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National Center for Hearing Assessment and Management - NCHAM
NCHAM-Family Perceptions and Experiences with the Early Hearing
Detection and Intervention System in Rural Communities

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>> This is once again an audio check for today's
webinar brought by National Center for Hearing Assessment
and Management at Utah State University. Today's
presentation is going to be provided by Dr. Matthew Bush.
Entitled Family Perceptions and Experiences with EHDI in
Rural Communities. For those of you who have just signed
on, you can go ahead and adjust the audio to your liking
on your own computer speakers or headsets.

If it is not to your liking and/or you are having any
disruptions in the service you might want to sign back
on. It looks like I have one person who is not receiving
our audio today. So I will make a if I can note here to
them.

[Pause]

>> Once again this is an audio check for today's
webinar.

I have posted the sign-up here for the people that are
not actually hearing what I am saying now. There are two
people.

A couple of you have indicated that the quality is
poor.

And again, I would -- because everyone else said it's
"good" or "excellent", that generally means it's on your
end. First check your computer speakers and see if you
just need to turn it up. The second would be to sign off

and come back on to see if you can establish a better connection.

And if you have any other further problems, there's technical support available. You see the phone number there on your screen and over to the left.

And last, but not least if for some reason the transmission today is not adequate. This will be recorded and posted on infanthearing.org. Never fear, you will be able to enjoy today's webinar one way or the other. So thank you, everybody for your feedback.

On our audio. I am glad that the majority of everybody is letting us know that it's fine.

I am going to turn on a little music here so you, you know you have retained contact with our audio system.

[♪Music♪]

Those of you who are hosts or presenters -- you will not hear it. It only goes through your computer speakers. We will be starting in just a couple of minutes today.

[♪Music♪]

[Waiting for webinar to begin]

[♪Music♪]

>> Once again, this is an audio check for today's webinar being brought to you by the National Center for Hearing Assessment and Management at Utah State University.

Matt are you ready to get started?

>> MATTHEW BUSH: Yes, sir, I am ready anytime.

>> Okay and Erica are you signed on and ready as well?

>> I am hi, there.

>> Hi. I am going to go ahead and initiate the recording of today's meeting. Just everybody sit tight for a moment.

[Pause]

>> OPERATOR: Audio recording for this has begun.

>> Thank you, everyone for joining us. This is one of our NCHAM webinars that helps to bring the national EHDI conference to our computers. Thank you so much for joining and welcome Dr. Bush he's currently a Assistant Professor of otolaryngology Head and Neck Surgery University of Kentucky. I had the pleasure of seeing his presentation at the National EHDI Conference last spring and he is here to present to us today little bit more on Family Perceptions and Experiences with EHDI in Rural Communities.

Thank you so much. And Dr. Bush?

>> And just let me just jump in for a minute --

>> WILL CHRISTENSON: This is Will from NCHAM. You will have an opportunity to address our presenter today through a Q&A field once presentation is complete that's not currently displayed. But when it's time to do that we will reveal that for you and have the remaining time for some questions and answers. Thank you.

Dr. Bush?

>> MATTHEW BUSH: Thank you, Erica and Will for this opportunity. It's really a privilege and an honor to be able to interact with you. Those of you that are involved in Infant hearing healthcare and advocates for Early Intervention and early diagnosis, I applaud you and I want to encourage you to keep up the good work. It is not -- though it may seem fruitless and thankless at times there are many who are benefiting greatly from your efforts.

So I am a bit of an anomaly within the field of EHDI. And within Infant Early Hearing Detection and Intervention -- managed hearing healthcare further down the line usually after a diagnosis has been obtained or perhaps after a child has been fitted with hearing aids and doesn't seem to find benefit from hearing aids and may indeed be a cochlear implant candidate. An otolaryngologist may become involved in the care of a child in that regard.

But as I have said I am a bit of an anomaly I am interested and engaged not only in the clinical aspect of things from birth and also the research side of things and I am really trying to straddle the fence and walk on both sides of the fence when it comes to what's going on in the research realm, as well as what goes on in the clinical world. What goes on in the clinical world. I want to present data that, I think, may be of benefit to you as we look at Family Perceptions and Experiences with EHDI in Rural Communities.

I will need some assistance in advancing to my next slide or to the first slide of my presentation.

Perfect. So by means of disclosure let me mention to you I am a surgical Advisory Board member for the MED-EL corporation, I am not personally reimbursed for my services, but do engage with the MED-EL Corporation. I have research funding that's provided through the National Institutes of Health, specifically the National Institute of Deafness and -- disorders and grateful for their support of our research through funding. And all the research I will present to you has been approved by

our institutional IRB as well as an IRB through our cabinet for Health and Human Services here in the Commonwealth of Kentucky. I am obviously preaching to the choir. Those of you that are listening, infant hearing loss is a national priority. We would all proclaim a hearty amen to that, but we know the United States preventative Services Task Force helps to bring some emphasis and focus what we all know to be a priority. And we all know and agree early identification of hearing loss leads to utilization of early intervention services. According to what we want to follow within our position statements, as well as from what the Joint Committee on Infant hearing as found is we want to make sure screening testing is completed by one month of age and all of diagnostic testing should be completed by 3 months of age.

If there is indeed hearing loss identified then treatment should be initiated no later than six months of age.

It's complicated. Obviously when we take guidelines and apply it to the real world problems and the real-world geography that we face within each of our states and each of our districts. I will tell you a little bit about our backwoods in our backyard, the University of Kentucky is poised just on the edge of the Appalachian region of the United States. Appalachia is not something that's just isolated to one state, but still a great frontier and involves a vast geographic region. This area was once Playground to Frontiersmen such as Davy Crockett and Boone. A lot of challenges area in great need now as we consider healthcare. Now the healthcare needs cover all types of healthcare whether heart disease or diabetes or head and neck cancer within the field of otolaryngology. But we feel and we have investigated this and see that those that are in the Appalachian region are at great risk and challenges to care and proceeding with timely engagement within the EHDI systems. Now much of Appalachia is a rural region, quite large geographic rural region that stretches from New York down to Mississippi. And 8% of the U.S. population reside within this Appalachian area certainly there are some urban centers and large city environments that are within this geographic Appalachian region, but the majority of the area just by landmass is primarily rural. And some of it being very rural.

Now some of the counties in Kentucky that are in Appalachia are some of the most economically depressed counties in the entire U.S.

So our Appalachian contribution in the State of Kentucky is one that's very rural and sees significant difficulties when it comes to healthcare and timely access of care.

Obviously, any the things we may discuss about children living in Appalachia may not be generalizable to your region, but I think as we begin to talk about some of these things and I share some of our data, I think you will see that you may face some similar difficulties and similar challenges, perhaps in some of the rural regions.

And even when one considers the rurality and the influence that rural life has on healthcare, there are other common themes, such as socioeconomic status or education, or perhaps insurance barriers, that may also be generalizable for those that may be in urban settings.

So I hope those of you in the big city or urban regions, don't tune me out, because I think there may be things that could be useful for perhaps the programs that you're involved in.

Based on some previous research that we have completed and had published here at the University of Kentucky we have found that rural children specifically, those that are in Appalachia are at risk for delayed diagnosis -- hearing loss diagnosed at 7 to 9 months of age Depends on the geographic region. Obviously delayed beyond our three-month diagnosis milestone.

Those that we have also looked at the data and found many of those in the rural region were amplified or may have received their hearing aids at an average age of about 1.7 years of age which obviously is way beyond the six-month timeframe.

And then what's been really concerning is that children that were in Appalachia born with general hearing loss, they are not acquired type of hearing loss, but born with hearing loss, were implant on average age of 4.5 year of age and this is really concerning that a child has gone 4 ½ years of life without sound and without the opportunity to have auditory development.

So based on that, we ask ourselves, what factors are at play with this disparity, this display that's going on? Not only the delay in diagnosis, but perhaps delay in treatment and even the delay in cochlear implantation. So the purpose of the study we have recently conducted is to assess parental knowledge and attitudes regarding

barriers in the diagnostic and therapeutic process following abnormal newborn hearing screen.

So the first study that I will share with you, this data is actually published in otology and neurotology in January 2015 and this was a pilot study that we utilized a questionnaire we developed with some colleagues that are engaged in our College of Public Health and do research within the rural Appalachian region.

And so what we wanted to do was focus on parents of children who had failed a newborn hearing screen during a three-year time block.

And with the identified 450 participants throughout the State of Kentucky, 117 of those participants were residing in rural Appalachia. What we wanted to assess were demographics as well as their experiences and barriers with the newborn hearing screening program and the follow-up in the EHDI system, as well as assess what their attitudes in general were towards Infant hearing loss. And then we wanted to compare the responses and the data from the Appalachian participants from the non-Appalachian participants. You will see on the first data slide there were differences that may be intuitive regarding the socioeconomic status, as well as even the -- concerns. We didn't specifically ask them the household income. But we did assess their insurance status and as you might expect, that those that were within the rural region of Appalachia shaded blue here there was a very high state insurance coverage with Medicaid provider compared with about 30% in the non-Appalachian counties, indeed a statistically big difference. Less than 12 years of education was nearly 35% in the Appalachian parents, compared with about 22% in the non-Appalachian participants.

Another thing that was really concerning is some questions that we asked -- data regarding questions we asked with awareness of newborn hearing screening results.

So shown on this slide here in this graph, you will see the differences between the Appalachian and non-Appalachian participants, when we asked the question, were you aware at any point in time in your child's hearing healthcare that they had failed a newborn hearing screen and interesting 17% of the participants from Appalachia never heard at any time their child failed a screening test. This was compared with about 3%, 3 ½% in

the non-Appalachian parents. Looking at this going from the right set of bars, you will see that the question next question we asked them was: Were you aware at the time of discharge from the hospital that your child had failed a newborn hearing screen and 14% of the Appalachian parents had to idea compared to about 7% in the non-appalachian parents. That represents a major red flag if you have 14% of parents that had no idea that their child failed a newborn hearing screen left the hospital how could you expect them to follow up or expect them to understand what to do it's asking way too much of a parent to figure it all out when, really, as a system or as a community we sort of are failing in certain scenarios in communicating the results in a timely manner in an understandable way.

The next slide represents a variety of different barriers that the participants identified and you will see that, really, one of those became quite an obvious difference between the Appalachian and non-appalachian parents. We found the parents from Appalachia reported that distance was a major problem for them. Make it either difficult or very difficult for them to proceed with outpatient diagnostic testing. Over 20% of those Appalachian parents reported distance being the main barrier.

Compared with about 7 ½% in the non-appalachia participants. Also just in general the Appalachian parents found was more difficult to go through the process of outpatient testing.

The next study that we'll talk about towards the end of the presentation will further elucidate and you will hear from even in the parent's own words what types difficulty they faced.

There's a variety of other noticeable barriers that, really, parents of either setting experienced, whether that was the lack of a primary care physician, reinforcing or supporting outpatient testing. About 10% of parents -- of both groups -- found that their physician represented a barrier for them to proceed with testing.

There may be other things such as trying to obtain an appropriate appointment, or insurance concerns, maybe responsibilities at home or responsibilities in the workplace may have prevented timely diagnostic testing.

Another question that we asked of all participants and we compared those that lived in a rural county, now this

may include parents that may not reside in Appalachian, but perhaps were in a rural county in either central or western Kentucky, Appalachian importance of Kentucky is in the Eastern part of our state and encompasses about 25% of Kentucky's population. But what we wanted to look at in this question was: How have you heard or aware of a cochlear implant?

And 45% of parents from a rural county have never heard of a cochlear implant compared with about 32% that live in a more urban or suburban county.

So there may be an additional aspect of awareness of hearing healthcare and treatment options for hearing loss as it pertains to children.

So another question we asked them was: What types ways might you be able to -- or would you be interested in, in accessing hearing healthcare? Would a closer center provide benefit? And obviously this question is related to that potential barrier that distance may play and you see this non-statistically significant trend that the Appalachian parents reported about 50% of them, reported that a closer center would make it easier for them to obtain timely hearing healthcare for their child compared with about 40% of non-Appalachia and we asked their willingness in engaging in telemedicine or tele-audiology within their community or more local or centralized location for them. And this was very promising and very interesting to the majority of Appalachian parents, about 55% of them were very, very interested in this type of option.

And perhaps less of an interest, or less of a need for some of the non-appalachian parents. So obviously a questionnaire study has biases and weakens. There may be a poor presentation of those who perhaps are transient. We find this sometimes in rural communities that families may change mailing addresses and may, depending on financial difficulties, that they may face, they may live with certain family members and they move to different locations, it may be difficult to get ahold of some of the rural participants sometimes for this type of research, whether it be a phone number. And if there's a lower level of education perhaps there may be a lower level of literacy that could potentially bias these research findings. As I mentioned at the offset, that there may be a lack of generalizability of this type of analysis regarding Appalachia, in comparison to with where you are. But I think some of these rural themes

are present in this questionnaire study and we'll further expand upon that.

So what we wanted to do to address this limitation, these limitations, that we conducted a second study to further identify and further tease out some of these barriers and some of these perceptions and experiences that these rural Appalachian families face in receiving hearing healthcare for their child.

So this second study in collaboration with our Cabinet for Health and Human Services and utilizing the Commission -- here in the State of Kentucky helps us administer -- our EHDI program. We work in conjunction with the Commission to be able to identify rural Appalachian clinics that have managed and cared for children who have failed newborn hearing screens. So using a centralized clinic that many, many parents throughout rural Kentucky Appalachian region access care in clinic we wanted to identify parents, guardians, whose children perhaps had experienced or were in the midst of different phases of the EHDI program. Came to the outpatient EHDI clinic to be able to get their diagnostic testing and subsequently passed their outpatient audiological testing.

Another group of parents we wanted to determine get some perceptions and some experiences of those who failed the newborn hearing screen when they followed up their child was diagnosed with hearing loss. In the outpatient setting. And those who had failed the newborn hearing screen and still were in the process of diagnostic testing. So it's sort of getting some different aspects and different time points within the EHDI Program.

So what we did is we conducted semi-structured telephone interviews with parents or guardians of children who had failed newborn hearing screen.

And what we wanted to assess were parental knowledge, attitudes and experiences as they progressed or as they were in the midst of the follow-up and diagnostic and/or even treatment for hearing loss.

And all of these interviews were recorded with the participant's permission.

And these interviews were transcribed and then underwent qualitative data analysis using -- coding analysis to identify these common themes within these issues.

So we identified 40 participants for this study.

And the overwhelming majority of the participants in this study were indeed mothers as you might expect, two

were fathers and 8 were grandmothers. We find that in the rural region of Appalachia that grandparents play a significant role -- and this may very well be true in your rural communities and networks that grandparents play a significant role in the healthcare, hearing healthcare of their grandchildren.

The ages range between 20 and 360 years of age -- 60 years of age and the hearing status of the children for these participants 29 of the children had passed outpatient testing they were referred on the newborn hearing screen and subsequently were diagnosed with normal hearing.

Two were still in the diagnostic process and nine of these participants' children or grandchildren were actually diagnosed with hearing loss and were receiving treatment for hearing loss.

I will show you a little bit about the demographics.

You will see here on the left of this slide, the counties that were represented and the participants, number of participants that were from those respective counties. And you will see here there's a variety of different Beale codes. Beale codes are USDA codes primarily population-based. Even though your county may have very sparse population in your county is adjacent to an urban county with a high population, it will give you a higher Beale Score, this is a 9, a code system that has nine different classifications.

It's not adjacent to a metro area. For the purposes of this study, any county that was 1, 2, or 3 would be considered an urban county. We have no urban counties within the Appalachian Region of Kentucky. Most of these counties are either considered rural sort of a 4, 5, or 6 on the Beale Code scale or very rural, which is a 7, 8, or 9.

Similar to the first study I presented to you, you will see the insurance status for the majority of these 40 interviewees --

-- completed high school education compared with other 50% who had gone beyond high school education.

What I will share with you are some of the results in the participants' own words about some of the barriers and it was very clear that the themes that came to the forefront were related to distance, financial stress as well as misinformation. And we'll share some of this data. This data is not published yet; it's -- we're

working on that right now and it should be hopefully published soon.

So 25 of the 40 participants really found that distance and transportation created major barriers and challenges.

One parent reports that it was just kind of out of the way. We had to drive an hour and so she would sleep the whole way then she wakes up and they can't do the test.

Obviously this parent is referring to a sleep-deprived audiologic test such as a ABR and having to travel a great distance and keep a child awake for that period of time was quite challenging and to have to reschedule the test just represented a great frustration for them.

Another parent reports it was better than going to Lexington, which is where the University of Kentucky is located. Lexington takes four hours and Hazard which is --

[No audio]

>> MATTHEW BUSH: More local town within Appalachian Kentucky. It's a big trip I will go with us. Many of you may understand this situation even within geographic region that may not be --

[No audio]

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>> MATTHEW BUSH: A long distance from as far as the crow may fly to use a Kentucky phrase, these rural roads may not be the easiest or the best route of transportation and may be difficult to traverse some distance on rural roads and it may indeed be a very big trip and sort of a family affair to be able to take loved ones to the doctor. At the time we didn't have a dependable vehicle. Another parent reports, the first one or two we didn't go to, we had to reschedule because of our car broke down.

The brakes just was bad on the car and we was afraid to put babies in it. Obviously using -- this is the participants' own words here and the grammar you see, but it just helps you to see that this is an issue that of perhaps reliable transportation, maybe relating to some of their socioeconomic status and the ability to handle rural road systems may not be the easiest thing to do.

Regarding financial barriers, a number of them of the participants reported different types of concerns whether it would be work or home responsibilities or insurance challenges or even a lack of funds to deal with this. One parent reports whenever you are a single parent you

don't always have the cash to work on stuff right away, and this particular phrase, is really an issue that we really need to consider when it comes to the recommendations. It makes sense to us and we know that the data says about Infant hearing and screening, they may see things that are not necessary. So it's our responsibility as a community that are engaged in Infant Hearing Healthcare to try to support families not only to educate them to maybe provide some assistance in different ways and there's certainly the sky is possibilities on us developing programs and methods to try to help those that have difficulty in helping themselves or helping their children. Another participant reports, sometimes it's hard to get the money to get down there. But you know like I said she is working now and the father just left them all so I am helping her. This is a grandmother reporting assistance of her daughter as well as their grandchild who is needing the diagnostic testing. So financial constraints is an issue for the extended family and not just the parents themselves.

Another participant reports: The audiologist had tried to get in contact with them, but they would never answer and she would keep leaving messages and then finally, after like two weeks, and she had already ordered them they still hadn't approved it yet is why it took so long. This participant is referring to obtaining hearing aids for their child that was diagnosed with hearing loss.

And so you see challenges of getting insurance or getting approval for hearing aids and obviously, audiologists being overwhelmed with, you know, the needs of children who are being fitted with hearing aids and trying to battle against the insurance companies to be able to get the hearing aids in a timely manner. It's really a frustrating problem on both sides of the clinic fence, if you will.

Another participant says, I tell what I had to do. I had to have a change, because the doctors up here they wouldn't take that no more. I had to change it to WellCare, which is a state Medicaid providers so this parent or this participant is bringing to the forefront that to be able to access care, may not be an issue of just the distance, but perhaps they just can't get the appointments because no one will take that particular form of insurance.

So that may place onus back on the parent to have to change insurance to be able to get coverage for their child to be then seen. That's awfully complicated and difficult. I would venture a guess if any one of us as participants those of you who may be listening, had to do that for your family, your child right now, it would be a major headache and it would certainly probably ruin the rest of your day to flip-flop and find the appropriate provider to meet a healthcare need.

Another participant reports if I had to take her to Lexington, maybe stay all night or something, I would have to have somebody watch the baby, because my husband worked in the coal mine so he couldn't watch her and go. Again, similar to another participant who reported a whole family venture to be able to get to a center or an area where diagnostic testing can be completed. This was a problem for this family to be able to family that needs and depends upon a father, a husband's income in this rural setting. And the difficulty in trying to navigate and get to a diagnostic center.

Let's talk a little bit about misinformation that can occur in the system. And a number of participants talked about they were just given wrong information and even reporting difficulties with their primary care physician or pediatrician. Similar to some of the findings that were in our questionnaire, published questionnaire study. One participant reported: So I thought, you know, they are all going to have the same programs. Well, they didn't. So it took us forever to get the number. It was just a big mess.

This participant is talking about getting some first steps or some early intervention services. And it may not be available in all communities or all centers.

And so trying to find in a rural community who can do what for what child is really a complicated process. But still there may be other that may be within a rural region, but maybe still a great distance away. Another participant reports: She went every two months. She never passed it which I didn't realize until the, you know, she was going on two years old. So sometimes there's challenges with getting accurate diagnostic information.

And a parent being confused and maybe not getting a clear picture that perhaps this ABR was not diagnostic today and we need to repeat this in "X" number of weeks. And this communication barrier or gap, represents a problem for many of those in rural areas. Another

participant reports his pediatrician never told me about First Steps, he's only about two or three months behind. If she would have told me then she was born to put him in therapy then he would have been in it for an extra four months. So even this participant realizes the importance of prompt diagnosis and treatment, but perhaps those that are in the medical community may not be providing the most up-to-date information. Perhaps this pediatrician may have known that this child was appropriate for Steps, but First Steps, but maybe didn't provide the assistance or the information to be able to meet this need and to enroll in child in a timely manner.

I dare not walk in the shoes of my colleagues that are in rural healthcare. Either pediatrician or primary care physicians. I will tell you being a provider in a largely rural state that they are overwhelmed and underpaid and thankless work for so many providers who are doing so much for their rural communities. So it's really quite challenging. We have published another study looking at physician perspectives when it comes to Infant Hearing Healthcare and many primary care physicians in rural communities feel overwhelmed and perhaps undertrained in being able to manage, or provide, timely advice for families who may need to go through the EHDI System. We certainly don't want to point fingers at primary care doctors, that they are doing everything wrong, no, they may be just doing all they can do with the time that they have.

Another provider or another participant reports. A lot of people don't take it that seriously. For example, I can go to Lexington and get my questions answered and be in and out, whereas I can sit in the waiting room in Somerset and still get nothing from it. So there perhaps may be some confusion about what's the appropriate next step for this participant when it comes to Infant Hearing Healthcare. This participant was expressing some frustration of. Another participant reports every time I had a concern she just played it off like I was a paranoid new parent. I think those of you engaged in this EHDI research or clinical care can understand this; that indeed, failed Infant Hearing Screens and the early diagnostic and treatment process raises the parent's or guardian's blood pressure and levels of anxiety and frustration, but we would all be concerned that that being concerned over legitimate healthcare need is an important one. And so we would be doing a great disservice if trying to assuage concern or anxiety over a

potential healthcare problem for a child and not be addressing that in a timely manner. This is certain a matter for addressing education on a local, regional and -- level with pediatricians and primary care providers, that Infant hearing loss matters and it makes a big difference and timely intervention and diagnosis is not only available throughout the U.S. and but we're ready and willing and able to come to their aid to support them and families. Obviously like the first study I presented this other study has inherent biases and weaknesses as well. Being an interview study it's possible that just culturally, some of the participants may not have been able to really pull off the gloves and really say what they felt or their and perhaps those who participated in this interview studies were getting more of the disgruntled or upset parents, but I think you can see parents are not necessarily upset or angry about transportation or distance barriers, but just using their own words to describe what life is like when you life in a rural community. Additionally there may be a portion representation of the families that couldn't be reached by telephone. We attempted to reach a number of other participants, but maybe the number was disconnected or we could not actually get in contact with some of those families. So that's another potential barrier to access this data. As I mentioned before this lack of generalizability of the result is something to take into consideration.

So what kind of things can we conclude from this data?

First of all, we can see that this lack of education and knowledge of Infant Healthcare, are significant concerns potentially within this population of Appalachian parents or guardians.

Additionally distance seems to be a very clear recurring theme to advanced hearing healthcare and that complicates the process.

Another thing we need to realize from this data is that personalized education, or correct information, and even Tele-Health avenues of delivering hearing healthcare --

[No audio]

>> MATTHEW BUSH: Could be important links to -- I am blessed in so many different ways --

[No audio]

[Audio cutting in and out]

[No audio]

[Lost connection to Adobe webinar], attempting to reconnect at this time [.

>> CAPTIONER: Unable to reconnect to Adobe at this time, continuing to try.

[Getting message that Adobe server is not responding]

...

>> Derek if you are on, can you help with displaying the Q&A field? I have been kicked off unfortunately and I am trying to get back on. Or Erica if you could look that as well?

>> Support families in follow-up, but also engaged in actually conducting subsequent hearing screenings.

[In Progress]

>> Can you make that available? Thanks.

Peer-reviewed journal. You can search my name on PubMed and identify that particular article, that's questionnaire data not the data that comes from the qualitative analysis from the interviewers that will hopefully be coming in the near future. Another question, what kind of outreach and assistance are the laypeople providing? Great question. As we might consider the role of community health workers or community health advisors or patient navigators we don't want them to be providing otolaryngologic testing providers to maintain the integrity and fidelity and quality getting quality testing accurate testing there may be a way for trained community health workers to be involved in automated testing that could be done in follow-up settings.

That's something that others have considered.

So that may be an option to consider down the road.

The main thing that navigators -- not only provide education, but helping to provide resources.

So where do you go? How can you go there? What types things might you expect? And we really don't have enough in the workforce of community health workers or advisors that are involved in Infant Hearing Healthcare. Diabetes and other types of chronic conditions yes, but not in Infant Hearing Healthcare. Another question that comes up is: Are children in Kentucky typically screened with Automated ABR or OE or combination of the two? If only offer -- to address -- great question. Let me do my best handle majority of it.

By far most of our birthing hospitals offer two-stage testing. And by far the majority of them do automated ABR testing.

So that's what is done here University of Kentucky. Two of my four children were born here and they both underwent automated ABR testing the screened modality. A small minority that utilize OE -- alone working to change -- we're seeing little higher fail rate with OAEs, certain an issue to be cautious of not combining the two or not utilizing moving more towards automated ABR as primary means of testing, more expensive, lots of challenges looking in the public and Statewide.

Let me move on try to get another couple questions here before our time is out. Another question is do you use the Mercy medical Angels transportation or children's special healthcare for travel assistance?

Great question. There is not a specific travel assistance program that's available within our state. Although some of the insurance carriers do provide some support there's some local foundations, but it tends to be on more of a.

[No audio]

>> MATTHEW BUSH: A local regional thing to try to provide -- parent and education. Great question there are some programs it's not something that's currently being utilized in Kentucky, but great idea again tying into what's already in the community, can we connect with what's already there? We have one last question let me hit this and then close up shop. I wonder if parents are afraid to face the new problems for their child with hearing loss. I think this is a great question. And I think it's something that needs to be further flushed out. The challenges of doing a phone interview are immense. And I think having now dabbled in a bit of focus research and face-to-face interviews of learning from what parents really experiencing and what they are feeling is important.

I think it's important as a clinician, it's important as a provider, I think it's personally important as a parent, of children myself to understand what families are going through. And I think the fear of the unknown and fear of what they may face is an issue. And probably isn't adequately assessed within our research methods yet, but thanks for the questions and comments. Really great opportunity for me personally to be involved with this and I appreciate your time and your attention.

[No audio]

>> Excellent presentation today. Everyone this presentation has been recorded and will be posted on

infanthearing.org, which is the NCHAM website. And we invite to you go there and to share it with others who might benefit from in really valuable information.

Dr. Bush thank you again.

>> MATTHEW BUSH: Thank you.

[End of File]

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