March 19, 2018

Capitol 3 Block 3

5:35 P.M. MT

Unilateral Hearing Loss and Single‑Sided Deafness: A Specialized Developmental Monitoring System.

>> If those of you in the back want to come sit up front, if you can't see, that's fine. And we'll have to close the doors and not let people in.

And I think we'll go ahead and get started. My name is Marcia Taber and I'm a room monitor here. I love to accommodate everybody and get plenty forms for you. Our speakers today are going to be Karen Carpenter, and I'll let them take it way.

So thank you all for joining us today.

We will try to move things along rapidly enough so that after lunch and cookie break you don't just want will all want to fall asleep within the first two minutes. I said something yesterday I've been doing afternoon presentations that ‑‑ you know, there are a lot of cultures that believe in the concept of a siesta.

And I think there are days when I would really like that concept. So like I said, we'll try to move it along. I'm Dinah Beams. I'm the program coordinator for the Colorado Home Intervention Program.

I don't want to bore anyone but I also don't want to make assumptions.

So just to let you know in Colorado we have a statewide family centered in‑home early intervention program. In the outreach Department of Colorado School for the Deaf and blind. So I'm the program coordinator for that program.

In our state. Some of may know it from the acronym CHIP and some research that's come out by various people including (saying name) over many, many years with the CHIP program. I'm going to let my colleague introduce herself and take it away. You'll need a mic.

 >> KAREN CARPENTER: Karen Carpenter I'm Karen Carpenter and I'm the unilateral hearing loss coordinator for Colorado. That's all.

 >> DINAH BEAMS: So how many of are you from states where unilateral hearing loss is an established condition or the kiddos are categorically eligible for services? This is an area where we in Colorado envy you. You're going to find out what I mean by that statement as we move along.

So our learning objectives today we're hoping that you will gain from the information we share a little bit about the monitoring program that we have come up with in our state.

We're monitoring children with unilateral hearing loss. Want to digress just for a moment. I know in this field terminology changes often. It changes from one region to another. So we're going to be using the term "unilateral hearing loss" occasionally we may say something about single sided deafness so I know there are multiple terms but just to be clear we'll probably just stick with that term. I want you to be able to identify the key players in your state. You probably know who those people are. But you may not.

And then appropriate assessments for monitoring the progress in the areas of language and communication for these little ones.

So I feel like again just in this ability to give us all a little bit of context, these are our statistics from 2016 in the state of Colorado all the data from 2017 has not been crunched yet. As you know firm data takes a little while to pull all those numbers together. But we've held pretty steady 65, 66,000 births for quite a while in our state.

So right in there. You can see our screening rate is very good as other states have very successful newborn hearing programs and we have about 106 ‑‑ there were about 160 children we confirmed with permanent hearing loss either bilateral or unilateral in 2016 by two months of age

Okay.? So that's kind of here we are. I always laugh a little bit when I do presentations and as some state will say but you don't understand we're really a rural state.

You know, every state in this country virtually has those families that are not in a place where they can readily receive services. In our state, it's over the mountains and so, if we could go by helicopter, or if God had given me wings we could see these families very easily. But when you have to go over the mountain passes that close in the winter or due to rock slides as one of them did yesterday, that's a different story. But when I lived in North Carolina it was drive across this island, get on a ferry, drive across the next island, get on a ferry. So everybody has their rural challenges. We're kind of all in that together.

So in our Colorado system, as I said, children birth to 3 are referred typically into early intervention and that generally means into the Colorado Home Intervention Program. To one of the area coordinators.

I've already said that we're a statewide program through the outreach Department of School for the Deaf and blind. And we have this system a statewide regional coordinators, there are 8 of us who offer basically technical assistance to families. So we meet the families, get them started, so on and so forth.

A number of years ago we realized that we were all under water in terms of capacity with eight of us around the state trying to do all of this. And that's when any friend Karen stepped up to the plate and graciously agreed to partner with all of us and to become our coordinator for the children with unilateral hearing loss. And we are ever so grateful. So in Colorado, a number of years ago children with unilateral hearing loss were categorically eligible, were on our list of children with established conditions.

Our part C agency as they were reevaluating, who should be in that list of children with established conditions, and who should not, children with unilateral hearing loss were removed from that list. So those of us who had been operating with ‑‑ you know we can provide the service, direct services to all these families where all of a sudden what do we do now? We're really concerned about these kiddos how are we going to monitor them? We've always operated from this premise that the children would receive direct services just like the children with bilateral hearing loss oh, no. What do we do now. We were really concerned that children would fall through the cracks, now, the exception to that is if the child has another established condition, then if the child has Down's syndrome, we can definitely ‑‑ unilateral hearing loss, we can definitely get in there and serve that child and be put on that IF SP, but, if they don't have another established condition they cannot receive direct services in our state until there is a documented delay. Okay?

Well as we all know this documented delays typically don't show up until the child is quite a bit older than that two months of age when we were starting. When this change happened we kind of all did this ‑‑ they've done what? What has happened to our list? What do we do now? So we faced with a number of problems. How do we identify which of these children with unilateral hearing loss needs support and services and ‑‑ meaning direct services and which of them may be don't or are doing just fine. How do we establish a coordinated system of care and what does that system of care look like in light of this change and how do we avoid these children falling through the cracks. So with that in mind we came up with this collaborative monitoring program. We developed a statewide system for monitoring infants and toddlers with unilateral hearing loss. We developed it in 2010. So a number of years ago. Before we did this, we started off with a pilot program to really begin to look at a pilot study to try to get some data in our state when children were identified through newborn hearing screening with a unilateral hearing loss, what percentage of those children were demonstrating a delay at what point in time, what are the variable that were a part of that? You know, we were looking at if it was the right ear that was impacted, was that more significant than if it was left ear, did it depend on the degree of hearing loss? What exactly were we looking at to try to wrap our mind around it as we moved into this monitoring system that we established.

So we completed that pilot. We established Karen as our designated coordinator for this population. She's not going to brag about herself so I'm going to do it for her. Embarrass her before she comes up.

But like I said, Karen has been so helpful to all of us, she is an audiologist by training. So she brings that wreath of knowledge to that position and she's just been fabulous at answering families question, getting them hooked up to services. Really helping us to move this whole system along.

We share specific information and she's going to talk about what with share with these families part of it is the results of the pilot we did so families know there is a study behind what we're doing. With do assessments at established intervals. So there's absolutely, you know, it's not just operating from our gut but what do these assessment packets look like. She's going to talk about what those assessments look like as well.

We connect the families to hands and voices to the unilateral guy by your side in Colorado so that they have that kind of parent to parent connection. Which again has proved IP valuable to these families and we do tracking and data collection. That's an overview of what the system looks like and Karen is going to go into some of the specifics because I think sometimes the specifics are aware we can ‑‑ things are go awry. That can be really helpful to us.

 >> KAREN CARPENTER: Karen Carpenter as the unilateral hearing loss coordinator, I received my referrals mostly from audiologists. Using the diagnosing audiologist or the managing audiologist. Sometimes one and the same and sometimes from cohears when they get the first referral and then refer down to me.

I contact the family usually by email and I explain our program to them and ask if they would like to enroll at no charge, no cost to our families in Colorado. And I talked to them about the aspects of the program. We provide home visits if a family asks to be contacted in person.

If they have specific questions and often times I ought to refer that visit out to the cohear because the cohears are the ones with the real information about resources and what's available to the families.

We also have done home visits for families whose native language is other than English. Most were Spanish but I've also done home visits for Arabic, Nurada, a family who spoke that which is an Aztec derivative in Mexico.

And they had some basic Spanish as well.

And we found that when we made that personal contact. There's a bigger buy‑in from the families. They're much more willing to participate in the program because they had a chance to ask the questions and understand what it's really about. As part of the program I send out assessments at intervals from six months to 33 months. So there's five assessments total. Six months to almost three years.

Now the reason it's ‑‑ okay. we'll just two to that side and then I'll come back. The reason we have those intervals is because they're in accord with state standards.

For early intervention and when they perform their evaluation. So, if a referral comes from us to child find, which is what we have in Colorado, then we're on the same schedule for what's already been evaluated and what may need to be evaluated.

The assessments then are returned to the University of Colorado in boulder. They're scored and a summary is sent to the family.

And to me.

And to the regional cohear.

So, if we start to see a delay, one of us will make a decision to make a phone call and I'll call the family or cohear and then she may go ahead an contact the family to see if they need to move forward. An evaluation to qualify for services.

Also, as part of the initial conversation, and then what's included in the information they get flexibility, the ‑‑ we talk about the hand and voices. So they have a chance to become involved with those resources. Including the newsletter and the parent to parent connections.

Also that ‑‑ my job gets easier all the time because the pediatric audiologists are so good at introducing our program to the families either at the initial diagnostic visit or follow‑up visits and they say that if the family would like, I'll make a call and tell them more about the program.

So that by the time I call the family they're receptive.

And sometimes I get tips from the cohear as well. They'll say something like this family is eager to participate and they would welcome a call from you. Or there's a hesitation here they said they could call but they're not sure they want to participate at this point. Sometimes a namely will say not right now because we have other issues and challenges going on.

Call me back in six months.

And in thinking about this, over the years, over the 7 and a half years we've had this program, I would say that I've had an outright refusal about once a year. That's all. They just said no thanks, don't want to do it. Now that doesn't mean that they complete all of the assessments and return them. But they are a part of the program.

Child find of course which is the evaluation process that we go to them when we see a delay.

During the contact with the families and they say yes I'd like to participate, they say I'll send them information about unilateral hearing loss. And I have the packets. I had two sample packets up here, one in English and one in Spanish if you would like to come up and kind of rifle through it and see what we've got in there after the talk. A consent form for them to agree to the program and allure them that there's confidentiality and they can withdraw at any point and it doesn't commit them to anything. Tips for parents about unilateral hearing loss. Distance hearing, hearing and background noise.

Developmental milestones for auditory skills and for speech and language development.

There's also an article about middle ear infections.

The cause, the concerns. What to do about them.

As Dinah spoke about the unilateral hearing loss study that was conducted from CU in 2000 to 2002, there's the child find contact information.

So that if opportunity they want to make a direct contact, they can of course.

They could ask me about it. They could ask a regional cohear about it too to try to facilitate a visit. The cohear coordinator contact list so that has their information on the region in the state of Colorado and the pressures about hands and voices and more information about unilateral hearing loss and cohears.

We already did this one. Do you remember. I'm going to quiz you.

And the protocols we have ‑‑ it's an abbreviated assessment relative 20 what children with bilateral hearing loss get.

At the intervals. They can't inventory of skills. Are you familiar with these, some of you, all of you? Okay.

So those are ‑‑ that's a general development.

And we use that as a baseline for the next assessment which comes at 15 months. And from 15 months through 33 months, they will get one or the other inventories Minnesota child development inventory. You'll notice at 21 months they get both. And we have a note in there base asking the child to choose based on the inventory they're different for boys and girls. For boys it's above or below 50 uttered words and for girls above or below 70.

I think this is you, Dinah.

So as Karen has already said, the assessments are scored at CU, the summary of the results are sent and are shared with the coordinator with the families.

If the results show a delay in language and communication based on those assessments she just went over, then we are going to as a program, we're going to make a contact with family.

We are going assist the family on getting scheduled with a child find evaluation in their local community.

The cohear coordinator will then attend the child find evaluation with the family.

And if the child is determined to be eligible for services by the child find team, then at that point in time, an IFSP is written and CHIP directs services are begun.

It's kind of the whole protocol on how we work through that.

So, if the child is showing a delay, Karen then, since she's doing the monitoring refers the family back to the cohear coordinator for the region. And we then take up this whole process with the child find team, with the IFSP team. Ashed moving toward direct services. So this is just our experience, okay?

In our experience, these delays and communication, speech, language, are typically showing up between 21 and 27 months of age. Shouldn't come as very much of a surprise because before we had newborn hearing screening, how old were those children with bilateral hearing loss typically being diagnosed? It was when they had a delay that was evident to the parent, to the physicians and people started digging deeper.

So this really shouldn't be a surprise. Prior to that there's a lot of your child may be a late talker, don't worry, it's going to come around. It agency boys, got two older sisters, that wars the case with my brother. So there are a lot of reasons given but then as that child gets right around two years of age, it's like ugh, not so much. In case you were wondering how many different children do we have in a typical month in Colorado. So a typical month CHIP is 33 Four‑piece children in this slide. I just ran our stats for the month of March. It was 350. So somewhere around ha mark and at the time I ran these stats a couple months ago, 101 children unilateral hearing loss that we were monitoring or that we were following. 80 consult and 21 is direct service.

The other thing I will say to you since we started this monitoring program is that we have seen the referrals to the program go way way up. So when Karen started, we really did not have a lot of children with unilateral hearing loss being referred to us. And we have seen those numbers steadily grow to the point they are now which statistically, seems about right. What that says to me, our larger community, our other community partners be they in the medical arena or with part C are feeling like this monitoring program is working so they're pulling us into this discussion.

So of the cult in that instance would be a little ‑‑ would be this monitoring that children has done. We ‑‑ she has a system set up where she is in contact with those families on a fairly regular basis. Checking in with them, how's it going? Do you need additional help? Do you have additional questions? Do you need help with the assessment packet we just sent out. Those things. There are times she will contact one of the cohears and say this family really has a lot of questions about this. Can you go out and meet with them? So then it may change. Had there are times when the part C agency even though the child hasn't been deemed eligible for another reason, maybe the family is not ready for direct services from CHIP but the part C agency will pull us in as a cult for several visits to kind of talk through with them. About that.

We have our integrated data system. I know everyone has their data system they're working with.

And so Karen is unilateral coordinator inputs this data specific to the assessments.

What those outcomes look like on the assessments. Already contact with those families. That is all logged in our database as well. And then the cohears put in that information with children with bilateral hearing loss. For those of you who were administrators in the room, we can never get away without talking about money.

So the funding for this project is really a collaborative endeavor. The Colorado School for the Deaf and blind puts money toward it as does our HERSA universal newborn hearing screening and intervention grant. In our state, there is very little that we do that is not what I finally refer to as a patchwork quilt of funding.

Because it's like this person ‑‑ this agency we can put this much and this agency we can put this am and somehow we get there. It may not be the most streamlined process but we make it. And then we went ahead and put the references in the Power Point. For those assessments in case those are assessments that you're wanting to look at, these are the same assessments we use with our children in the program who have bilateral hearing loss. So I just thought some of you might want to know about those assessments.

We just have a couple of minutes. Are there any questions that we did not cover in this very rapid fire approach? Yes.

The question was how are we defining delay. These assessments are assessments that are normed on typically developing kiddos.

So, if the child ‑‑ when we do these communication assessments, if the child is showing up with a delay on those assessments, we then have that discussion with the family and it would be a significant delay.

So we would then have the discussion with the family that do you want to pursue an evaluation with your child find agency to see if your child actually is delayed enough to qualify for services

Okay.? For direct services. Yes.

 >> AUDIENCE MEMBER: I I'm not familiar with these assessments. I'm in the audiology realm and my PIP providers would be probably the ones that are doing these now. But are these all parent report or how are they administered to the namely? Are these questionnaires, these inventories ‑‑ how are they administered to the family? (off mic).

 >> DINAH BEAMS: So in case you didn't hear Karen, what she said is there are parent checklists so the parents do respond but we have normative data on them. They're available in English and Spanish and the MacArthurism has been normed on both populations.

>> I just always worry about underreport especially in unilateral cases, I feel like sometimes we ‑‑ not everybody but some of our parents that we work with kind of under‑‑ it's just sometimes I feel like they're not reporting as accurately as what we would like. Has that been an issue or do you feel like that's not really a concern at all?

 >> DINAH BEAMS: You know, we really haven't experienced that as an issue. But I do appreciate that caution.

And like I said, our stats pretty much flow with what you would expect in terms of the number of children that are being identified. So yes. Thank you.

 >> AUDIENCE MEMBER: I just a question. What percentage of your unilateral kids end up showing a delay? Because it sounds like your system works so well that part C is not going to pick up these kids again because you found a way to fund your monitoring program. And they're not showing a delay until almost transition time.

 >> DINAH BEAMS: Right. When we go back to that when the children are in direct service out of that 100 children, so we've got about 20% of them that are receiving direct service because they have demonstrated a delay. Again, some of those children have other issues. So your question is very true and you always ‑‑ I feel like in this field, we're always balancing things between how do we plug this hole to make it work so we don't have a gap and how do we let the chips fall a little bit so that someone else will realize there's a need here. It's a tricky one.

I think we've got one more question and then probably our time is up.

 >> AUDIENCE MEMBER: I you mentioned that the assessments the questionnaires are certainty out based on age.

And the five groups.

What standards are they based on? Are they from the state? Are they national standards or what?

 >> DINAH BEAMS: So the assessments that we're using are all ‑‑ they all have reliability and validity data. They're norms on typically developing children. So the Spanish MacArthur is normed on typically developing children in Mexico.

Because their vocabulary words, their early words are not quite the same as children in the U.S.

So they are ‑‑ vocabulary. The normative data is really solid but they're national and even internationally recognized assessments.

>> All right, we don't have time for any more questions but I'm sure Dinah and Karen will stay around and there's packets up here if you want to look at them. Thank you very much.

 >> DINAH BEAMS: Thank you, everyone.

(Applause)