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EHDI

Mineral D/E – Block 1

Utilizing Regional Educational (Early Intervention) Audiology Providers to Increase Timely Diagnosis for Iowa Infants

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>> Hi, everyone. I'm Emily Nightengale, your room monitor. I left some evals out on the table, I'll be in the back, you can hand them to me.

>> We'll try to get through the slides pretty quickly since we only have 25 minutes. We can get to the meat and potatoes of the presentation. Our contact information will be at the end.

So... an overview of today's presentation, we'll talk through some of the objectives. The demographics for Iowa, infrastructure, data, pilot, outcomes, pros and cons.

Our objectives for today's presentation for you to be able to identify one success fall strategy using regional educational audiologists to improve timely diagnosis for kids.

We'll also learn what type of training and support is needed to set up a successful partnership between EHDI program and regional audiologists.

And also learn the benefits of collaborating with regional audiologists to improve timely diagnosis.

So a little about demographics for Iowa, we're a pretty rural state. The capital is Des Moines. We have about 3.1 million in the total population, about 99 counties and 72 hospitals. I don't think you can see it there at the bottom. Our birthrate is about 1 to 2% or 39,000 to 40,000 births a year. Iowa is considered, not surprisingly, an older than average state in the U.S.

We are a slow‑growing state, however... with our growth rate being about 12% from 2000 to 2010. We do see our share of young children has grown and now is comparable to the rest of the U.S. From 2000 to 2010, Iowa's total population grew 4.1% compared to 9.7% nationally. In that same period, the state's young children population grew 6.7%, compared to 4.8% nationally.

So, we do see that now, young children in Iowa do reflect that of the U.S., 6.6% compared to 6.5% nationally. We do see relatively slow growth and it's still projected to continue to be the same through 2020.

Iowa is becoming more diverse. We do see that the child population is leading the way in the state. All parts of Iowa are becoming more diverse and population growth among children, especially that of Hispanic descent is the sole driver of the population growth in that age group. In Iowa, young children zero to five. We do see single parenting and parental work involvement have risen dramatic click over the past decade. We see about, rose from the percent of thirds to ‑‑ single moms froze 7% to 34% from 1970 to 2010. We see that has grown quite a bit. We see that Iowa has one of the highest shares of young children with parents in the workforce. Three out of four parents working.

When we look at our Iowa EHDI program, we're located at the Iowa Department of Public Health and it's one of the three newborn screening programs at this state. We do have a pretty strong law and rules that requires reporting of, of children's hearing screens, rescreens and diagnostic assessments within six days of the test, for children, from birth to three.

However... we are upping the mandate. We're supported by HRSA and CDC grants and do receive a small amount of funding from partners such as title five. We have a total staff of two and a half. Tammy, myself, and another person.

We have quite a few hospitals. We are a two‑stage screening state and we see our refer rates, normally is around 5% and once they come back for the rescreening, drops to 1 to 2%.

For audiologists, those are young children, we see about 80 of them educational and private audiologists. Up to the age of three and... five providers have been added recently. Four of them being the regional educational audiologists that we'll talk to you about today. The regional educational audiologists are the ones that have been trained to be EDRs for the local communities they're serving. We do have an integrated data system through OZ Systems and we have a newborn hearing screening and dried blood spot screening, critical congenital hearsay disease and EHDI, all in one.

When we look at the data for about 40,000 births a year, we see that it's pretty comparable for the screening rate to that of nationally. We see about 98% average. First screening, we're pretty consistent for the good and the bad for diagnostic rate and also enrollment tutorial intervention.

We average about 2,000 kids that need follow‑up after their first screen and that drops down to about 500, that has, that don't pass their out‑patient hearing screen and the diagnostic assessment and then, in any given year, we average about 70 to 80 kids that are diagnosed with permanent hearing loss.

We do in‑house follow‑up. Myself, we average about six contacts per family. We do call centers that farm text calls to families. We track all those in an integrated web‑based system. We have seen that a lot of our efforts have improved loss to follow‑up rate, especially when we brought our follow‑up efforts into the department, previously was done by early intervention providers and then we brought them in‑house, about 2010, 2011 and we saw a big drop and it's continued to drop since then.

That puts you in the mind of what we're talking about when we're looking at providers and Tammy will talk about, now the pilot.

>> Tammy O'Hollearn: I'm here to talk to you about how we're using our educational audiologists in the state. As you can see, we have a large number of kids that need to be rescreened and then we also have, even though that number was set to 80 audiologists, there's only five or six diagnostics centers. That's not very many places. They're typically in highly populated areas and not in the rural communities.

So... you might be asking, what are educational audiologists in Iowa? They're typically referred to the area education agency or AEAs. They work with a variety of people, they do special education services, they do part C and BD and work with school districts and just a variety of folks to be able to provide services. They contract with OTPT, audiology, they have itinerant teachers, there's a variety of professionals that they contract with every year. To provide these services for children who qualify.

So... I wanted to give a little bit of background about how we got to this point. Because... I know tele‑audiology is a big deal and people are really trying to get that going and things like that. So... from 2010 to 2014, we actually tried to do tele‑audiology and in that area, that's highlighted above, that's a pretty rural area. People will have to cross over the border to be able to get an assessment or they have to drive two and a half hours in some cases, three hours, to be able to receive a diagnostic assessment, unless they crossed the border. We tried tele‑audiology there. On the other hand was our children with special Health Care needs, a nurse from that program. There were issues with connectivity at that time, because it's a rural area, you know... there weren't a lot of diagnostic assessments that need to be done and... it seemed like even though we communicated with the physicians in those areas and let them know this was available, a lot of kids weren't being referred.

So... it was definitely under‑utilized during that time. Even though, it was nice partnering with our children with special Health Care needs, but it just wasn't used. So... we needed to figure out a different way to be able to work with families and get them screened.

I will tell you, in the four years there, were 12 children, actually tested and... no children were found to have a hearing loss. One had a lot of transient issues, but there were only 12 children tested. So... we brought this back to our Advisory Committee. And... she loves to do this stuff. Yeah?

>> [Speaker off mic].

>> Tammy: Okay, so, in our state, typically what happens, they're screened at the hospital and we've really worked with our hospitals to bring them back and do the rescreen. Especially in rural communities and that kind of thing. However... the area education agency with audiologists, they used to work with a lot of the hospitals, they'd do a lot of rescreens. There wasn't a good tracking system, so... at that time, there wasn't ‑‑ it was hard to know which kids they screen, not screen, those kinds of things. Now... we've really kind of tried to twist their arms and... bring them back to do the rescreen and then also stressing the importance of it. We feel like parents are usually comfortable because they have their child there, happen to retell all their information to someone else at a different place, sometimes is a challenge.

They go back to the hospital, the majority of them, there's a couple that are still holding out to not bring them back. Does anybody else experience that?

So... the other thing, we wanted to make sure that kids were, that they were being ‑‑ that unsedated ABRs were being performed. We wanted to make sure that kids that were referred there and kids that had unsedated ABR, we could potentially use other resources.

Also, the Area Education Agencies, you'll see in upcoming slides, there are nine of them, across the state, and... so, they all employ audiologists on their staff. So... they, like I said, they do serve birth to 21. But... they are part C, part B, all those kinds of things.

So... they have done a variety of things. So... we talked to an Advisory Committee and... so we were trying to figure out what can we do to, you know... be able to get more kids in in a timely fashion. So... we came up with the idea of using the educational audiologists. We sent out information to them and they were thrilled. Some of them were really excited about the opportunity to be able to do this.

Now... training, they had ‑‑ I mean, all of them have been trained at one time to do ABRs but it'd been awhile for some of them. Training was definitely something that needed to be done.

So... we actually, our lead audiologist is a part of the University of Iowa and then another audiologist that we ‑‑ that provides technical assistance to our hospitals and audiologists across the state.

They actually provided the training to them. And then, were available for coaching. If they had a family in there and wanted to confirm the results they were seeing on forms were correct, they'd be able to communicate with them. Typically that communication was done through e‑mail or occasionally a phone call. But... typically the training just needs to be done up front and... after they get about eight, eight ABRs under their belts again, then they can back way off.

So... we did our first pilot in the spring of 2015. In the northwest AEA.

So... that's clear up in the northern part of the state where kids have to go to South Dakota sometimes to have a diagnostic assessment and... and it was also an area where kids were being lost for a variety of reasons. So... we went ahead, it was a seven‑month pilot. Trained, we trained initially just one of the audiologists and then she trained another one in there and they actually did it so they could tag team. And... stuff, when their schedules allowed.

We wanted to make sure it wasn't going to be something that would take away from their regular jobs, because... we knew, then, that'd become a problem and we probably wouldn't be able to spread this across the state.

Two children were identified with hearing loss right away. One had a mild unilateral loss and one with a moderate bilateral hearing loss. There were 13 children that had normal hearing, they didn't have to travel all that distance. Typically the AEAs are located in an area where there's usually no more than like a 30‑minute drive, maybe 40‑minute.

The equipment, they could ‑‑they typically they kept it in one place, but they had the ability to move it to another location if it was, transportation was an issue for families.

>> [Too far from mic].

>> So, initially there was funding through a grant. So... we had that equipment and we moved it to this area. So... that was one of the things we did. So... then, we decided, since it was very successful and I will say, the audiologists went out and met with a couple big hospitals that we have in that area and then, we also sent out communication to the smaller ones. They were thrilled to be able to send kids, locally, versus having to send them out‑of‑state and those kinds of things. That was another positive thing.

So... then the pilot was actually expanded. We received some funding ‑‑ the EHDI programs that were actually done to audiology at one point, HRSA sent out somebody in the fall and to those programs to expand on the tele‑audiology and do that kind of thing. I asked, actually for an exception kind of deal and said "here's what we're doing, we found this to be more successful," sent them the data and those kinds of things and I was able to, we were able to use that funding to purchase that equipment to train another place.

Actually, we trained another one and then they were trained in the fall and then we trained, we had a second pilot that was trained in the winter of 2016. So... and then we added two additional sites in May of 2017.

The one in the green, the one in the blue and the two pinks. So... those are parts of the state that are covered. If you see the one that's labelled ‑‑ and I know it's probably hard for you to see, you see the one labelled Heartland AEA? That's a greater population. AEA, Grant Wood AEA, the University of Iowa exists there. If you remember Keystone in the northeast area, we didn't have a lot of success there at the time. The Green Hills area is close to Boystown and Children's Hospital. A number of our kids are diagnosed by them. Although... that's an AEA excited to try this. If we figure out the funding stuff coming up.

Here's the outcomes from the pilot. You'll see... there were 40 kids that had normal or transient losses and were able to be managed than locally, we had 13 kids with bilateral, 5 with unilateral, we had two kids that were identified with auditory neuropathy. We had a couple that declined testing, which was fine. And then we had... three that were late onset and one that moved out‑of‑state. They scheduled an appointment, came, but needed additional testing. They were someone that lived in another state, we tried to make a referral for them.

There were 66 referrals during this time.

So... 12 of them, we don't have the timing for. But, for those that we do, nine were not shared by the educational audiologists before this time and then there were three late onset kids. That were determined ‑‑ we don't want to count those. For the 54 that we have the timing for, out of those, 42 were diagnosed under 90 days, but... if you actually look at the kids that were referred and maybe had one screen, we were up to 91%.

Which is, is huge for us. You saw the timing, we still struggle with getting them in for diagnostics in a timely manner and I think that because this pilot has been in the past ‑‑ we aren't going to see some of the fruits of this until our data comes out for 2017. And some of those kinds of things.

But... the issues that, was either the child needed to be retested for what, you know... obvious reasons ‑‑ or different reasons, or the family had cancelled and no‑showed and needed to be rescheduled. If you take out those things, 91% of those kids received timely diagnosis.

There was only one child that was actually lost in the pilot. Again, we had timely assessments, the families were served by a local provider and here's one thing that ‑‑ it's up there somewhere, one of the things is because they, the part C provider, how cool is that? The audiologist that diagnosed him could be potentially the audiologist that works with him through the part C program. Timely referrals for kids that are identified, which is another area that you saw, were at like 71%.

The travel time for families was reduced from one and a half to three hours down to about 30 minutes, which families were thrilled about. They were very excited that they had that option. Right now... the service is currently free of charge to the families and that's just partly because of the way the AEAs operate. They actually could bill and certainly, we want to encourage them to bill for that service.

So... if there's a normal result, they don't have to, you know... or if it's transient, they have providers in that area that can work with them on that.

The coaching and training was provided by the Pediatric audiologists and it didn't take very much of their time and... they said it was a really positive relationship and... the audiologists were great at communicating with them if they had questions and things like that.

The majority of the children were seen in less than 45 days. Let's see what else? I already talked to you about that.

So... lessons learned. The issue for us is sustainability, obviously. However... I will say that the one hospital up in northwest that piloted it at first, took the old equipment or the older equipment and... took it over there. They're at the point where they probably need to be looking at replacing equipment and they are in the process of writing a grant to be able to get that from some local entities. We also, were told by one of the other AEAs that does testing in one of areas that their local club is interested in providing resources, they purchased tools already, but are looking into purchasing equipment. A loft times the clubs are serving older adults and they're interested in actually expanding and doing more with children.

Let's see... one thing we learned. We needed to keep reminding people, the hospitals that this is available to them and they can refer kids. I would say that's the only thing. Most of them are excited about being able to refer them and they can call them and schedule appointments without having to have an order from a doctor. That's nice too.

So... are there questions? We stand between you and lunch.

>> [Speaker off mic].

>> So, she was asking about the type of testing being done. They... so, in the area ‑‑ so, depending on the area, they're able to be fit, because they have people that can actually do Pediatric hearing aids. In other areas they may go for another test or they may go there to be fit with hearing aids. It depends on the area.

>> I wonder, I know that sometimes because there's not a lot of kids identified, these educational audiologists have, maybe, some ‑‑ have you wondered about, when you get to that tipping point. What you're going to do. You identified these kids and now... all of a sudden, those educational audiologists ‑‑ their workload has increased because there's more kids to be seen. I'm not trying to point out a problem ‑‑ I'm just wondering what do you do with that tipping point?   
 >> One of the things in the northwest AEA, that was one of the things we were concerned about. We want to make sure the workload didn't increase a lot. And... one of the things we ‑‑ I serve on the Executive Council for Hearing Services in Iowa. I already presented on this once, I need to take back and present to them again. I think it's a good partnership because... they are getting kids, then, really quickly, for early intervention services. And... that's something they would be providing anyway.

>> It's basically a child find activity for early intervention.

>> But, the biggest thing we're looking at is to try to figure out the funding piece. We're also hopeful that one, if they'd bill, that'd help. Hopefully, the AEAs, if they see it as a, you know... a positive for them too, hopefully that's something they could build into their budgets. Just think about it, it might be another option for you. Thank you.  
[applause]

[Presentation concluded at 2:14 p.m. ET/12:14 p.m. CT].

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