

AUCD

2014-02-26 15.01 Autism Spectrum Disorder in Children Who Are Deaf or Hard of Hearing

The broadcast is now starting. All attendees are in listen only mode.

Hello, and welcome to today's webinar, Autism Spectrum Disorder in Children Who Are Deaf or Hard of Hearing. My name is Meaghan McHugh. I'm a Program Manager at the Association of University Centers on Disabilities, or AUCD. I want to thank you all for joining us today, and for those of you not familiar with AUCD, the Association of University Centers on Disabilities is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. The AUCD network members consist of 67 university Centers of Excellence in Developmental Disabilities, 15 intellectual and developmental research centers, and 43 LEND programs, or Leadership Education in Neurodevelopmental and Related Disabilities. For more information on AUCD and its network, please visit our website at www.aucd.org.

Today's webinar is sponsored by the LEND Pediatric Audiology Training Program and is made possible through a cooperative agreement with AUCD and the Maternal and Child Health Bureau through HRSA.

Before I introduce our speakers, I want to review a few important details. First of all, this webinar is being recorded. An archive version with a written transcript will be available in three to five days at the AUCD website. If at any time during this webinar you experience technical difficulties, please contact rcarmen@aucd.org.

We are fortunate today to have a very diverse audience of several hundred participants, so unfortunately it is possible that we will not be able to get to all your questions within the hour. However, we will certainly do our best to answer as many as we can. Please submit your questions via the chat room at any time during the broadcast or through the survey you will receive at the end of the webinar.

Due to the overwhelming interest in this topic, AUCD and our speakers today are discussing the development of a webinar series. Please use the survey at the end of the presentation to share your thoughts on future presentations.

And now it is my pleasure to introduce our speakers for today. Dr. Susan Wiley is a LEND core faculty member in pediatrics and an adjunct Associate Professor in both the Division of Developmental and Behavioral Pediatrics and a secondary appointment in the Division of Otolaryngology – I always pronounce that word one wrong. She is also a Program Director for the Development and Behavioral Pediatric Fellowship Program at the Cincinnati Children's Hospital Medical Center. Her primary clinical and research interests are with children who are deaf and hard of hearing with additional disabilities. She collaborates with the Ear and Hearing Center, an interdisciplinary clinical model for children with newly-identified hearing loss.

Michael Scott is our second speaker and he is an auditory implant program coordinator at Cincinnati Children's Hospital. He coordinates a multidisciplinary team including professionals from speech pathology, developmental pediatrics, oral rehabilitation, ENT, social work and audiology. Clinically he works with children ages birth to 21 years providing diagnostic hearing evaluations, management of bone conduction implants and cochlear implants.

Dr. Wiley will begin our presentation. Dr. Wiley?

Thank you. I'd like to thank the Association of University Centers on Disabilities for hosting this webinar, and also thank Michael, my co-presenter, as he is an audiologist here who I personally seek out many times to help me figure out the best approach for children who are deaf and hard of hearing with additional developmental challenges. He has a lot of creativity and willingness to work with families and children where they're at, and so I'm sure you'll appreciate his input as well.

I am trying to move forward the slides and having a problem with that. There we go. Okay.

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So, when initially asked to do this webinar, the focus audience was audiologists participating in the Leadership Education in Neurodevelopmental and related Disabilities programs (LEND). We realize the group has expanded far beyond the field of audiology, but hope that these learning objectives are still relevant to those on the webinar. We hope you'll be able to describe the aspects of atypical development in children with a dual diagnosis, identify some communication strategies which can help children with a dual diagnosis, and gain an understanding of family perspectives.

With the successful implementation of universal newborn hearing screening, children who are deaf and hard of hearing are being diagnosed at earlier ages, optimally by three months of age. This has moved the language outcomes into the average range for those children who were effectively identified and received appropriate interventions for their needs. Now that we have less reason to blame struggles and language development on late identification, we should be striving for earlier identification of coexisting autism spectrum disorders. However, this is challenging for a number of reasons that we will discuss.

The reason the early identification of an ASD among children who are deaf and hard of hearing is important is that there are now two reasons for communication challenges, and unfortunately the expertise related to each of those reasons spans two separate educational fields, deaf education and special education and autism specialists. This lack of cross training and knowledge –

Dr. Wiley?

Yes?

I'm sorry. This is Meaghan. We're not seeing the slides move. Can you please make sure that you show your screen has been –

Okay. You know, that's where it hit pause so I don't know – is that –

Perfect.

Okay. My apologies. All right.

So, back to – the lack of cross training and knowledge can make it difficult to implement an effective intervention or communication strategies for children who are deaf and hard of hearing with an autism spectrum disorder. The setting in which a child is served may directly impact the communication approach which is suggested, the peer group for social skills development as well as the expertise of those working with the child.

I think I'm a little behind, then, aren't I? Sorry about that. So I think when I – here we go. Okay. My apologies to those.

So we recognize that about two to three per thousand children, per thousand children, are born with hearing loss, and six per thousand have a mild to profound loss by school age. It's been a little more challenging to determine the rate of an autism spectrum disorder among children who are deaf and hard of hearing. But the range which has been reported hovers around three to four percent. Rosenhall did a study of children with autism who also have a hearing loss and found that among children with autism, about eight percent have a mild to moderate hearing loss and 3.5% have a profound loss.

There are a number of challenges in identifying children with a dual diagnosis. We see a substantially older age of diagnosis among children who are deaf and hard of hearing. The literature suggests children receive the diagnosis between the ages of about three and 15 years, which is a pretty broad span. The comorbidities significantly impacts language development, however, there are a lack of validated evaluation tools and expertise to tease out the impact of hearing and the impact of communication disorders such as ASD. Many professionals who diagnose ASD do not have experience or knowledge of typical language development in children who are deaf and hard of hearing.

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Although it is best practice to use validated standardized tools with an interdisciplinary team when diagnosing ASD, there are no validated standardized assessment tools which can be applied to children who are deaf and hard of hearing. This leaves professionals deciding to diagnose children based on assumptions or through interpreting a child's performance on existing tools. With the current models of care, children may receive a diagnosis of ASD when they, in fact, don't have one. Or the alternative, they may not receive a diagnosis when they do exhibit characteristics of ASD. And, really, neither of those options are beneficial to the child and family. For children with a dual diagnosis, the management of hearing loss and communication disorder are complex and really need a multifaceted approach.

To review the core deficits of ASD, there are three main areas of impact: atypical communication, social interaction, and restrictive repetitive interests. DSM5 maintains three domains of impact, specifically difficulties in social emotional reciprocity, difficulties with nonverbal communicative behaviors used for social interaction, and also difficulties in developing and maintaining relationships.

Some of the challenges in DSM and the diagnosis of ASD is the diagnosis relies on a behavioral checklist of a child's difficulties, and therefore interpretation can impact reporting on specific behaviors. It's clear, though, that these difficulties don't just span delays but should be atypical communication social interaction. For example, children who are deaf and hard of hearing don't typically use echolalia in scripted language, and whether they are oral or signing, this should be viewed as a red flag for ASD.

While language delays can impact social interaction and play and social skills, these play skills and social skills should, at a minimum, be at similar levels as the child's language capabilities. So difficulties with nonverbal communication, social reciprocity and unusual and intense preoccupations are not typically seen in children who are deaf and hard of hearing.

So, what are the language needs among children who are deaf and hard of hearing? This question likely has a multitude of answers, but I've limited it to the big picture view for this presentation.

A deaf and hard of hearing child must divide attention, so they visually look for the communication information even if an auditory or oral approach is they may need to rely on lip reading and look back to what the speaker is talking about. Following that they have to retain this information in their memory, integrate it from the information to the activity, and really integrate that information to understand what is being talked about.

Many educators to deaf and deaf parents recognize this added processing burden and use strategies to insure they have the child's attention for key communication and allow time for them to shift focus from the activity back to the person conveying the information. I often liken this concept to a double jointed attention demand.

So if added language processing demand is present in children who are deaf and hard of hearing, then when might you suspect an ASD or atypical language learning pattern among children who are deaf and hard of hearing? Problems in pre-linguistic communication should always be red flagged for a possible autism spectrum disorder. Joint attention eye contact, requesting, showing, and turn taking and choice making should all occur at fairly young ages.

Another approach when looking at the quality of language development is evaluating the functions of language that the child is exhibiting. For example, many children with autism spectrum disorders tend to use language to demand and regulate the environment but may not use language as effectively at sharing information or clarifying misinformation and asking questions and so forth. Gaps in social understanding and reading gestures and nonverbal cues are also areas of concern which could indicate a possible ASD.

This chart describes the age at which the suspicion of ASD among hearing children should be considered based on a lack of skills, so we often see something that is not there rather than an obvious symptom. The majority of hearing children will give eye contact and respond to their names before eight months of

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age, and we're seeing pointing and gestures developing before 12 months of age with pretend play occurring by 18 months of age. Although these are critical items on the MCHAT and are useful in hearing children, similar concepts are applicable to deaf and hard of hearing children, as long as their language input and language modality is taken into consideration and that that actually meets their needs based on their degree of hearing loss and communication modality. Pretend play may be one area that could lag if language comprehension is also lagging, so those should be fairly commensurate.

Our research group at Cincinnati Children's sought to understand our own children seen within the developmental pediatrics group, so we reviewed charts of children seen in our division to understand the impact of degree of hearing loss and severity of ASD on the age of diagnosis of ASD and also reviewed communication strategies these children utilized. Among 24 children of varying degrees of hearing loss and severity of ASD, the median age of diagnosis of hearing loss was 14 months, with a range of one to 71 months, while the median age of diagnosis of Autism Spectrum Disorder was 66.5 months and a range of 33 to 106 months.

This graph describes the age of diagnosis of ASD as well as hearing loss, by ASD label and degree of hearing loss. So in this graph, the X axis on the left shows the age of diagnosis in months while the Y axis at the bottom describes the degree of hearing loss and autism label. The blue circles describe the age of diagnosis of hearing loss while the triangles indicate the age of ASD diagnosis.

As you can see, among children with severe to profound hearing loss, their age of hearing loss identification is relatively young irrespective of their label of an autism spectrum. So both autism and PDD had a relatively young age of diagnosis of their hearing loss. With children with mild and unilateral, their age of hearing loss was a little bit later, as would often be expected. And the other difference between the two groups would be the age of diagnosis of an autism spectrum was younger than PDD-NOS or *Pervasive Developmental Disorder- Not Otherwise Specified*. That's also somewhat anticipated as that occurs within the hearing population as well. What is interesting to note is children with mild to moderate or unilateral hearing loss have a shorter duration between their age of identification of hearing loss to their diagnosis of an autism spectrum disorder.

In our group, the earlier age of autism diagnosis was linked to more severe degrees of hearing loss and a greater severity of ASD symptoms. The age of diagnosis was not correlated with ideology of hearing loss or amplification.

We also looked at communication modality by the entire group, those with autism, those with PDD-NOS. So on the X axis on the left, we see the percentage of children in each category described, and on the Y axis at the bottom, the communication strategy is described. The blue bar represents the entire group, the red bar represents autism, and the green bar represents PDD-NOS.

It's helpful to recognize that the children with the dual diagnosis span multiple communication modalities and strategies including oral communication and sign language. However, there are a number of children who also relied on behaviors and augmentative communication strategies, such as picture exchange communication or technology, in order to build up their communication capabilities. So it's really important to think about how we explore effective communication strategies and building the communication foundation for children with a dual diagnosis.

In further analysis, improved communication was correlated with higher non-verbal cognitive quotient and lesser severity of ASD than less severe hearing loss. Interestingly, the age of diagnosis of hearing loss did not correlate with language outcomes, and this is likely due to the impact of ASD and interventions targeted for the communication disorder.

I'm going to hand this over to Michael, and I need to give him the mouse and keyboard. Oh. Thank you for your patience in that transition.

Okay. Do I have control over this yet? I do.

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So I get the opportunity to discuss some of the clinical, practical hints and tips that might be applied for both diagnosing and managing kids who have ASD. And I'm really going to try to address some of the challenges that we might face even getting to that point, but in doing so, I want us to all keep in mind what we're going to use as our definition for success. Of course success can be defined in a multitude of different ways, and aside from describing imminence; I think we should focus on how we want to define success for the patient and how the parents will define success for their child. And deciding whether or not these match up, and if they don't, then what do we do about that.

So some issues to consider have already been described to some detail by Dr. Wiley. Really the fact that some disabilities aren't even easily identified early on is something to be very aware of. And it can go both directions. Not only diagnosing hearing loss but diagnosing other disabilities can certainly impact each other. Despite the best efforts of many professionals, it is difficult to diagnose those learning disabilities at a young age, so we may not even have them realized until they are much older.

Special populations in general. Forty or 50% of children with hearing loss are going to have an additional disability. That is the large grouping, not just ASD. But we know that earlier intervention is certainly going to be more beneficial for these kids. So we certainly need to be aware of this as a possible impact on our diagnosis. Disabilities such as autism in particular may not be identified until the child is at least two to four years of age. And realistic expectations is what it all boils down to. Making sure that we have expectations understood by both the family and everyone else the child is going to work with, from school to healthcare professionals.

So to address some challenges. Audiologists certainly face challenges of their own if they're not comfortable working with children who have other involvements. Perhaps they just aren't exposed or don't have a patient population that's large enough to get to work with kids who have multiple disabilities, in particular ASD. They may not realize a child's full potential, so what can that child really do, what are they really capable of, until they've had a lengthy opportunity to work with that child and family. And then providing education to caregivers. If we aren't as knowledgeable as we need to be about the subject area, then how are we to educate those that are taking care of the child on those appropriate expectations

In diagnosis, earlier, of course, is always better, but we are sometimes confounded by other medical issues that sometimes take priority, and that is entirely appropriate in many circumstances. The parents, of course, may be overwhelmed not just by a hearing loss diagnosis, but other diagnoses as well. And hearing loss, as we all know, is not a physical disorder, so we can't just look at the child and say, oh, they're behaving this way, or they have such-and-such going on with an extremity. The child may, of course, be difficult to test, as is often the case, and there may be additional concerns for sedation if we're going to try to go down that path for getting objective evaluation for hearing.

Hmm. I seem to have lost control. Susan, it appears that you may have control? Are you – there we go.

So other diagnoses challenges. We may be so focused on the hearing loss as practitioners, hearing practitioners, that this could delay other diagnoses. The parents may also be so focused on the hearing loss that we ignore other signs and symptoms for ASD or other speech and language impairments. Something to just kind of keep tucked in the back of our heads as we manage these patients.

We also need to look beyond auditory behaviors and know when to refer for other services such as developmental pediatrics, OT or speech therapy, as they can both guide us in the diagnosis and allow us to parse out hearing versus other issues.

So some amplification challenges, of course, with late ID comes late intervention. We may have inconsistent test results that also lead us to that late intervention. Again, those medical issues may take priority, not only over the diagnosis but over even keeping hearing aids or cochlear implants on. I'm more worried about getting that autism diagnosis than getting the hearing aids on my child. It is yet another piece of equipment, so if we have other pieces of communication equipment, such as boards and so forth, then that's just one more thing to deal with if we're talking hearing aids or cochlear implants.

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And then some kids are going to show you signs of sensory integration issues with use of the devices. Is it that they don't like what they're hearing? Is it that they don't like what they're wearing? And then how do we determine how they are benefitting from the use of that device if they are so resistant?

When it comes to evaluation, both before and after identification, we may not be able to use traditional hearing test measures or methods. So we might not get very consistent test results. And as many of you probably, in the audience, know, objective measures aren't also the way to go. The gold standard, of course, is the behavioral responsiveness of the child in the booth, and quite frankly in the real world. But the child may not be interested in performing traditional tests with traditional stimuli. So you may have to keep in mind other ways of kind of mixing it up, and I'll bring those up in future slides.

If we don't get ear-specific information, we could miss unilateral hearing loss, and there are plenty of studies that demonstrate that even unilateral hearing loss can have a significant impact on a child's ability to perform in school, may be held back a grade. And then, certainly, if you're adding this to another diagnosis such as ASD, then this may be further confounding.

Neurologic insults and ASD can certainly result in, or cause, abnormal AB audio results, so that would be an objective measure that you wouldn't necessarily always be able to rely on, but it's still a good tool.

I'm not sure how I can advance the next slide. I appear to be stuck again. I apologize.

So in evaluating these children, we need to evaluate for communication ability, not just hearing sensitivity. We need to evaluate the child for what they're doing in the real world. What is it that they are able to do to show us that they're hearing or have an improved communication ability? So we need to ask ourselves, does the child make use of the information that he receives from his other sensory modalities, from vision to touch, and how do they use that information? Could we use that information to help us either with diagnosis or management? Some examples are coming up in future slides if I can get to them.

I want to talk about going beyond audiograms and speech perception measures. Whoever is in control, if they could advance a couple more slides. Just some things to ponder. Is there other information that could be considered for closer analysis, so hearing thresholds don't mean the world. We don't talk in beeps and buzzes. And we certainly talk at a constant level in a noise-controlled room, such as a test booth. So what happens when you get outside of that appointment? That's important feedback to get back from the parents. And educators. It could be, also, that we're getting this information without evaluating – truly evaluating – its value. The parents may come in and tell us, oh, Johnny is able now to do this and this and this. Isn't that wonderful. Since he got his hearing aids he's now much more social. Those could be factors that define success as opposed just to just hearing thresholds.

So some management tips and tricks. These are things that are not necessarily grounded in any research that I've done, but simply experience after getting to work with these kids and letting them, quite frankly, teach me, parents teach me every time I see the child, on their specific child, but then I also kind of come away with ideas or thoughts about what to do for the next session.

You really do – I know this might not be practical in your typical clinical situation – but you have to take time to get to know the child. You may only have an hour scheduled, but it may take a couple of hours just to get and understand what pushes that kid's buttons. So I adjust a little bit by saying you have to follow the child around through the clinic for an hour or so, but quite frankly, I've done that because it was necessary. Thinking about letting the child show you what they're interested in or what they're comfortable with is certainly going to be much more advantageous for you in the long run than sitting them down and saying, okay, well we need to do this test this way because this is the way we do it.

It might be very beneficial to involve an established party, so if there's a therapist or a child life specialist, a teacher, of course the parents, they may be able to give you a little bit more guidance on the things that will or will not work for that particular child. Everyone is definitely going to be unique.

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Thinking about the timing of your day and the child's day might be very helpful in trying to figure out what's going to help the child stay on task. So earlier in the day might be better just because they're fresher, more awake. Or maybe later on in the afternoon is better because they've had time to get through the routine of their day and taking them out of that routine is going to throw them for a loop.

So thinking about new games, ways to make the evaluation and treatment process fun for the kid might be the way to go. I know that we in audiology always stick with our ball-in-the-bucket routine, and that certainly isn't going to cut it for every child. These days children are exposed to so many different games and so much input and stimuli, you might have to think about a new way to get the child to do what it is that you want. Over on the right-hand side of the screen there you can see something that I've borrowed from the audiologists at Boys Town. They use this as a way to get the child to believe that they're getting the little doggy to their bowl through the maze. Every time they hear a beep, they push a bit button and the audiologist is really in control of the game, but it certainly gets them to remain motivated and sometimes more focused than just the ball-in-the-bucket game. Gotta be flexible in all of this.

You do have to have a variety of toys simply for the reason of having the flexibility, but also more so for some of the kids who come in with tactile issues. In our clinic we have these little stars that the child gets to put in the bucket and it has a lot of different motion and texture to it, so perhaps that's not going to work for you because the child is defensive to the ridges that are on the side.

You also have to think about potential distracters. I had a child who had autism and was obsessed with words and numbers and letters. So I had to make sure before I saw him that every time he was going to come into the booth, I had to make sure that every last piece of writing was taken down. May have to think about lighting issues. Perhaps it's going to be too much, too little. Having a dimmer switch is certainly advantageous. And then think about to where you're trying to get the child to remain. So a chair that has a nice good footrest, keeping the feet planted might be helpful for getting the child to feel grounded. But then there are some children who seem to need that movement in order to stay focused and not (inaudible), so a chair that swivels or spins could be helpful. Of course, keeping control of that chair might be a challenge.

There are children who, I'm calling it environmental responsiveness. I guess kind of my term. Have not read that anywhere, necessarily, but I've learned that there are some children who will perform one way in one environment, for example, their therapy session, versus the same way or different way in my environment. So perhaps for managing that child you have to go to where they are, or go to where they are going to be most comfortable. The picture of the elevators is somewhat of a joke, but thinking outside the boxes here, I do have a patient who, again, is obsessed with elevators, so it maybe wouldn't be a bad idea to go to where they're most interested. Or perhaps that would be something more distracting because they are so obsessed with it. Just kind of feeling that out and, again, thinking outside, or perhaps inside the box is going to be key.

So sensory integration issues don't only come up with materials that you use during your testing, but also for your intervention with hearing aids or cochlear implants. It is going to be very difficult to get the child who is tactilely defensive to keep hearing aids on. For one, it's a new thing, and so it's something to not only resist but to explore. So being as encouraging as you possibly can to the parents is going to help them be more successful, or feel more successful, and then, of course, instill that success in their child. And you may have to consider working closely with occupational therapy. I have done this with many, many, many of my patients, just getting them used to keeping the device on and being persistent.

So other management tips and tricks for the device. When it comes to cochlear implants, perhaps you need to make a goal that is a little bit lower and just doing that of keeping the coil on as opposed to getting the whole processor on. The whole processor doesn't have to be on. It's okay to just have the coil on until we can get the child a little bit more used to that sensation, that feeling. Perhaps we need to think about doing this without auditory stimulation until we have the child comfortable enough with wearing the device. So put the hearing aid on without batteries. It may seem very strange, but, obviously, they're not going to hear anything if they don't get the hearing aid at least on their person. Taking those baby steps and building upon small successes is going to get you a lot further in the long run.

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You do have to have active involvement of the parents and other providers, clinicians and so forth. But perhaps consider involving the child more than you typically would. It may seem kind of odd just showing the child this is what the program looks like for your hearing aids. Or this is what I'm looking at when I'm doing my cochlear input programming. But that might help them feel connected with what it is that is happening to them. I think too often we sometimes approach this as I know what the prescription should be and here it is, as opposed to involving the child in what the prescription might end up becoming. Of course, I would not hand them the mouse and keyboard, but sometimes it takes showing the child and making them aware of that connection between what they hear and see to garner that success.

So during programming, we do have those objective measures that we all have to keep in our back pockets for making sure the hearing aids, the bone connection devices, cochlear implants, they are all fit appropriately. We do have real ear measures, for example, with the hearing aids and objective measure such as to Auditory Brainstem Response or ABRs that we can run through the cochlear implants to verify its fit and function. But that's certainly not the end all, be all. In the real world you do have to make sure the patient is tolerating the stimulus that you're providing them with and the change that you want to make to the device in the future.

Subjectively, really observing the patient, watching for what it is that they are doing when you do make a change, is going to help you make further adjustments in the future.

Loudness scaling really is not done, I don't think, by as many clinicians or audiologists as could be, or perhaps should be, simply because, again, we don't know what the child's skill level might be. But the kids might surprise you. They might be able to turn it into a game themselves which allows you to get that additional information.

So then the determination of benefit. Again, we have to go beyond what we're able to do at the audiometer and think about even when we do need to use the audiometer mixing it up, using different voices. Perhaps bringing the parents into the tester side of the test booth, for example, and using their voices as opposed to your own would be more helpful for getting the child's response.

There are functional outcome measures that we should be using more often. There are plenty of them out there. The advantages of having these available to us is that we don't have to have the child responding to us or with us right then and there. We get the information from the parents or from the educators who get to spend more time. The Linksys sound test is certainly very, very beneficial. Very auditory. Shows us the complete spectrum of how the child hopefully is able to respond. And some kids will respond to link sound before they'll respond to sounds in the test booth, or even speech.

Observing the child during programming, during testing. Learning, again, what it is that they are willing and able to show you during the test measures is going to help guide you on your next ventures, which I will - .

So this is just a quote that I wanted to leave everyone with. It's in many of my presentations. And it's just pointing out the fact that all the children develop auditory skills not quite as quickly as other children. Skills may still be able to be improved given the fact that you are providing them with a connectedness to the environment that they may not otherwise have.

So, Mike, there were two questions during your section. One is, what is ABR, and what is ANSD? If you could spend a little time explaining those letters.

Sure. An ABR is an auditory brainstem response. It is a way for us to evaluate how a child hears, either while they're sleeping or while they are sedated. And it gives us a good representation of how well the child might be able to hear, but it only gives us responsiveness up to the level of the brain stem. Unfortunately it isn't going to tell us anything about how the child can function or what they do with the information at the higher levels of the cortex.

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For ANSD, that is an abbreviation for Auditory Neural Spectrum Disorder, and that is a type of hearing loss that has a particular definition that is not necessarily sensory neural in nature, and those children have a wide spectrum of how well they are going to do with treatment, either with hearing aids or cochlear implants.

Great. Thanks. And there was also a question about what is PDD-NOS, and I will apologize that there's old lingo and new lingo. The new lingo by DSM5 pretty much collapses all subcategories of autism into Autism Spectrum Disorder. The prior categorization included autism and pervasive developmental disorder not otherwise specified, which is a milder degree of autism symptomatology. So children have similar characteristics but maybe not as many in each category.

So we'll move on to the final section and hope that you're thinking about questions to throw into the Chat box.

This next session is really going to be talking more about some focus group information we've obtained from professionals and families. So we really wanted to explore the needs of children with dual diagnosis through two focus groups, one with professionals and one with families. For the professional group, we wanted to understand the involvement of professionals who work with children with dual diagnosis. We had 15 participants spanning the field of deaf education and autism, and invited participants that all known to have been working – having working experience which involved the dual diagnosis. And we explored a number of topics, identifying useful tools, appropriate educational options for children with a dual diagnosis, how teams and families choose educational settings, how professionals work collaboratively on the team, and what an ideal program would look like. Themes which arose from this discussion included aspects of educational settings, partnerships between medical and educational systems, the importance of family education, and the role of ASL interpreters within the school and medical settings.

Within the educational setting, it was clear that the educational setting needs to take into consideration the child's unique needs and was really seen as more child dependent. People mentioned that focusing on the greatest need at the time may guide a more appropriate educational setting and children may require many different resources and providers. And these things may change over time as well.

The group also discussed the importance of building peer communication, and this prompted discussions around inclusion of children with ASD into deaf education programs to facilitate peer-to-peer communication.

There was a notable effectiveness described by the professionals around the use of visual supports and tactile and hands-on experiential learning for children with a dual diagnosis.

The participants also recognized there needs to be better collaboration between medical, therapeutic and educational settings.

Within the area of medical and educational teamwork, there was a desire for better cross-discipline training, each group, those in the office realm and those in the deaf education realm, saw a need for greater knowledge from the other group. If the broad team had an understanding across disciplines, a united perspective could be provided to families. Children were also noted to perform differently in different settings, and with improved communication between the settings, and the whole team understanding a child's unique needs and strengths, this would more likely allow to build an effective program and plan ahead.

There were challenges noted in the desire for improved communication across settings. Barriers such as methods used for communication, identifying specific content which should be included in the communication, and lack of dedicated time for communication were identified. There was also a desire by the group to provide stronger educational materials for families, specifically targeting improved understanding of the basics and foundations of communication. This spans both the impact of hearing

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loss and ASD on a child's communication development. The group hoped that by providing improved information and education to families, families could then be better consumers of health and educational information. This strategy was felt to potentially encourage families to perform as equal members of the team.

There was a lot of discussion around the role of the interpreter within educational medical settings. Some of this discussion stemmed around the unique communication needs of children with a dual diagnosis. Those who use sign language may have idiosyncratic signs, as well as need information presented in a manner that the child can more effectively process. If a child has idiosyncratic signs, a new provider or interpreter might not recognize the communication that was occurring.

On the other side, if an interpreter presents the information to the child in a way they can process it, this may be different than a testing protocol, and therefore the integrity of testing might be impacted. It was thought that if an educational interpreter could attend medical appointments, this would be the best opportunity to allow access to communication for the child with the dual diagnosis.

Another stream of discussion involved the role of an interpreter at IEP meetings. Often interpreters felt that they were there as a way to be able to allow communication access for the child within an IEP meeting but not viewed as key members of the team with unique knowledge about a child's communication abilities, which could really impact, and positively impact, and guide program planning.

We also completed a focus group of families to understand their experiences. Although we recruited widely and had child care and dinner available, we only had three participating families. The children ranged in their severity of hearing loss and severity of ASD. They also varied in their communication mode and educational settings from anywhere from mainstream to autism classrooms. Children have experienced a multitude of prior educational placement, such as schools for the deaf or special needs preschools. They also had quite varying communication capabilities, but all of them relied on visual schedules to help support their understanding, and families thought this was a very helpful communication strategy.

The group discussed experiences during diagnosis, impact of the dual diagnosis on the family, resources they found useful, and items for a wish list. And the responses fell within some themes of family impact, social skill development, and academic considerations.

There was a very strong emphasis on the development of functional skills. Families indicated difficulties between balance social skills development and academic performance. One family specifically said at some point I'm going to look at him and say it doesn't matter to me if you know your multiplication table, I can't take you anywhere, I can't take you to the grocery store.

They also indicated challenges accessing social groups as many opportunities for social skill development were not geographically close to their home neighborhood and competing demands with an already busy schedule impeded their drive to these resources.

In general, parents were very happy with the services their child received in schools. They saw this as a high area of good resource. But they were worried about the impact on funding cuts, such as if school levies don't pass and what that might mean for their child's programming.

And although they appreciated that many of their children could access extended school year services, the structure of this program did not fit the child's needs for a more consistent routine and schedule. So it looked different enough from the academic year's schedule that it was not as effective as they thought it could be.

Families definitely wanted better training for professionals so that people working with their children were proficient in knowledge of both hearing loss and ASD.

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When asked about resources, families uniformly indicated schools were their main source of information and support. They indicated that strong communication from their child's teacher allowed them to support their child's development at home. In fact, one family member said it all depends on your teacher. We used to get materials to bring home that we could work on with her on vacations and breaks but now we're not getting that. So they noted a big difference from year to year.

Families also identified visual schedules as important to their child and family. And the internet was another consistent resource used by all families participating. The internet helped them learn more about strategies to help their child, network with other families, and connect with professionals for guidance on specific problems.

Their main wish list that they had was to have a desire to observe their child's outpatient clinical therapy so they could try things at home and also have available someone with knowledge in both domains of autism and hearing loss so that they could contact them, email, call, whatever, with questions they had.

So we've learned that families want more information, and both professionals and families view better education of medical and educational professionals as a priority and that communication across all of these folks is key.

As we complete our webinar, we leave you with some closing thoughts for serving children who are deaf and hard of hearing with an autism spectrum disorder.

Having a strong foundation of collaboration among professionals and families is essential.

Being creative by thinking from the perspective of the child. Being willing to adapt strategies and try new things can open up new avenues of support for a child with a dual diagnosis. And we also might want to begin considering how to define and build the peer groups for expanded social skill development for this group of children.

The remainder of the slides are mostly resources and references to guide your next learning. Some of these are easily downloadable and others are a little bit harder to capture. Get on a hospital listserve or something. But we really did try to expand some of the other resources and knowledge. And we'd like to thank you for your participation and look to see what questions we may have from the group that could spend the next five to ten minutes talking about.

Thank you, Dr. Wiley. Yes, we do have some great questions here. The first question actually was regarding the PowerPoint presentation. It is currently available on the webinar event page at the aucd.org website, and I will also be including it with the archived recorded version. So you will be able to get that online.

Another question is, have you seen any research with ASD when using different sign language systems? Specifically sign the exact English versus ASL?

So I have not – the main research I have seen is really limited. So sometimes you'll see a case report on picture exchange communication system. And it's one kid, and we tried it, and here's what happened. I've not seen good literature, and maybe I'm missing something in the educational field, but there's – I've really not seen much on that. I think my personal experience would suggest that we have to build the foundation of communication before we can get to an abstract language no matter whether it's signing exact English, American Sign Language, or auditory oral. And so the other things I've learned from others who are interested in this topic is sign language is still quite complex and is a language, so sometimes you'll see kid signing to themselves because that's how they are viewing it from how it's being presented to them. So they can't put themselves in another person's shoes and realize that they have to turn that sign around and present it back out to the people. So I think you really have to look at motivators for the child and what they are motivated to communicate about. What is it that they're processing? Is it the picture? Is it a photo? Is it the object? What are they doing to communicate? Do they rely on gestures?

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Do they rely on their hearing? This is similar to hearing children with autism, so some children with autism who are hearing will pick up sign quickly, and others will not pick up sign because it is a gestural – I mean, it has a gestural component and it has imitation required of it. And so, for some hearing kids, signing is the way in and they start expanding their communication. And others, they're speaking what they're hearing, and they echo it back, and until they echo it back enough to kind of start decoding it and using it effectively, then they build their communication that way. So I think what's challenging is, even among children with autism spectrum disorders, there is a wide range of how they process information, whether it's visually or auditorily. And so I think we have to respect that in the deaf or hard of hearing child as well and really kind of get down into that deeper level of what is it the child is doing, how are they communicating, how can we move them up the ladder of communication. If we have to understand that turn taking is a part of a foundation of communication, until you can turn take, you're not going to realize we can communicate back and forth. So you really have to kind of break it down and build it back up.

That was a long answer. Sorry.

Thank you. I have another question here. Who do you believe is the most appropriate professional to make the ASD diagnosis, or do you think maybe it should be an interdisciplinary team's decision?

My personal bias is that an interdisciplinary team is a much better way to diagnose a child with an autism spectrum disorder, but I also recognize the limitations and the knowledge and who is sitting at the table. So I hear many stories from families and professionals saying, you know, professionals who really know children who are deaf and hard of hearing, sending them off to the autism specialist, who people will then say, oh, it's because they can't hear that they're not communicating. And that's really frustrating because you've built this kind of case and you're trying to get families on board to realize we have to do something differently. So, you know, the best case scenario is someone who understands both worlds. But those folks are far and few between. So I think one approach that I have encouraged folks within the deaf education realm to really kind of indicate is explaining to the professionals who may not know as much about deafness why this child seems different than other kids, and what it is that you're noticing. That is a typical and helping broaden their view and kind of explaining why most kids with similar hearing loss or similar situations or similar communication environments would show more progress or look different.

Great. Thank you. Have you seen poor wave form morphology in the ABRs of children with ASD and normal hearing?

Michael, do you have – I know there's been some ABR studies in kids with autism. I don't know that I'm as up to date on that knowledge. I don't know – Michael, do you know?

Not to my knowledge. Not that I can think of off the top of my head. But I would have to go back and do a little bit more of a lit review to answer that more precisely.

I think, you know, what's probably embedded in that question is that children with autism definitely seem to process sound differently than kids without autism. And, you know, often the first question in a child who has autism is are you deaf. And we take them through the whole shebang, all the way to sedated ABR, to insure they are not deaf if we need to before we say, okay, yes, this is probably something else. So there's definitely differences on how kids process information and what they seem to respond to auditorily.

Can you take a moment to explain visual schedules?

Oh, sure. So visual schedules is one broad approach to helping children understand what's expected. So often we give directions and we set things up for kids, you know, once we're done with this, we're going to go to that, and many children with autism spectrum disorders don't quite get the first/then scenario. So we may have a schedule where pictures are of different activities that they may do. So if you have three activities you're trying to get them to complete in a session or in school, or to get out of the door in the morning, you'll put pictures of them doing those activities, or pictures representing those activities to help

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them know kind of what's coming. That really helps a lot of children who struggle with transitions. Many kids with autism spectrum struggle with transition, so it's just kind of a way more salient what's kind of coming and what's happening next.

I will say I also see a lot of time people indicating, oh, yes, my child uses visual schedules and that's our communication system. I would argue that that's a communication system that helps the child understand what's expected of them, but it's not really giving them choices or allowing them to request. So there's other strategies that really uses pictures to encourage them to request or indicate things, such as anything as quite formal as this thing called picture exchange communication system where you give a picture to get a picture, you start building sentences and moving things up. So I think of visual schedules as a way to help a child understand what's coming, what's expected, maybe help transition better, but often they're not used in a way that allows them to meaningfully request and meaningfully participate. It's very helpful, but it's not the entirety of what they're needs are going to be.

Thank you. And I think we have time for one last question. And I do apologize for those that have submitted questions and we didn't get a chance to get to them, but this one is for Michael Scott. Would you expand briefly on evaluating for communication ability?

Sure. So what I meant by that was instead of just looking at the child as one that we need to find out how well do you hear, or how much can you repeat back to me. Really we want to look at the child in the light of how well they can provide us information about their hearing. Not just thresholds, but what is it that you're able to do with that information out in the real world. So to that sometimes we need to take some of those alternative test measures, such as functional questionnaires, questionnaires sent to the school, sent to along with the parents all the way down to quite simply our case history. Sitting down with the parents and asking them what is it that you see your child is doing differently now that they have some amplification. It might be that they are using sign as their primary mode of communication expressively, but then receptively you might find or learn something completely different as you continue to evaluate in this way.

Great. Thank you.

And I want to thank both of our speakers today and all of you in the audience for attending this webinar. Please take just a moment to complete our brief survey. When you do click off this webinar, you will receive the survey automatically. Please just take a moment, provide your feedback. We do read all of your survey responses and we do appreciate you attending today.

Thank you very much for joining us and hope to hear from you in the future.