Please stand by for realtime captions.

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>> Okay. This is Haylee Marcotte with the National Center on Deaf-Blindness. We will go ahead and get started. I went to begin by welcoming everyone to today's session. I will run through some important housekeeping items. To begin, also lines have been muted and microphones have been turned off to reduce background noise. Please keep your phones on mute throughout the entirety of the presentation. This is session will include participation through the use of poll questions . The presenters will read out the text on screen. If you need to respond within the chat pod, that's fine. You are also welcome to respond in the poll question. We will also be sharing two videos. The videos will be captioned on screen. If you have any questions, please put them into the chat pod at any time. The chat pod will be monitored throughout the presentation. This session will be recorded and archived. The recording along with all other materials shown in the presentation will be posted on the website. I will start the recording and I will hand this over to Julie Durando with NCDB .

Good afternoon. I am Julie Durando, evaluations coordinator for NCDB. This session is part of a succession series for the virtual deaf blind Summit 2020. These sessions are of interest to families, educators, state personnel, and other individuals interested in deaf blindness in children and in youth. On July 29, we were pleased to have [ indiscernible -- low volume ] Establishing routines at home. That was particularly [ indiscernible -- low volume ] These topics will include American standards , I'm sorry, academic standards for students with significant cognitive and disabilities, accessing [ muffled audio ] and [ muffled audio ] IEP development. Our topic today --

Julie?

Yes. >> This is Haylee. It is a little muffled on this side coming through. Can you move your speaker a little closer ?

Yes. Thank you.

Thank you, Julie.

So today's topic is tran one.

-- Meeting the Needs of Proficient Communicators . Nancy O'Donnell, Director of outreach will address proficient committee caters with Usher syndrome. -- Proficient communicators with Usher syndrome. >> Hello. I'm happy to be with you today. I want to say a quick thank you to Linda and Christie and NCDB for inviting me to join in this discussion and to Nancy for agreeing to partner with me and a big thank you to [ indiscernible name ] whose lead this effort in Texas and around the country to identify this population and to build resources and strategies so that we can all better serve them. The other thing I want to just acknowledge up front is that I have a 6-year-old and a five-month-old puppy . So we are just going to, I guess, I probably need to say no more about that so we will just do our best. >> The first poll question is how would you define a proficient communicator . >> I will give a few minutes for answers to come through into the chat. >> Have you heard this term before? >> Someone who uses language, symbolic , expressive communication, fluency with language , yes. Yes. You are all right. Mutually agreed-upon symbol system , thank you. We will talk about , in a little bit, some of the identifying characteristics that we have come up with. Haylee, how do I get out of the poll question? There we go. Thank you. This presentation is going to feature a lot of proficient communicators in the first half and hopefully I will remember to acknowledge them all. This is a lease. She is now a second grader. She is most definitely a smart cookie. Historically here in Texas, almost all of our projects, technical assistance requests were emerging communicators. The exceptions for on-site for students with Usher's syndrome who were very different in their communication and academic standing that emerging communicators. Our field, nationally and internationally, had developed many T8 resources and strategies for emerging communicators. We had Doctor van , Barbara Miles, we had speakers at conferences and videos and resources . We were equipped and we still are equipped. We can assist teachers and families and students who are emerging communicators. Trying to lead the way on developing resources to serve Usher syndrome in support of the projects and technical assistance to district and school-age families.

This is our second poll question. On a scale of 1 to 5, how confident are you in your knowledge and skill providing TA for students who are proficient communicators? >> You can check 1 for low confidence, 2 for somewhat low confidence, 3 for neutral, 4 four somewhat high confidence, and 5 for high confidence. 40% are somewhat high confidence. 8% , the brave souls have said they have low confidence and that's okay. That is why we are here. Okay. Haylee, I think we can hop out of there.

This is Julie. We had a question in the chat pod, can you define TA, technical assistance.

At the deaf blind project, when we get referrals to our project from a family or from a school, we call that technical assistance when we go out and provide our second set of eyes and ears and provide recommendations and do observations. That is part of what we call technical assistance. It also includes training. Good question. >> Okay. So a few years ago, some things began to change. We began to get a number of contacts regarding a different type of child. They were congenitally deaf blind with formal language. That is little Henry there.

As we began to gather information , there seemed to be some common elements. Some of these students were on the state general education curriculum, not on an alternative curriculum. Most of them did not have an intellectual disability. And they were accomplished in the use of a large array of technology.

Several years ago, our colleagues , Matt Schultz, was invited to do some consultation for the young man in middle school. During the consultation, Matt realized how helpful it could be to others

[ muffled audio ] how they were putting the intervenor model to use in the general [ muffled audio ] so I will show you a clip of that video. Matt along with Nathan Wagner who is a member of our A V team went back several times together footage and they put together a 12 minute video that includes interviews with Colin the team and footage of him learning in the classroom and information about cognitive development and how that relates to students who are deaf blind. I will play a little clip of that. I think if I do this,

-- >> [ pre-captioned video is being played ] >> [ video has concluded ]

Matt and Nathan did an amazing job on the video and hopefully soon it will be shared out . Although there are some similar series with students with Usher syndrome, there were distinct differences with this congenital population and we did not have a bank of resources to help. And there were so many of them. I am going to talk to you about approximately how many of them there are in just a minute. So we started looking at our deaf blind child count.

In Texas, in 2020, [ audio cutting in and out ]

we had 820 children and young adults who were identified as deaf blind. The state testing age in Texas starts in third grade through 12th grade. So in 2020, 455 student were tested.

Of those students, 142 --

[ Adobe connection lost. Captioner reconnecting to event. ] >> Yes, people are noticing more at 55%. Yes, I think we can all agree, not just in Texas but all over the country, we are seeing more proficient communicators

and that is why we are all here to figure out how can we program better. Okay. Thank you. >> As we began to collect information on this group we call proficient communicators, we are sharing a snapshot of what our project has learned about proficient communicators who are congenitally deaf blind. Our next speaker, Nancy O'Donnell, will address proficient communicators who have Usher syndrome.

Proficient communicators are faced with some of the same underlying problems that emerging communicators. They have problems with gathering important incidental information that can lead to incorrect key concepts as they grow up. Additional time is required to gather information, process, and respond.

In general, these kids look like they are just fine but they are not. It really hits in middle school. The pace it's faster and the scope becomes wider. They start to stand out more and more. These students are really hard workers and are motivated to keep up . When they nod and say yes, I understand, people often take them at face value and move on. Over time and across multiple on-site's, our project compiled a list of 12 specific recurring needs. We only have enough time to talk about five of them. But they are all included in your handouts.

One of those recurring needs was modifying the curriculum. Being deaf blind is an information gathering disability. Gathering information takes much longer than for their typical peers. This means that the pace of instruction should be slower. The scope of the information in a general education classroom can be overwhelming. That means the curriculum should be prioritized so it is both manageable and instructive. These students are just not able to learn at the same rate and same amount of information as their peers who have typical vision and hearing. It is not possible. We cannot expect that of them. And we should not teach them to expect it of themselves.

As I mentioned , in Texas, we have , our children do not start taking state testing until they enter third grade. But these kids are talking at younger and younger and that is particularly exciting to me because I am in early childhood head on a team in Texas and I am seeing them. We, of course, need to get better at identifying them [ indiscernible -- background noise ] more portly, for me, not more portly, but equally as important [ muffled audio ] because we know how much that means to start when they are young and help prepare them so that, down the road, in a general education classroom, they are prepared to get the most out of it that they can. So the next video is going to be a short video of one of our little proficient indicators, Henry . He is headed down a path of proficient communicators in a general setting. >> [ pre-captioned video is being played [ Adobe connection lost. Captioner reconnecting to event. ] >> Let's get the ball rolling.

Thank you. Sometimes these students are able to tell us what they need help with. But they are busy but doing their best in real-time instruction. And so we need to be alert for what they might need help with. And there are signals that if there is an intervenor or a teacher, these students have signals that led us know that they might not understand what they are hearing or seeing. I had a student who, when she was reading braille, she would pause ever so slightly and turn her head and it was like, oh, I'm not going to stop her here, I'm going to let her keep going but I will write a note that whatever she was reading, I need to look at it and revisit it. None of that matters if we don't go back and explain. >>

We can create at least one elective of this can be done at the district level. Summit have created innovative courses that allow districts to offer state approved innovative courses that enable students to master knowledge and skills and competencies not included in the essential knowledge and skills as a required curriculum.

Pre-teaching core subjects will help students become familiar with jump topics, concepts, and vocabulary before entering the real-time instruction environment. This will allow for more effective and information gathering and processing in a larger setting. These students are working hard for visual and auditory access in the regular education setting and the ability to process the information in real time is limited. So reteaching the main components of the material will allow them to make the conceptual connections needed to restore and retrieve the information from their memory. The comprehension checks, the effective comprehension checks we mentioned and encouraging a back-and-forth discussion is required for effective processing. Time for discussion and inquiry and investigation will help students develop a complete understanding of the course content. >> Students often require technology to compensate for the combined hearing and vision loss. They are savvy with technology and they maybe responsible for many more devices than other students. So questions need to be asked how will the students not only use their technology but manage it ? Who will repair it? Where will it be stored? When will it be charged? Does the student need help getting it from one location to another? A plan needs to be made. And I think I noticed that Patty McGowan is here as a participant and she gave us some resources that we put in your handout

for guides to making those plans and a framework that will help make that easier and available to share with the team. >> These students are working much harder than their peers together information and often experience fatigue. Strategies to reduce or eliminate homework may be necessary for some students. These students should not be given busywork. They are busy enough. If the class has to do 30 math problems, they should, the goal should be that they demonstrate they know the content. Can they do that in 10 math problems? Maybe so. They might need alternative assignments or projects. But really giving thought to how hard they are working at how much they are taking home at night and how much longer it takes them to complete that work than their peers with typical vision and hearing.

We are learning so much about the biology of stress. Science is now telling us that there is some stress that is actually beneficial for us. Prolonged stress can and does have biological implications. Students who are deaf blind put forth a great deal of energy and effort over the course of the school day. In addition, they may be staying up late at night to get their homework done and prepare for school the next day. They have to work hard, much harder than their peers, to keep up with real-time instruction. They are not just trying to keep up academically. They are trying to keep up socially. This can result in extremely high levels of stress as well as feelings of inadequacy and failure. And we do not want that. We do not want that for these students. Stress, if not addressed, these students are at risk for developing toxic stress which can recap got healthy development of both physically and emotionally. Here is poll question 4. What are some of the need you are noticing for congenitally deaf blind proficient communicators? >> Hard to prioritize, everything seems important, not noticing what they are missing, yes. Practicing self advocacy. Finding the right support. Knowing takes ownership. These are all great answers. We will scoop them up and look at them later. Thank you for your input. >> I am short on time. I do not want to go over into Nancy's time. I am going to speed through some of these Texas activities and national activities. We have them for this year. In Texas, our grant is going to work on identifying children younger than the testing age of third grade . We are going to use our child count to try to make an email list of professionals and parents of those 142 proficient communicators. We are going to make a list and we are going to develop some webinars that we can share with those professionals and parents and people around the state and country. We are starting a literacy initiative for young deaf blind proficient communicators. We are compiling our resources that we have and reports from on-site. The requisite concept evaluation which I can talk to you more about later on during this presentation

or I am happy to speak with any of you by phone or email but that is in its final pilot. Nationally, we are receiving help from NCDB , Christie Provost has been our leader in the group for proficient communicators. And NFADB , family to family communities this year, they have already begun a series on supporting academic families getting together and talking about the children who are in this group. I want to thank you so much for your time and interest in these school kids. And I am looking forward to Nancy and I'm sure you are also. She will talk to us about proficient indicators who have Usher syndrome. >>

Okay. Nancy O'Donnell here. I will give everyone a second to readjust your cells in your chairs and get comfortable. >> I would like to thank you , first of all, Deanna, for setting up a great introduction to this unique group of proficient communicators. As mentioned, I will focus on proficient communicators with Usher syndrome. I would like to think NCDB for including the Usher syndrome coalition in the group as well as inviting me to present here. As you know, the Usher syndrome coalition is the largest international group focusing exclusively on children and adults with Usher syndrome. And I really recently worked with NCDB together information that I will be sharing in this presentation . I interviewed some parents, some staff on the deaf blind project, and some students and former students, students who have transitioned out because it was together and put. So let's move on.

I saw this quote any American annals of the deaf from 1886 which reads the best elements of the home, of the school, of every department of human life should be so gathered, combined, and administered as to promote in the period of his youth his highest educational well-being and so to qualify him the peer of the hearing to discharge with pleasure and honor the full functions of an American citizen.

This quote is more than 100 years old.

Usher syndrome has been recognized as a distinct syndrome for more than 100 years. But our goal is still the same and that is to have students, school-aged students and adults with Usher syndrome and all proficient indicators, full members at full citizens of our community. That is to the best of their ability and to the best of our ability to serve them.

Usher syndrome to give a brief overview was identified in 1914. It was named after Doctor Charles Usher who was an ophthalmologist who had in his practice about 69 individuals who , in addition to the vision loss, had hearing loss. Many of them were multiple children in the same families, congenital, bilateral, and adventitious vision loss . Most severe hearing loss also exhibited balance issues , lateness in sitting up, walking . So those are some of the issues that came to be described as Usher syndrome.

The last bullet, no associated intellectual disability, which I have started added to the presentations about the last year or year and a half. When we address the general public, sometimes they hear congenitally deaf, vision loss, there must be something going on. It is not part of the center. In fact, there's a photo here , this is a collage of nine different pictures of youth and adults with Usher syndrome, fully engaged in their communities. I have found working with this community for many years, I have found many individuals who are so clever and creative, resilient, and resourceful. And it is my honor to be working with this community. I consider the children and adults and the families of children and adults with Usher syndrome to be the real experts in this content area. I will certainly give an overview today of what we know about the group. >> Learners with Usher syndrome have historically been proficient communicators.

Those who are born with Usher type I with severe or profound deafness often attended schools or programs for the deaf. They had native language models , in signing which model, in the schools for the deaf. And those who had more moderate or later onset hearing loss as in Usher type II and type III attended local schools and basically followed the general curriculum. Many report receiving support services through their schools in terms of speech therapy, services of the teacher of the deaf and teacher of the visually impaired. >> It is interesting to go over a little bit of the population estimates. This is a real quagmire in the community because we do not have any hard and fast numbers. Even researchers have various wide ranges of what they tell us they believe the prevalence of babies with Usher syndrome is. So if we look at data from the early hearing detection and intervention program, the estimate would be for cumulatively, children between birth and 21, that there could be between 3200 children with Usher syndrome, up to 11,000 . It's quite a wide range. Using the prevalence of 17 out of 1000 births, the range could be between 4600 to a prevalence of 15,000. And some subtypes of Usher syndrome, there are actually 10 identified genes right now that cause Usher syndrome. Some of them are more common in certain geographic areas or cultures. We have the Ashkenazi Jewish community, the Cajuns in Louisiana, the Amish community, and individuals of Finnish heritage. >> The Usher syndrome coalition maintains what we call the you SH trust which is the international registry . As of August of this year, we had 255 children , birth to 21 in our registry in the United States. Interestingly, the youngest in our registry was born in October 2019 and was registered in May. So what we are seeing here is an earlier identification of children in the Usher community. Several of them were genetically diagnosed under the age of 1. Even 10 or 15 years ago, that would have been unheard of. 209 of those 255 children were genetically verified so their diagnosis was confirmed . And again, 10 to 15 years ago, genetic testing was just not available to definitively diagnose children or adults. So the numbers that we are getting now are more solid than in the past. And we feel more confident that Usher syndrome does exist in the other groups that we have in our registry. Then if we look at the state deaf blind project and go back a few slides to the thousands of children who are expected would have Usher syndrome, in 2018, nationally, only 345 children were reported with Usher syndrome on that snapshot date of December 1. And in 2015, over 51% of those children reported had cochlear implants. That is those with Usher. That compares interestingly with the general report of 11.3% of all children in the children's senses who had cochlear implants. So 51% with Usher had cochlear implants. That is compared to 11.3% of all children in the census. It's very serendipitous that this morning, Robbin Bull who manages the state deaf blind child count, shared with me that the new number is at 58% of the children with Usher syndrome in the deaf blind census have cochlear implants. That is compared to 11.7% of all deaf blind children. So we can see that cochlear implants are really changing the profile of the Usher community and they are also changing the way that we work with the kids because , in my personal experience with younger kids and teenagers and even those who have transitioned out of school, I've come across many with Usher 1 , the most severe type, and they are oral communicators. They have been implanted for many years. They function quite differently from their older generation counterparts. Those are mostly signers. This is something for the community of technical assistance providers and educators to think about as we look at a whole new profile for kids with Usher syndrome.

Diagnosing Usher syndrome thankfully , newborn hearing screenings are catching more and more children who have congenital profound deafness or moderate to severe hearing loss. I've heard stories even recently about kids who passed the newborn hearing screening and one mom described her child who is six months later, they were hearing in six months later the hearing went. They have been genetically diagnosed with Usher syndrome. Thank heavens for Doctor Google. She is an amazing tool and parent to go home and found out their children have failed the newborn hearing screening under saying to themselves I wonder where this came from, it's not a family, so they go online and, bingo comedy find out what the diagnosis is. Unfortunately, a lot of pediatricians and family doctors say to the parents I do not think that diagnosis is for the child , you are concerned, you are worrywart, thankfully the new generation of parents are quite pushing for the genetic testing and finding out they were right. Also you should know there is prenatal genetic testing taking place. And that has come to the coalition's attention in the past year or so. As I mentioned before, genetic testing is quite prevalent in the Ashkenazi Jewish community. For example, because of the high incidence in their community, young people will be tested and know that they are carriers for a variety of syndromes. We've gotten calls

from your parents that are already expecting and have gotten the panel of testing back and found out that indeed the child they are carrying has Usher syndrome. It's a whole new world coming down the pike to prepare you all who are working with this community.

Why are the numbers so low? We saw several slides back that there should be thousands of children birth to 21 with Usher syndrome. According to prevalence from various sources, we see that [ muffled audio ] reported 345 in 2018. The numbers are low from what we have seen and understand.

The diagnosis is missed by healthcare providers, sometimes by teachers who have not been made aware of Usher as a distinct syndrome . A lot of folks are not familiar with Usher syndrome in general. Or they may say they have a vision loss and they are a little hard of hearing.

But they may not know to put that together as a distinct syndrome. We know the vision loss does not become a serious issue until later because the visual associated with of Usher syndrome is slow and progressive and, in many cases, unpredictable as to when it will occur. Cochlear implant have totally mitigated hearing loss during the day in classrooms or so we think. Usher becomes invisible. We've met many parents who may not want to reveal the diagnosis to the child or to the school. With the way that education has changed over the last years, many students are now attending the local school district across the country so education is not centralized as it was when I started in the field many years ago and kids would go to the school for the deaf and there would be a deaf blind program. I'm not saying they don't exist but it's not as prevalent as it was back then. So you have maybe one child in a school district with Usher syndrome and you do not have the ability for educators to get a sense of what Usher syndrome is in its entirety and how to best assist in support the student. And years ago, statewide screenings were routinely taking place for Usher syndrome. And now, from what I have heard, and I did a women are back in 2017 , the screenings are just not taking place for a variety of reasons and we know that the number used to be 90% of the kids on the deaf blind children's senses had additional learning issues , cognitive issues, health issues, et cetera, and they were taking up the majority of the resources of the state deaf blind project. Honestly, the case with Usher syndrome were seeing, okay, their vision loss

wouldn't really affect them until later, they have hearing aids and cochlear implants and they are doing fine and I have kids who really need my attention and that is understandable but we are so thankful that the group of proficient communicators are kind of coming back into full view. So how are proficient indicators with Usher syndrome different from the group that Deanna described? This is not a poll question. This is just my amusing and introduction to the next section of the presentation. >> Students with Usher experience unpredictable and progressive vision loss which impacts the visual fields,

the vision in dimly lit areas which we refer to as night blindness but I think that is such a misnomer because then people think it is only at night but it could be in the gym or when lights are turned out for viewing movies or when lights are turned down with younger kids for naptime or in the winter when lighting may not be at its optimum outside. Then the adaptation to different lighting can be an issue for kids with Usher as well. Strategies that worked yesterday with a child or student may not work tomorrow. It depends on what type of a visual day the child is having. So an interpreter sitting at a distance with an older child who has a visual field that is really reduced may now need to move in closer in darkened environments so the student can visually track signs or do some speed-reading. One day, regular print maybe find. And then the next day, there has been a change in vision or a cataract has developed and a larger font may be necessary. Then there's always the question of braille. When you introduce it , should we introduce it, how do we introduce it? As vision loss progresses, speed-reading may be affected. This happens in the adult community as well. But it can often be misdiagnosed as additional hearing loss. But it's actually that the child is not in the best visual environment so it would be difficult to speech read a teacher, a peer, the lighting is dim, et cetera, so the unique interaction between the laws of visual field, the impact of lighting, and the impact of hearing devices or assistive listening devices. Usher equals constant change. >> Usher students can be invisible. I have heard many stories of students, adults , sorry, telling me, well, as a child, they thought I was clumsy because I was constantly tripping over things and it wasn't until I was older that I realized that I just couldn't see things that are on the floor. I was accused of being antisocial because I could not hear from a distance or, in the deaf world, I missed the handwaving to get attention on the side of my face where my peripheral vision had already gone. Students may be described as inattentive instead of blind. I was interviewing a woman yesterday who said they always thought I was testy it's just that I wasn't hearing or seeing what the teacher was telling me. I have found so many students who cleverly and seamlessly adapt to their waiting vision. They may intuitively stop outside the classroom, scan from left to right to get a sense of who is where, where the chairs are, where the teacher is, and then they step in with that mental image before they enter the classroom. Students function very differently during daylight or school hours than at home or at afterschool events due to the problems with night vision and night adaptation.

And they also, because of this, may be more attentive in the morning and, by afternoon, as Deanna said with her group of proficient indicators, they are just exhausted. They are tired of having to spend so much energy listening , seeing, using whatever residual vision and hearing the half. Adults have told me that they were accused of being disinterested, they had poor grades, they were defiant. In many cases, that was just sensory exhaustion. So I think it behooves us all in the children and adult world to schedule smart. >> What might students with Usher need as proficient communicators? Well, as I mentioned in the previous slide, they may need time to visually scan, gather information due to restricted fields. I've spoken to parents who have reported that their children are losing visual fields in the first

four decades of life that I know a 14-year-old girl with Usher type I whose degrees are down to 10 degrees of vision. So this is a serious consideration. And again, maybe , it may be a little bit invisible. As a child, they have natural adaptations. Students may be traveling from class to class and they need time to set up and manage their screens, their assistive listening devices to make sure they are hooked in, maybe with Bluetooth to make sure that their iPad is set up, are they on Wi-Fi, is there captioning, some students may be starting to use braille in the older years of birth to 21 so managing technology in the classroom can take some time. As Deanna mentioned, troubleshooting when technology fails, I participated in a youth camp for children with Usher syndrome last summer in upstate New York. It was run by the nonprofit Avis voice. It was a life-changing experience for me and many of the students or campers were just loan away with the experience as well but, interestingly, one of the campers showed up and the processor on the cochlear implant was not working so troubleshooting, could we get out of the processor, when he is hundreds of miles away from home, do we have a contact information for the company that made his cochlear implant, what alternative methods of communication could be used in the meantime to make sure that he felt fully included ? So plan A, Plan B, and that now what do we do plan. Sensory breaks or something that are much more common in the adult world and I'm not sure how the classroom handles it for students. But in many of the conferences that are run by and for adults who are deaf blind, there's about a five or 10 minute break, so tactile signers get to rest their hands, those who are watching signs visually can rest their eyes, those who are watching CART can rest their eyes, just time to breathe in and refresh. Another consideration in the adult world that would apply in educational world would be emergency evacuation plans. Use X on the back. Does every student of that if you get a X on the back, that means follow me and when we get to a safe place, then I will tell you exactly what is going on. And do all of the professionals , the support staff working with the students no appropriate human

guy techniques because if the power goes out, students with Usher are functionally blind. The last light here, Lotto training, it was meant for active shooters which was unfortunately a big topic that we were addressing a couple of years ago. I was on my local committee in my town to participate in this and was at the Helen Keller National Center in my same local group of police and EMTs went to provide training and awareness to the adults at Helen Keller National Center. But some of the issues that came up are just issues would be good to talk about before they happen which is how would you communicate in the dark, how would you

silence a cell phone if you are not supposed to be making any noise, and where do you wait for help, where is it a place to hang out to make sure that you are not going to be walking in the hallway, maybe a buddy system in each of the classes, so these are the needs that we may not think of academically but they certainly make it different. The title for this slide is accommodations not modifications from our good friend Patty McGowan. She taught me that accommodations alter how a student learns. They do not change what the student is expected to learn. I want to refer you to what we consider

an excellent webinar highlighting to proficient communicators with Usher syndrome. The presenters were Patty McGowan whose son Hunter has Usher and Carly Fredericks whose daughter has Usher. And it was curated and sponsored by NCDB and I was lucky enough to participate in it. So that was created in 2017. It is a long webinar but I suggest that you sit down with a glass of wine and watch a tent take notes. There are great suggestions from two moms that are wonderful advocates. >>

When I started with the coalition, we started to put together and revitalize some of our handouts. The first handout that I made was ask the experts. To me, those of you who have Usher syndrome , are living with Usher syndrome, for the many amazing advocates in moms and dads of children with Usher syndrome other ones to consult with. You all have taught me in the community so much because you are living a day-to-day and you see things that are not in the textbook. You see practical issues as we have gone through the whole distance learning. We will call it opportunity. It is the parents who are seen firsthand the challenges of the children and who are working with their kids in the school to come up with some evolving solutions. So we have a tremendous number of experts among us that I hope that we can tap into.

One of the experts I would like to share with you because this particular expert has become a friend. This friend has Usher syndrome and he said to me what is your typical view of Usher. He is an adult in his 50s with Usher type II. I said, you know, Tim, it's a picture of you, if you Google RP, you see the picture with the two cute little boys and her face is smiling and then you see all the black and the two little faces smiling and that indicates the loss of peripheral vision. So that must be what it's like for our students and adults who have usher syndrome, right, it is just like the toilet paper roll, you know, the center of it, everyone holds it up when they are going to a training, so his name is Tim Chambers and he actually is a master painter. He does landscapes. The most amazing portrait artist I have ever seen. Tim did a presentation for the coalition for the recent USH connection and he said I want to show you because I can, I remember what things looks like and in certain situations of light, it still looks like that to me. But I want to show you what the same image looks like in four different situations of lighting because it is not just black. In fact, he said I see a lot of yellow sparkle in the periphery of my vision. It is not totally darkened out. So what he depicted in what you see in front of you are four panels of the same church steeple under different lighting conditions. And depending on how much light there is in the area, this is what Tim sees. This is what or how he sees the steeples. He goes into the effect and impact of lighting as well as the impact of the degeneration of the retina and the cone on his webpage that he just created, hot off the press called the USH view, and his goal is to educate mostly ophthalmologist because when he was diagnosed with Usher syndrome at the age of 30,

his ophthalmologist said, well, Tim, I know you're an artist, but I would find another career. And he is 58 and still going strong. So I present this to you. Tim is one of our experts. He has offered , if anyone wants to get in touch with him, who has Usher's syndrome and they want to describe they can see, he has offered to paint a representation of what they describe to him so that we can start to create a whole library of what living with RP actually looks like. There is a hyperlink in this presentation as well as on the fact sheet . I have a rhetorical question. How might this perception of RP associated with Usher syndrome influence your work with students , the documents, the images that you present, the lighting circumstances in which you present material? It certainly causes pause for thought. >> When interviewing young adults who have gone through the educational system and now are on the other side, either in college or employed, or looking for employment, one woman in particular said please tell the teachers out there that not everything is about Usher. I had undiagnosed learning disabilities, mental health issues, and dyslexia that were all assumed to be associated with the fact that I have usher syndrome. It took some very clever professionals to help me tease that out. She's an advocate and wonderful role model. She had an urgent need for me to share that with all of you. Some of the younger guys said please ask us what we need. We know what we need. We have been around living with it. Others to say we want to learn how to advocate for ourselves. This is in particular where the parents have been terrific advocates in preschool, elementary school, maybe even into middle school . As they get to high school, they want to take on more of their own responsibility and then especially with college kids right now who are doing either hybrid, maybe they're going in person to a college or they are doing it all online and now it is up to them to learn how to work with the department of support services or student services or even to find out what that department is called or referred to at various colleges and universities. And then the other thing, and this is certainly highlighted at the campus experience last year, kids want to meet other kids with Usher. They want a peer group . They feel like they are the only one unless they have multiple siblings with Usher syndrome. There is a transformation that we saw unfolding in front of our eyes when these young 11 to 17-year-olds met each other, 11 to 14-year-olds , the 15 and 17-year-olds were junior counselors and then we had adult counselors and what we call a strength coach which was a psychotherapist who would kind of camp with us for the weekend she has Usher syndrome. So to meet a peer group and to have role models, light bulbs.

How do we support proficient

litigators with Usher syndrome, their parents, and the professionals who serve them? Universal accessibility, whether we are in hybrid, online, in person, it is one of my particular passions and peeves . We really need as a community or I would encourage us as a community to try and come up with emerging and best practices. And as we know, we have seen fact sheet. We have seen materials that go up on the national deafness center Listserv and people are constantly asking questions and someone will say I have a student with this particular vision or with this learning problem or our area does not have enough interpreters or now that CART providers are at a premium, how do we find them and we use auto captions rather than having a CART, live provider . Image descriptions, oh, my goodness, I can be the worst when it comes to image descriptions. I always have to remember my Facebook page to include them. But to leave them out is to dismiss and to say that our community of learners, that is okay, you do not need to know this, and we should be setting the bar for the rest of the community and the rest of the world. Text transcripts which are not just the transcripts that we see in CART or in captions that you can download. It also includes who is speaking. And honestly, a robust text transcript should include the image description within them. So the person who is just reading text can get a full sense of the presentation without having to refer back to the visuals associated with it. Translations in American sign language are important , especially if literacy is at a lower rate in the deaf community than they are in the hearing community and English-speaking community. At the coalition, we have had several translations of our Chennai talk which are genetics and research in order to bring up the literacy level of the community. We are all familiar with the variety of print media necessary, large print, electronic documents which we want to make sure are accessible and PDFs are properly tagged and screened readable . Materials in braille which the hard copy seems to be at least in the adult world not as requested as it was in the past , accessible learning platforms, compare and contrast, there still a lot of room for improvement . Accessibility of websites, social media, and abs, I have heard stories recently of students who can use a website but the app that goes along with it was not accessible. And then we get into the whole area of providing environmental information for those whose vision is down to legal blindness or just need the environmental information. Haptics is touch cues who a person who is deaf blind in conjunction with her interpreters and so it uses the back and upper arms to provide tactile environmental information so that , especially with a tactile signer, you don't have to continually interrupt and say, oh, there is a person in the back who has their hand raised, there is a simple movement on the back where you would take a part of your hand like a karate chop by your pinky and you would rub it up against the person's back to show that a hand was raised and down to show that the hand went down. There are a lot of cool Haptics tools who can help those and this is an area we can learn from for the adult blind community in general. Support to parents, they are seeking guidance on decisions to tell her not to tell children about Usher, to tell her not to tell the child , to implant or not, what method of communication should we use, when to introduce orientation and mobility instruction, braille instruction, and high-level advocacy.

Emerging best practices, we need help . Learner fatigue is another area we could do some research on. What's already out there to use? I did a literature review as part of my work at NCDB and there are some timeless articles out there , an open letter to our parents, what we wish you had known. Adults with Usher syndrome said we wish you had no to tell us we had Usher syndrome. It was a fascinating look back about the usher community in Louisiana from an old DB perspective. In the classic Usher syndrome in the school setting, many of those could be updated as well as this list of fact sheets, overviews, screening guides, and a cool book that we use to sell at the Helen Keller library called understanding Usher syndrome, an introduction for school counselors. So there are materials there. They definitely need a makeover. And hopefully we can get a group together that might be interested in working on that together. Avis voice run by Carly and Tammy , their children are going through the distance-learning quagmire and they are putting together materials . There is a cheat sheet Ava uses with her teachers and a lot of collaboration tips, student led IEP link about how to incorporate IEP meetings with students .

Resources for youth, through the coalition, we recently created a Facebook group for individuals 18 to 28. There is a new blog on our website called seeing is believing, my college experience with usher 1 B. Ryan at HKNC regarding efficacy has put together a video , advocacy and the deaf blind world. We are hoping to run this summer camp for youth and as a hyperlink for that and we will open up positions for summer camp counselors. And at the Usher syndrome conference which will hopefully be in Austin, Texas, next year, we will run a one-day camp for all kids who attend . I have a whole flight here of resources for parents and families including global Usher syndrome awareness day which just passed on the third Saturday of September. Mark, our founder, did a periodic blog over the course of at least 10 years on his journey with his daughter who has Usher 1 B. We do have information about usher syndrome in American sign language, a series of 25 videos that have captions and are signed. I encourage anyone who meets a family who has a child with usher syndrome to encourage them to sign up in our registry because the better our numbers, the stronger the community. The family weekend, they can just get away together and just the families without having to think about what do we do with my child with usher syndrome, just family time. And a continuation of webinars , the national family Association for deaf blind, some great articles, a link to I can connect, equipment distribution program, practitioner resources, a webinar that I did in 2017 on finding children with usher syndrome, and of course, HKNC has a wealth of information and they continue to provide that on the website and the online courses are free through December 31 so please take a vantage of that as well. >>

Practitioner resources, I have a link to Tim Chambers the artist. There is a Listserv , professionals serving deaf blind consumers and some other resources . A quick survey, poll question, what updated material about usher syndrome does your project have to share? >> If you could fill it in, that would help us know where we stand. We are hoping there are some hidden gems out there that just have not come to our attention that we have no desire to reinvent the wheel. We know there are many of you who are working with the usher community successfully. And now is the time to bring it out and share it and post it. We would like to create a resource for everyone. >> That is at the end of that poll question it looks like we have some work

to do in terms of developing materials and who does your project after consulting about meeting the needs of learners who are proficient communicators in general. >> 94% of you have project staff persons with expertise. 100%, 17 said we do have persons with expertise and that's awesome. We had some out-of-state consultants and some internal or external consultants in state and persons with usher syndrome in Houston that is excellent. Okay. That's it folks. We have three minutes. I apologize for taking the time.

I've been looking in the chat box.

And moving forward, we can go to that, any burning questions ? We have the last poll question, what main issues would you want to address in the months to come related to proficient communicators? >>

Why is it abbreviated USH and the research community uses its of the coalition started using that and also US could be confused with USA the country. Patty McGowan said we are fighting more and more students in Pennsylvania that you think have usher syndrome with the same needs but you have USH . It's great to see it being addressed as a need the supports as all students do. >> I noticed a question in the chats. We are about out of time. Please email me or call me. I am happy to continue the discussion . What qualifications do the leaders need to do the pre-teaching ? This can be a little tricky but the prioritizing of the content that the deaf blind students are going to need to have addressed needs to come from the content area teachers. Another content and they can help prioritize it. They need to develop a habit, preparing their lessons in advance, giving access to those lessons to the intervener, so as -- it is not the intervener deciding how to prioritize. But looking to the content area teachers to gather that information at communicating back to that, what or where are they seen the gaps and definitely addressing those as they go along, but a real partnership team is so important for all of these students so that people are all on the same page. >> Please don't forget to take the evaluation.

Thank you. >> That was a wonderful presentation. We have all of the links that can be found on a website page and I will put that in the chat box right now. Please take the evaluation survey. We appreciate your feedback. That's the end of the session. Thank you for your anticipation. Have a great day. >>[ event concluded ] >>