart disease and she would require immediate surgical assistance to help her heart work the right way. We did not have a firm CHARGE syndrome diagnosis for her until she was about 15 months old, but it was suspected strongly when she was four-and-a-half months old and we discovered in addition to her heart condition colobomas in her retina and optic nerve. She has no usable vision in her right eye. Left one does all the work. Because of repeated hospitalizations and lack of inpatient access to audiology in Nevada, we were not able to get a good ABR until she was 14 months old. She was not aided until she was 18 months old. She had extremely noisy breathing. I had a wonderful parent guide when Martha was about four months old because of that screening fail. It was connected with Nevada Hands and Voices and enjoyed their educational and social events. I joined staff in 2020 as an educational advocate when our chapter started the ASTra program. I saw the need for additional support for parents whose children have additional disabilities and trained as a parent guide in 2022. I'm new in the role as coordinator in the Guide By Your Side role in Nevada.

The other hat I am wearing at this conference is member of the Board of Directors for the CHARGE Syndrome Foundation. When Martha was having an extremely tricky airway surgery, before her first birthday, I found the foundation's resources and was crying in her ICU unit because I felt seen. All of the complications that other families have but also the success stories.

That is who I am and I'm going to let my partner in crime introduce herself.

STACI PETRALBA: I am Staci Petralba, and I'm an audiologist who primarily works with adults and the mother of 4-year-old Addison and 2-year-old Benjamin who was born with CHARGE syndrome.

My family live in Las Vegas about 10 minutes from Penni Echols' family. Benjamin was born in 2001 it took our family on a wild ride. We did not know anything was wrong before he was born. It was a typical uncomplicated pregnancy. After he was born, Benjamin's nurses became concerned because he would pink up when he was crying, but when he was not crying he was turning blue. Immediately they were suspecting pulmonary atresia. He was taken to the NICU right away. Two hours later they'd informed us they had to intubate Benjamin and found abnormalities including life-threatening heart deficits, abnormal ear shape and other things I did not remember. He was then transferred to a different hospital the children's cardiac program is where he was found to have kidney abnormalities, colobomas optic nerve in both eyes and after eight weeks and four surgeries he came home from the hospital for the first time.

Benjamin was suspected to have CHARGE syndrome from the date he was born because he had all the major diagnostic criteria. Since CHARGE syndrome was suspected immediately, I spent a lot of time on the CHARGE Syndrome Foundation's website learning as much as I could.

I attended parent support meetings via Zoom monthly. We attended our first CHARGE syndrome conference last summer in Orlando. We are not quite as involved in the Nevada Hands and Voices as Penni is but we attend the occasional storytime at the library and the splash pad meet ups.

PENNI ECHOLS: Isn't she awesome? Our plan today is to share with you three of our meet ups and how they were mutually beneficial. I understand that our story is not demonstrative of all PTP support. It is not possible to always match a parent to parent with the same etiology in a short driving distance and the same parts of the state. But I felt like that is what making this relationship really effective at showing you these things today.

Parent-to-parent support is scientifically proven to be true. This is the conceptual framework and these are the old slides without the QR code you can go to HandsandVoices.org off to a great start where you will have access to a larger model of this in the parent-to-parent support activities guide. It is free to everyone. It is not exclusive to Hands & Voices. This model was developed by researchers Henderson, Johnson, & Moodie who aggregated findings of peer-reviewed findings from 2000 to 2014. It was published originally in the American Journal of Audiology in 2014. Hands & Voices then took it into their hearts and created activities that parents can use together to learn and grow. What I really like about this is the connecting arrows around the outside. That the supporting parent and the learning parent are drawn together by contribution and connectedness. And we grow together through support, information, and modeling.

These are in the wrong order. It says old on it. Okay. I sure can. Going to have a boss moment here. Sunday, Tuesday, 940. The one that does not say old. Presentation mode. Yes. Here is your QR code. It is real. It works.

We're going to go through three in chronological order of getting to know each other and becoming parent-to-parent support, friends, and explain how it works.

STACI PETRALBA: This is the first e-mail I sent Penni. At the time Benjamin was about three weeks old. We were in a hospital out-of-state in Utah to receive ENT care. At some point in the early days that Benjamin was in the NICU, probably within the first week after he was born, one of the social workers at the hospital gave me a printout from the CHARGE Syndrome Foundation with information about the state liaison program. And gave me Penni's contact information.

I reached out to Penni because I was looking for as much support as possible as I knew that we had a long road ahead of us, and I wanted some support and advice from someone who had been through a similar experience. I was looking for information to give Benjamin the care you needs as well as support for myself to help navigate this journey. I was looking for a community to interact with. Prior to communicating with Penni, I had talked to my bosses sister on the phone about eight years before Benjamin was born she had a son who was suspected to have CHARGE syndrome. His name was Gavin and he became an angel when he was three months old. When I got into contact with her, I thought she was more involved in the CHARGE community in Las Vegas, but she was not, which is what led me to reach out to Penni. Penni was my first contact into the deaf-blind world. Although Benjamin had serious life-threatening health conditions, the first thing I told the attending doctor who admitted him to the cardiac ICU unit before his first heart surgery was that his heart issues were the least of my concerns. I viewed the heart as relatively easy to fix. It's plumbing, electrical, they can fix that. I was more concerned as a parent about how to raise a child with deaf blindness, and that seems like a much more daunting task to me that fixing his heart.

Penni lined me up with the deaf -- and helped me enroll him in early intervention. The information Penni shared was different from what we got from providers because it was from a perspective of someone who has lived the experience. No provider could possibly understand what it is like to go through this experience unless they also had a child with complex needs.

It is really helpful to share the trials and relations with someone who really understands.

PENNI ECHOLS: Hooray for digital clutter. This visual breaks down the construct of knowledge. In this meeting I shared information that I had gathered from my own experience, but also through my training to be nonbiased and to let the parent make their own choice. Staci will always know more about Benjamin than I do. Staci will always know more about audiology than I do. I ask her a lot of questions. It helps me to know that the struggles that I went through were not in vain. That there is a reward for someone else for the struggles I went through.

STACI PETRALBA: Last summer we traded places in the hospital. Benjamin was discharged early July and then Martha went in for a heart surgery so she was in the hospital for a little bit and then after about four weeks in August Benjamin was back in the hospital. We were trading places back-and-forth that summer. We did not end up meeting in person until September. Penni was kind enough to invite me to her house for our first meeting. In Las Vegas in September, it is still a little hot to be hanging out at the playground. This was the first time I took Benjamin anywhere besides a doctor appointment. After meeting her family I felt the overwhelming sense of relief that things were going to be okay. I saw this family that seem to be functioning normally despite everything they had been through (Laughs).

Meeting them was like seeing a light at the end of a dark tunnel of Benjamin's 10 weeks he had spent in the hospital at that point. I think was helpful for my daughter Addison to know Martha and her siblings. Addison is currently four. She was 2 when Benjamin was born we met Echols' family. I don't think she understands that Benjamin is different from other babies. She just thinks he's a baby. I hope that she will grow up knowing more in hopes normalize a fact that everyone is different has different abilities and the ways of communicating. Obviously, Martha is Benjamin's best friend. I don't think he knows yet, but she has definitely decided that that is the case.

PENNI ECHOLS: I want to be clear that she was not on the Guide by Your Side. There was no breach of professional conduct there. There is a very short list of people in the universe that I would invite to meet me for the first time when I had been sleeping on a foldout couch and sharing in the lunchroom at the hospital. Lucky for Staci, we missed each other.

Martha does think that Benjamin is her best friend. For her to see a baby wearing hearing aids, being fed by a G-tube, and carrying some pretty bright surgery scars, she felt seen. She loves him very much. We all do.

When I look at the construct of well-being, I love that it is broken down to child and parent. Staci does a great job of taking care of Benjamin and I feel like it is my privilege as her parent guide as her friend to be a safe place for her to not have to mask when things are difficult and to be real with me in return, I've the same privilege with her now.

STACI PETRALBA: Empowerment. I attended the Nevada Hands & Voices ASTra Level One training. It is eight hours of training and educational law for deaf and hard-of-hearing students. After this training I had lingering questions about the early intervention team about developing language that I did not feel like was being addressed. I did not feel like he was getting the support from early intervention for language acquisition. So we had a meeting with the team and the decision was made to add a sky high trained developmental specialist to the service plan because there is not anyone providing ASL instruction.

She was not very helpful. She directed me to a sign language dictionary and no call, no-show for two appointments. I was livid because time is precious when you are working and managing all of the appointments that Benjamin has.

I was like we are done with that. Penni helped us to find a some support outside of early intervention. She introduced us to the communication matrix, which is a good tool for assessing pre- language abilities. She gave us resources for sign language learning and we also found a teacher of the deaf privately actually at Martha's birthday party who was helping us with language learning.

PENNI ECHOLS: This is one meeting where we have two different stories. And that's okay. After the ASTra training Staci and I exchanged e-mails for a few months about what that language acquisition piece should look like. Research IDEA Part C law, suggestions for her team, which were all, they were not received. She delivered them, they were not received. We even discussed filing a Part C complaint but based on my experience with the Part C complaint, that went nowhere. We decided to just roll with it.

In this meeting we were sitting in a circle on the floor I got the privilege of holding Benjamin. It was my favorite. He played with my glasses the whole time. It was good I was holding him. It was good I was holding him because when the supervisor said this I nearly exploded. I was extremely offended because my role as an advocate, my role as a parent guide were extremely disrespected. I would never imply that because my daughter had something someone else needed it or deserved it. I got to educate her team that day on what a parent guide really does. We help a parent enumerate their concerns. We help them take their concerns and match them to their parental rights. We help them research options outside of the system. We show up at meetings with them and hold their babies so they can do their business. So I want to make sure that we all understand that that is what parent guides do.

STACI PETRALBA: This construct of empowerment is so important because our lives are struggle. Advocating in the medical system, advocating in the educational system, in the community for access.

PENNI ECHOLS: Supporting parents. We switched the slides over breakfast and my brain is not caught up. Staci, Noah, and Benjamin would be fine without me. They have a supportive family network, supportive employers and mama bear comes out sometimes. The first two children that I met with CHARGE syndrome are angels now. Every time that Martha reaches a milestone that Tanner and Gretchen did not, I feel slightly eased in that pain. I do this work for the children who are not here. I do this work for children who are here. I do this work for me to heal myself. I'm constantly learning and growing, and I fear if I did not have the support that Hands & Voices Guide by Your Side gives us as a supporting parents that I would some way be failing my own daughter.

PENNI ECHOLS: As the learning parent, I reached out for support --

[Overlapping speakers]

I needed to know that everything was going to be okay even if things were not going well. I am grateful to have someone to lean on for support who truly understands the experience of having a child with CHARGE syndrome.

STACI PETRALBA: We did not get the tears out. I hope that you see that it is mutually beneficial. And founded on respect. Some of the things that linger in my mind as a Guide by Your Side coordinator now is what can I do to make that initial contact easier for learning parents. How can I connect better with families of different backgrounds than my own, different parts of the state, different diagnosis?

How can supporting parents avoiding secondary trauma and burnout? Because there a lot of triggers for spent time in the hospital. Thinking back to the IFSP meeting there was some secondary alarms that went off in my body and luckily Benjamin was there to keep me from going crazy. But to recognize the signs and ourselves as supporting parents with those possible triggers are in working through them so we can remain professional and how can we encourage the development of future supporting parents. We can't do this forever. I mean we can probably, but my husband would like to retire someday.

In closing we want you to reach out if you have any specific questions about Guide by Your Side about CHARGE syndrome, about the awesome audiologist sitting here, let us know.

[Applause]

>>: The old slides are updated and I will upload the new ones. There are plenty of resources here for you.

(CONCLUDED AT 12:04 PM)

**GRANITE A-C SESSION 6**

Enhancing and Supplementing the EHDI Information System

3/19/2024 11 a.m. - 11:25 a.m.

CAPTIONING PROVIDED BY PARTNERS INTERPRETING

Captioner standing by

Captioner standing by for audio

>>: You are attending Enhancing and Supplementing the EHDI Information System. This session is scheduled for 11:30 - 11:55 a.m. at the end, if you could kindly get up and go to your next session because there'll be another session coming in, please don't dawdle. The emergency exits are here behind me and at the other end of the room. Without further ado, let's get going. Thank you.

>>: Thank you for sticking around. It is Tuesday. I hope you have had a great week. We have some acronyms that we want to familiarize you with just to take a quick peek. These are also in your handout that is uploaded to the website. We also have what I lovingly call bingo cards because as we present, we talk about different websites and you all scrambled to take a picture to the QR code. There is an attachment in today's presentation that has our bingo card with all of the websites that we think you will need for this presentation. So I want to introduce you to our great group of folks who have worked really hard. I don't know about you, but I have not met any EHDI person who think that COVID is really over yet because we still are trying to battle the effects of COVID. Funding, staff, searching for IT time or an epidemiologist. What are those?

I want to share the positive side because in Illinois what we did is COVID hit and we decided we are all sitting at home and bored. We have a lot of passion and we want to work on projects. We were so fortunate that our vendor James Fritzler who was with Utah State University and HiTrack program was willing to work with us. That we had to fix and some of the new innovations that we did. There was a little, there was not a lot of grass growing under our feet during COVID.

You will see that James Fritzler is probably the one that steers the ship and helps us know what can we not do in our IT subsystem. He is not like a regular IT guy. API says well, it is going to take me a while. Would Friday be okay?

[Laughter]

The most responsive person. That is what has made it work. Not only do we see these tasks that we need to do, but we are also finding joy in what we do. That we have the two people that give constant input to what we are doing in our IT, innovations. And that is Carrie Balian who is our Hands and Voices coordinator and she has been for 15 years. Shout out to her anniversary. And then Kate Jordan who is an audiologist on the state EHDI team. She is the one working for day in and day out in our HiTrack system.

That little cart in the back, that that is mine. I'm kind of like aunt Edna who says you know we could visit the largest ball of twine on the way. I add projects along the way, but these folks are fantastic to work with and they make life much more, it is just a lot more fun when you work with people that you feel like you can have open conversations with. In your handouts you're going to see all of our disclosures but basically guys, none of us have proprietary -- we are funded through state and federal funding. We want to share what we have with all of you. Don't ever be afraid to steal or share shamelessly.

Before we get into our innovative new things, we realize that we have to fix a few things that were broken or not quite right.

I want to do the reminder to all of you as you are working on your data systems is build in money to fix things that you did not know were broken. Some of the things that we did not quite know (Laughs) that were broken or we had to revisit and we were able to budget for those as we had to do updates and software and servers. As you know, cyber security hacks are big. You have to spend a lot of time and money for that. You have to budget this little uh-oh fund to fix all of these things. We also wanted to double-check our processes and alerts. Make sure we have e-mail alerts. We had alerts set up when something would break, but those e-mails were going to a dead end. We had to create, we had DPH stat hearing reports at Illinois.gov and make sure that those alerts went there. If I retire or win the lottery, those alerts go to the next set of people.

Double-check those things. Check for unintentional consequences, which is what we had. We found out when we started coming over with birth certificates, we were very parent one centric, very mom centric. That did not work with our Part C. They are Parent 2 centric and all the kids' names were with Parent 2. We had to add Parent 2 to make sure it was coming across on both certificates. Originally they did not want to give us that. Sometimes, you have to wait for people to retire and move on.

[Laughter]

Eventually you get it done. That was something we had to fix. We also had, we are not really sure what happened, but we found out that our freestanding birth centers were coded two different ways. One way they were coded as a birth facility like a hospital. The other way they got coded to be a homebirth. All of a sudden change happened that no one told us about and data was coming in two different ways for those freestanding birth centers. We had to go back and fix that.

The last thing we had to take a look at is getting death data transferred in. That is totally separate from the birth certificate data. We now have a transfer for kids zero to 36 months because we reach out to children as they transfer from Part C to Part B and there would be nothing worse than to contact a family who has had a child who has passed away. That is one of our new integrations is to write additional code thanks to our wonderful friend to pull in that death data. I think Carrie can speak to that too as to what a change it has made. I think her guides have a lot more notes as a result of reaching out.

The good stuff we worked on during COVID and we're hoping it is going to improve in James is going to tell you about that.

JAMES FRITZLER: Thank you. We're going to talk about two main things we did. The first thing we did was to get data from Medicaid. Medicaid has more accurate address information, contact information, than the birth certificate does. That was from the first project. We had some good partners in IT that were able to link with us. We worked out the system were they would write to a database table for us and we helped them automate it in HiTrack. This is more up-to-date than birth certificates because it gets older as time goes on.

The other project we worked on was to bring data from the birth registry. It is called APORS in Illinois. The birth defect registry has a lot of other things besides just hearing loss obviously, but they do have data about the risk factors that JCH risk factors. When we worked out with them to do the crosswalk, between the HiTrack and birth defect data in their system. It is pretty cool. Kind of, not an exchange, but it is a two-way thing. Because the EHDI data is going to be extracted from kids who have been identified with hearing loss is going to be shared with the birth defects people, too. They often don't get data that late. I mean three months is not that late but they don't get that data that happens after birth very much.

We encountered a couple and then eventually the other goal is with the birth defects system as we wanted to get CMV data out of there. They have that. In other states HiTrack EHDI uploads data from labs but in Illinois this is a better solution. One solution does not work in every state. It is going to be pretty slick if we can get CMV data because we can link to that to do things for those kids.

We ran into some challenges. The risk factor mapping took some effort. What was the intent, the meaning, you have to get into the nitty-gritty research what the different indicators mean in different systems. They might be worded differently.

The other one was related to timing of the data load. I will go into too many details, but the timing of the data load was important because it had to do with something overwriting a date and those dates for follow up on notes especially were, or are really import for Illinois. There was a challenge that we learned a lot from. By timing the data load from the systems, with a schedule that worked with the data coming in from the hospitals.

Then my last thing to mention on this and that is kind of related to the next slide is that all of this progress is incremental. We know that IT is data IT. They are not always super eager to jump in and do extra things for you (Laughs). But we met them halfway. I think investing with them sort of like beyond at a professional level and a personal level has paid off. They know the EHDI staff now and I've got to know them, too. So over the years when we meet with them, could we improve this would you rather have this automated rather than writing a CSV file to a folder or something? State IT I often want to improve it. You have to grease the wheel. They don't want to start, they don't open up at first.

This part, faxing pediatricians and audiologists in Illinois is only possible because of all the other work, the data integration that we have done with Medicaid to get all the other contact information has been the stepping stone to go on and do this other stuff. The faxing has led to an 80% staff reduction in effort. You guys send 200 faxes a week and to moms, too, but instead of having to manually fax 200 times per week, HiTrack can do that for them automatically. The thing I would imagine mostly on here communicating with people, doctors and audiologists, more effortlessly is always going to help kids. That is where we are at. But also on the other hand, the state EHDI team, the clerical staff felt validated because the program took interest in their struggles and we invested in them.

Now they can do, they can be efficient in other ways. It is interesting the trickle effect when you invest in your state IT and your IS system. You actually get a team morale boost and that is always helpful. Even though we love babies and help them every way we can, you also need the morale boost.

I will let Ginger introduce the next part.

GINGER MULLIN: As James said, sometimes we have to convince people that it is worth their time and energy to do it, especially our state IT staff. One of the projects we had worked on were report cards for hospitals, but we did it very manually in the beginning. We would extract the data, spend hours putting it into graphs, and developing a report card.

We had the best social service program planner, too, which is just an Illinois title for a woman that helped us with our data representation. She helped us there continuous quality improvement to come out with what is a report card that is meaningful to the hospital.

We did it and tweaked it and used national standards. What she eventually came up with were bullet graphs to visually represent how well a hospital was doing.

Quick note on this: A lot of people use red, yellow, green to see if you're doing well or not. You can't, because that is not visual access. Because of colorblindness, you cannot do that. I apologize if colorblindness is not the correct term.

Through our quality improvement we had the idea of coming up with this report card and it had a lot of friendly competition because it shows the other hospitals in their perinatal network. So use that competition because they are fiercely competitive in a lot of ways. But through that seek UI we're trying to get them off of that. Hospitals look at that "I screen all the kids" and maybe "what was my referral rate?" I have to keep it between one and 4%. We want them to look beyond that. It's a what you do in the hospital before discharge impacts that child long term. We also included the goals for diagnostics and the goals for loss to follow up.

We were thinking that we were nervous in the beginning about that, but we were surprised at how much they embraced that. They wanted to note that long-term goal. In Illinois we have Chicago and our reality is we have a handful of hospitals if I were to go visit, there are armed guards. There are armed guards as I get on and off the elevator. That is a little bit of an oh, Mom is probably not going to come back to the hospital for an outpatient screening if you miss them or if the referral rate is too high.

We had these meaningful conversations to talk about how can we do the best we possibly can to be able to share the message consistently before discharge.

Side commercial: We worked with the newborn hearing training screening program and also translated their materials into other languages, but we have all of the videos that are within the NHSTC within native ASL. We have a native ASL individual who is married to a hearing individual who is the assistant superintendent for the school for the deaf and they helped us create those. If you want them, use them. They are open for everybody.

It was important to us that we had that and we were not using the little iPad that comes in.

We got folks thinking beyond those first few domains into all four. We got them on the fact of you need to do quality improvement, continuous quality improvement. Many hospital said we would love to do that because we write it up in our report and get credit for it.

We don't have a lot of bandwidth. We have a staff of four and two of them have FMLA. We are a staff of 2. We developed a matrix system if you are out of compliance. It is self lead, meeting the hospital can do it on their own to get started. The second phase you can work with our staff at public health in Illinois. We meet monthly with every single hospital and we get online and check their data.

We go through and try to clean up any of the data to try to keep people on track. We call it an education and audit meeting because it is really about educating them on how to use the data system. We now use WebEx. Most of those meetings are only 30 minutes. We go through it, we are done, but it is our contact to let them know that we appreciate them as they make a difference and keeping that data clean helps us with the long-term impact.

The third phase if it does not work to do it on their own or it does not improve on the one-on-one monthly calls, then they get to meet with me. I don't think I am very scary, but my staff seems to. You will never hear me called Dr. Mullin unless my staff has moved into this third phase. Dr. Mullin is going to talk to you about it. But then we use the virtual site curriculum that is already out there. It is on hearing.org. The resources are all there. It actually ties into a system that Kate will talk about later. We use the same platform for it. We steal shamelessly from that. You will see in our handout if you go out on the website, we have remediation plans for screening, diagnostics, referral rates. There's an example of all of those. We did use CQI to improve those, but if you guys have any suggestions, I'm open to them, e-mail me and say, hey, what if you did this? We want to improve those. We believe that we should hand you something that you can use by next Tuesday so please go out and pull out the handout, maybe it is something you can use. If nothing else the bingo card is something you could share with your staff or your hospitals.

The other thing that we had inside of our HiTrack system is something we shared with our friends in Utah and Idaho and Ohio. We ended up using a usefulness survey. This is the best way to do a survey because every time they log into the EHDI-IS they are reminded did you take it yet? We ended up with about 85% of our hospitals responding which we consider pretty good considering if we just sent e-mails. We use the same exact wording that our colleagues did in other states. We hope to eventually have conversations with each of them versus what did your say versus what does ours say.

One question is how useful are the site visits? We don't do site visits in Illinois, but I think they interpreted that as our monthly calls. It gives us a place to start and a place for us to dig into. If you have surveys link them to your EHDI-IS. It ended up being very helpful. It is about keeping every thing in your EHDI IS system because you don't want Excel sheets in other places, redcap you don't want it all in. I'm going to hand it off to Carrie who is going to talk about how we keep that EHDI data or family EHDI data in the system as well.

CARRIE BALIAN: Continuing down the path of quality improvement and data we are going to talk about FEHDI. It is family EHDI. This represents the family data. This project started at a thought that Ginger had before the world shut down at that 2020 conference at EHDI where how can we make sure that the information from state to state regarding family support is equitable and equal?

We had discussions with several other states to create a FEHDI workgroup to define definitions and a spreadsheet that programs could use to collect their data. The FEHDI definitions allowed us an opportunity to make that match across the parent-to-parent support programs because not every FBO, family-based organization, is set up exactly the same. The definition and the spreadsheet created by the FEHDI group gave us that starting point. For our team in Illinois, with HiTrack and James' help, we have utilized a services tab and a custom form a snapshot to collect our data within the information system. Again, one place for all the information. And with having it in HiTrack it allows me to have access to it and also Ginger's team. Nobody has to wait for someone else, which is really great saving us time.

This was really a springboard of where to start or the bare minimum of what we wanted to collect so that we can consistently analyze the data and understand those areas that may need some improvement.

The other benefit to sharing an information system is for the additional cyclists or as we call them specialists who add additional support between the EHDI and FBO program. We have two additional support roles, which we call our loss to follow-up specialist and our transition specialist. They allow us to share the road and provide information as Ginger referred to on the last slide, the data completedness, which includes reasons for not enrolling or participating in a program that grant funding requires.

If you scan this QR code it will take you to the MTRC page you'll see the PDF of definitions and history of the project and another link that takes you to that Excel spreadsheet that FBOs can use to analyze their data.

We're going to switch gears and talk about aggregate data. Up to this point we have talked about our child-specific data system. But we also had a need for an aggregate data system. We wanted to be proactive in defining our scope in Illinois EHDI as it goes to ongoing surveillance versus the other three early childhood programs and vision and hearing programs. We know the prevalence of hearing loss can triple by school age.

The STRATA reporting database was developed in partnership with Illinois EHDI and the school vision and hearing program and NCHAM, James too -- it is designed to collect aggregate data for three categories for OAEs for school-age division, and school-age hearing.

STRATA is only used to collect aggregate data. There is no personal health information being collected so there are less security concerns than when you're dealing with child-specific data. You know that in our profession we love our acronyms but STRATA is not an acronym. It is a layer of rock found in the earth or it can refer to a social STRATA. Here it represents the different layers of data represented in our program. There are three levels of users in STRATA and they have unique access rights. We have admin, state, and a user agency level. Those agencies or health departments within districts and so on.

Can also be used to conduct queries of users and agencies. So we know who has completed and who is not completed the queries. Which can be very useful.

Could be used to establish the baseline for example, how many children with confirmed hearing loss are in a given area and that is a starting point to work with the language and literacy data collection.

Moving on. This is a view of today's handout which Ginger loves to call the bingo card. I am sorry we did not have enough for everybody, but it is available on the conference website as well as attachments of the hospital report cards. Thank you so much for joining us. Do we have any questions?

>>: I know they're going to bring in a microphone but go ahead and we will repeat it.

>>: I was just wondering how you got the children's deceased data because I talked to a parent a few weeks ago and our nurses try their best to report those types of things, but it is kind of like risk factors sometimes they report sometimes they do not.

>>: We found out the hospital was very inconsistent. We would get some information from the blood spot folks as well, but we ended up going back, we had a parent very upset that they got a phone call because their child passed so we went to birth certificates and that is the Illinois record system and we gave them the parents' story and said can you send us the death data extract and they said oh, yes. We just use that data.

>>: If it happens like that for the hospital --

[Overlapping speakers]

>>: We get every child from zero to 36 months of age. We get a nightly upload of deaths if death is reported in the state of Illinois, that imports in as soon as it is registered into our HiTrack system. We use the parent's story to help facilitate that and help get that done. We were told do an MOU and within the same agency and we were told of vital records staff story they said no, we are going we are doing it now. That was positive.

Our report cards, we used all the information, I did not say this to them go to James and say can you build this into our HiTrack system? The point was we did it manually, did the CQI, we got the buy-in, and then we were able to have IT built into the data system. The STRATA system that Kate talked about we built that with federal funds, guys. That is open to everybody. That is not an Illinois thing. If you want to use it, talk to James. He will talk to you about what needs to happen to get you to use it where it is not an Illinois thing. You don't need to re-create the wheel.

>>: Thank you so much and we have people coming in for the next session so thank you very much, everyone.

[Applause]

(CONCLUDED AT 1:26 PM)

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Data Dashboard Development for EHDI 1-3-6 Tracking and Follow-up

CAPTIONING PROVIDED BY PARTNERS INTERPRETING

>>: Okay, everyone you are attending the Data Dashboard Development for EHDI 1-3-6 Tracking and Follow-up session.

You have your emergency exits. You are fortunate to have them all throughout the room. If needed if we can use those exits, the session is scheduled from 11:30 a.m. to 11:55 a.m. We encourage you to fill out the evaluations. You can fill out in the app. Let's get going.

>>: Welcome, everyone. My name is Liza Then and I'm the EHDI coordinator for the state of Rhode Island. With me here is Ellen Amore, and she oversees the EHDI data activities that are funded through CDC corporate agreement.

We also have Gail McDonald, and Gail is our EHDI audiologist and she provides her expertise to our program.

So this presentation will go over our EHDI dashboard in the state of Rhode Island.

For our learning objectives we hope that you will leave this presentation understanding our RI EHDI data dashboard and how it facilitates our 1-3-6 process follow-up process.

Before we begin, I want to provide you with a brief overview of Rhode Island's program, EHDI program.

As you all know Rhode Island is the smallest state. We have approximately 11,000 births per year. We have out of the five birthing hospitals, the largest birthing hospital that provides, that delivers approximately 75 to 80% of all births.

The program of all birthing hospitals are provided with screening devices that are maintained and we provide technical assistance, too. To ensure diagnostic evaluation the state has three main diagnostic centers that see children. All three diagnostic centers provide data to our database, and every child that is diagnosed when there is a hearing loss a diagnosis, we have a dedicated parent consultant who actually performs a referral to early intervention.

Our Part C early intervention program is housed in the office of health and human services. Out of nine early intervention services we have throughout the state, we have four main EI agencies that see all of our children who are deaf and hard of hearing. Now I will hand it over to Ellen who will provide us an overview of our EHDI IS system.

ELLEN AMORE: Good morning, everyone. So as Liza said I am Ellen Amore, and I oversee all things data around EHDI and all other data.

Our EHDI information system as part of a much larger child health integration system called KIDSNET. It is a web-based system that facilitates the authorized sharing of public health data really for the purpose of care coordination.

We have many partners. Of a particular note are these ones that are highlighted for EHDI so obviously, we partner with vital records so that we know who has been born. The hearing screening data are in KIDSNET and our EHDI-IS. Audiologists have access to the system where they can do data entry audiology results and we are working really hard to try to get it so that we can get diagnostic audiology right out of their electronic health records. That has been a long-term dream in a work in progress. We're getting close with one of them.

Early intervention data, and we have a lot of other follow-up partners that have access to the system that are authorized. These include primary care practices, early Head Start, managed care organizations, WIC and also family visitors. We also have hearing screening intervention on ages kids ages three to five because we care about them as they continue to grow from our child outreach program, which is our Part B Child Find activity in the state. That is really nice to partner with.

This slide describes our data flow. We import the brief birthdate, including home births, usually within 24 hours of birth. Remember this is Rhode Island. We have five, count them five, birth hospitals. Our largest birth hospital are close to 75% of births occur our data EHDI managers dream is to have one birth hospital, but we don't agree with that. The data are imported into the screener laptops as Liza mentioned and we provide those and they are synced to the handheld devices that we have given them and after the baby's are screened, the data are synced back into the laptop and sent over to KIDSNET where it meets all the other EHDI data in our dashboard. Gail is going to give you a demo of the dashboard that we use. I'm going to have Gail come up. I'm not sure how 50 friendly the head also be so we have handouts so you get the gist of it.

Gail, I'm going to let you, I am going to minimize that.

GAIL MCDONALD: My name is Gail McDonald and I am the EHDI audiologist in Rhode Island. Hopefully, we can get the demo set up. I'm going to be demonstrating how the data, sorry, is that better.

I'm going to be demonstrating hopefully how the data flows through our system once the screeners screen and that they transfer the data to us directly then it comes into our dashboard and on our dashboard we have 10 separate columns. The data flows from one column to another after a certain action has occurred.

Do you need me to login?

In our EHDI team, we are each assigned a column to work on. As soon as we perform the action for that column, then it moves directly automatically into the next column. Next hour follow-up correlator can start with her actions and then once she sends a letter or does whatever follow-up required then it moves into the next column. It flows so seamlessly that we over the last two years since this was implemented have really noticed that it has really reduced our lost to follow up because we all know when to do and what to do and when to do it.

We were hoping, we came an early trying to get this all set up but then it went away. So in the first column the babies may come in from being transferred. I review all the screening results and then I assign a recommendation. If the baby was missed they need to come back for an initial screen. If the baby needs a rescreen in the outpatient clinic, then I will assign that recommendation. Once I assign the recommendation, it moves to the next column. Our follow-up coordinator then knows that the baby needs a letter sent out and we can generate the letters right from our dashboard so she just pulls up the letter, generates the letter, print it out, mails it out. When that is done, it goes to the follow-up and complete column and that is where Maria, our follow-up coordinator, works magic calling pediatricians, calling parents to get those babies back in for their screens.

Once the baby gets their outpatient screen, it automatically jumps over it if they need a diagnostic because they are referred then I follow up with diagnostics and make sure the parents have an appointed schedule earth they need help scheduling their appointment are audiologists get but the diagnostic results in into the KIDSNET. Then those diagnostic results automatically come into our dashboard, and if they are a pass, the baby drops off. If it is a referrer, then the baby jumps into the cohort so our parent support or parent liaison can then call the parent.

It is really over the past two years, we have done a lot of tweaking of it, but because the data flows so seamlessly from the screeners, from KIDSNET to the screeners, back to KIDSNET back to us, it has really reduced our loss to follow up.

I’m sorry. Oh it is capital T sorry about that. There we go.

There we go. It is trying to come up. Okay.

This is what our dashboard looks like. Every morning we come in, these numbers are constantly changing. As babies get screened, if they pass they automatically drop off. If they refer, then they come back on, come on.

Let me just right and example of one. Also, if the screeners add the outpatient appointment into the screening software, then that appointment comes through to us also, which is great because that way we know if they have a follow-up appointment scheduled. This is an example of the demographics that come up. This is what our screening results would look like. I would assign that recommendation from this column.

I'm going to skip over to diagnostic so they can see that. Almost there.

This is a baby who has had their screens and now they need an evaluation and I know to do the follow-up with this baby for diagnostics. Once that diagnostic results, once they come in, then they will move over to the cohort for Gladys to do her parent support.

For the sake of time, it do you have any questions while I have this up? Yes.

>>:

(Off mic)

>>: How much did your loss to follow-up drop?

GAIL MCDONALD: The question is how much did your loss to follow-up drop? That has been very hard to figure out because–

(Off mic)

(Inaudible.)

(Audio lost.)

Captioner standing by

Captioner standing by.

>>:What one thing that would be helpful I think would be to have a better flow of early intervention data. That remains very challenging for us.

The other thing would be the audiology data to get it out of electronic health records directly into the system with which we are working on.

>>: That makes sense. I hope you are able to find a way to make that all happen with everyone's support. Thank you.

>>: Can you speak a little bit about all the different people that have access, what do they have to do to get access? Like the process by which say I'm a private audiologist moving into your state, how do I get access? Do I have to have people assigned to me so I could see their cases or do I see, you know, what is the?

>>: The process to get access, only people who have a need to know and are authorized, the program that oversees the data sets the data intervention, they decide who are the people out in the community that would be authorized to see their data, they work with their legal teams, there are individual data use agreements within each one of these programs so it is a time-consuming process to get all of that in place.

When they're all set up, they would contact one of our provider relations team so somebody moving and could say, hey, I am a new audiologist. I want access.

Typically each audiology site has an agreement with us and they have what is called a KIDSNET administrator and that person at that site hands out usernames and passwords because they know that they work for them and that they are authorized to see the information. Does that help?

>>: I am a training and develop specialist in Arkansas and we actually do trainings. Do you have different trainings for different users so like for PCPs, early interventionists?

>>: We do. We could do individualized training. I also have online training that is available based on the user group that you are part of that you can click on when you are in the system and go to the online training. does this answer your question?

>>: I am an audiologist, I can see the records I put in, yay. What else can I see in the system? Can I see that they have an IFSP, or do I have to in agreement with EI --

[Overlapping speakers]

>>: For audiologists in general to see their data, then you can see any child.

>>: Okay because my state does not do blanket consent that I can share to any audiologists. It would have to be to that person to that person. I was just --

[Overlapping speakers]

>>: If the parent has consented to share it through KIDSNET, once the parent has consented to do so, they don't need to get individual consent each time.

>>: That is our time, everyone. We do have this luxury of backing up at against lunch break. If you are available you can speak to our presenters. Thank you.

(CONCLUDED AT 1:55 PM)