

DISCLAIMER: Raw, unedited transcript from webinar. No guarantees are made for the accuracy of the content.

>> Please stand by for realtime captions.

>> We will give it just another minute as people are settling in here.

>> I am showing it is at the top of the hour. Are you ready for me to get things started, Sheri I am. Can you hear me?

>> Yes.

>> Great. I think we can get started and start recording.

>> Okay. Very good. I will start the recording. This is Robbin Bull with NCDB. I will start by welcoming everybody. There are a few housekeeping items that I will go over first before I hand it back over to Sheri. All phone lines have been muted to reduce the background noise. We would like for you to stay you did during the webinar with the exception of the presenters. The question-and-answer session will occur at the end of the presentation. However, you can type your questions in the chat pod throughout the webinar and it will be monitored for that question-and-answer session at the end of the webinar. We do want to let you know that this webinar will be recorded and archived for future viewing. Please be mindful of your comments in the chat pod and refrain from writing personal or sensitive information.

>> All right. I will now turn it over to Sheri Thank you, Robbin. Welcome to the -- The Charge Syndrome Foundation second and a three-part webinar series on interveners. I am the director of outreach with the -- The Charge Syndrome Foundation. We are pleased to have you join us tonight. Tonight we have a wonderful presentation for everyone. We have two of our presenters back again. We have Linda Alsop, the director of deaf blind programs at the sky high Institute at Utah University and Sally Prouty , mother of an adult son with CHARGE

syndrome who has worked in the field long time and is currently legislative liaison for the national coalition of deafblindness. They are both provided wonderful information on intervenors during last month webinar. And I welcome them again for part 2. This is entitled intervenors how what training is required and how can the need for those services be determined. This webinar will address the importance of training for intervenors. Linda and Sally will be joined by three guest presenters. We have Christine Jay, a nationally credentialed intervener and she will share her perspective on training and described her experiences working with a child who is deaf blind. Next he will have an explanation about how the need for an intervener can be determined by Beth Kennedy and the online intervener training program at Central Michigan University. Finally Jodie Beavers, a parent of a child with deafblindness will describe how those services change the life of her child. Again, this webinar will be recorded and archived for future viewing. So please be mindful of your comments in the chat box. It will be seen by anyone viewing this webinar, so we ask that you please refrain from writing personal or sensitive information. As you know The Charge Syndrome Foundation is a nonprofit organization that provides support to individuals with CHARGE syndrome and their families. Our world is better for people in this to gather develop and maintain and distribute information about CHARGE Syndrome syndrome and promote awareness and research regarding its identification and cause a management. Providing webinars is another way that the foundation furthers its mission to lead and partner to improve the lives of people with CHARGE Syndrome locally, nationally, and internationally. This is true outreach and education and research. If you like what you see tonight and you believe the work of the foundation does on behalf of children with CHARGE Syndrome and their families is important, please consider being a member of the foundation or making a donation to our website. The presenters request that the question-and-answer session be saved until the end of their talk. If you write a question in the chat box, please note the response will occur during the question-and-answer session. We thank you for your continued support and for joining the foundation and the presenters receiving. Enjoy.

>> Okay. Can you hear me?

>> Yes.

>> Thank you, Sheri and Robbin. We are honored to be able to do part 2 in this webinar series and there is so much information to be able to share, especially with parents around

the country that we're happy to have the opportunity to break it into smaller pieces so that it is not quite so much so quickly. Tonight we're going to talk about what training is required and we will be talking about that first and also have Beth Kennedy and Jodie Beavers and Christine Jay to discuss different training components and their experience and perspectives on that. When we get to [Indiscernible-low volume] be determined Sally will take the rain and speak about -- as a co-author of the booklet that we put together and from experience as you know as a CHARGE parent. That is how we will proceed and if you have questions feel free to put them in the chat box and we will be happy to respond to those. So as we get started tonight, one of the things we wanted to do was make sure we were all on the same page and we have some parents that were not with us last month. And so we thought just a few slides on a review was good. But we are all on the same page in how we are thinking that if we looked at intervention for a child who is deaf blind, it needs to have specific components that are general categories again and we talked about [Indiscernible] because this deafblindness disconnects one from the world because of the sensory disconnect we need to look at connecting obviously and that is part of intervention. Also because deafblindness interferes with access, and you will hear us talk about that a lot, the clear and consistent visual and auditory information, that has to be part of intervention and then communication is high on the list. So the development and the ability of do communication must be a part of intervention and now we know and can support this definitely through research and we have to look at social and emotional well-being and asked if the intervention in place is promoting social and emotional well-being. So if we look at what an intervener is again we have shared this definition last month, it's fairly simple and two parts. It's a person who works consistently one-to-one with a child who is deaf blind and the most important part is the training piece, the specialized skills. We know that it is not a new model to have one-on-one with deafblindness children. That has been going on for years and years. And eight or somebody would be with a child. What is different in the last 10 or 15 years and also what we are emphasizing tonight is the training and what skills and competencies they need.

>> Again, one last bit of review. The role is three pieces that we talked about. It is to facilitate access to environmental information that is missed or inconsistent partial through vision and hearing. It is to facilitate the development and use of expressive and receptive communication, and to develop and maintain a trusted interactive relationship that promote social and emotional well-being. So these our are three umbrella categories. Underneath each one is more specific. The full again be able to refer back to as a look at training tonight. That is basically what the intervener is and what the intervener is there to do and this role again applies from birth to death. So if we look at Helen Keller and Annie

Sullivan how we had an intervener. You can read about her life. She had somebody with her whole life who was for intervener tech person ended these three things for her and gave her access to information and help to with communication and helped her to feel safe and no where she was and who was around her. So both of those three categories.

>> So let's jump right into our training. That has been a conversation that continues on. Early on it was not as big of a conversation 10 or 15 years ago because let's just put in a warm body and we should be okay. But we know now from the research and the results that that is not what really makes the difference. We don't see the child outcomes a must that intervener has the specific set of skills and competencies that are very deaf blind specific and that intervener applies that to the child that he or she works at the child. Last month again and I won't go through all of this again, but I wanted to highlight tonight kind of two of the landmarks that were part of our historical perspective. In 2003, that is when a group from the national intervener task force got together to say we have to figure out what makes a intervener . What competencies to these people have to have and what separates them from being a classroom aide or even an interpreter or somebody else? What is that? That group worked over the next couple of years to come up with competencies for training to work with children or students who are deaf blind. And that was the title of the document. It was also vetted by the field and showed high levels of agreement. So we do have a bit of research on that particular set of competencies.

>> In 2008, about 2007 Cal we began the efforts with the Council of exceptional children. Again, the goal is to professionalize this practice and to have the approval of a nationally recognized organization and it was an important step. So now the concept for exceptional children has a set of competencies that they had in their bread book and on their record as showing they have approved these competencies for those who are acting as intervenors with children who are deaf blind. That is one of the few levels of competencies that they have. So that was an important step.

>> So what I want to do with these next few slides is not make you go to sleep because you will see a lot of writing. What I wanted to do is just show you what those competencies look like. I wanted you to get a sense of what skills and knowledge these intervenors have. When you read through them. I hope you will be impressed with the knowledge and the skills that these people have to have to be called an intervener. So I will go through these general standards and this will be recorded and you are welcome to go back and look at these or if

you need a copy I will be happy to get those to you in another format. But as you can see there is knowledge about deafblindness and learning differences and we have what are the effects of deafblindness and we will go to standard 2. This is learned development and where we talk about the individual learner and the likes and dislikes and what about the optimal logical and audiological conditions of the person or what about additional disabilities. All of those are still part of standard 1. In standard 2, we look at learning environments. You consider the knowledge that the intervener must have and then we start looking at skills, establishing a trusting relationship and providing an atmosphere of acceptance and promoting self-esteem. All of these things, including utilizing health and safety practice, all of these things are part of these competencies that these students who are training to become intervenors must show if they indeed have this knowledge and skill.

>> Standard 3 has to do with calendar systems and 4 has to do with data collection and modern. 5 is the most [Indiscernible] standard and I would recommend that anyone look through this. There are 34 competencies under standard 5 because it's all about instructional planning and strategy. We are looking at the how to and how do they work with these kids and what do they do and for example direct learning experiences, looking at anticipation and motivation and communication and confirmation. Adapting materials and helping with self-care, responding to behavior and promoting self-determination. This is a very impressive list. Again, if any of your interested to go back to those, feel free, because we are going to them quickly and the ideas here is for these parents to understand when you have an intervener with your child, you can also expect to have some skills and competencies and that is part of this. It's not just having a body in place with your child. You can see more there. This is knowing how to work with specialists and facilitating language and literacy and communication and expressive communication and these are very deaf blind specific end this makes these people outstanding and we have that been shared tonight and she has mastered or shown that she has competencies and all of these areas that we work with.

>> Standard 6 has to do with professional learning, and ethical practice and just like an interpreter, if we like in the intervener profession to the interpreter for fashion we have to have aspects and roles and responsibilities and some type of professional development. And then standard 7 is all about collaboration in working with teachers and working with team members and family. All of those are competencies that have to do with that. Again, a very impressive list. As we talk about what components are part of their training, they have to show competencies when they go through the process of doing that.

>> Let's talk about what kind of training has been done in the past. When I first got involved with working with intervenors here in Utah, there were a lot of different trainings being done and we didn't have very many intervenors in Utah early on and there were just a few until we really got the program up and going. But whatever we could do, conferences or a workshop or we would hold in services or some type of self-study or on-the-job. All of those were part and I was involved specifically and a lot of in-service training you'd -- early on but again any profession involved we have learned that we have to have a more rigorous type of training, a more coordinated and structure type of training than can be offered in any of these other specific formats. We have moved toward training in the last few years and again that is part of our goal to professionalize the practice so why is higher education important? Why have we moved in that direction. One of the things that we have noticed is as we look at other professions, it is very helpful as you are looking at systems changes or trying to professionalize some things, you look at other professions and say how is it done there and what did they do and what passed did they follow and the interpreter from Dutch profession is when we looked at closely. Interpreters, as you know, are listed in IDE a which is the law as related to this so they are they are based on their work to become recognized as professionals. So again to follow a similar path, that is again a part of higher education, the interpreter training program that used to be done on an in-service basis are not done anymore as they have moved to higher education programs and interpreters now here and you talk have to have a bachelors degree and in some states they have to have a Masters degree. So that particular profession continues to up the bar in terms of what kind of training you need. The other piece is state and local systems for more inclined to recognize the value of training to higher education. That is something that is part of life around the country and in different states and the value there is in higher education, groups of being national organizations endorsed that higher education or competency part so that is part of moving forward to professionalize the practice. One of the advantages of the University and community colleges, there is always a system in place already, checks and balances in place to ensure quality and sustainability. So when I was doing in-service training, I did not have the luxury of all of these things as I click down through them. I was doing on-site and a day here and there. When you look into a more structured setting like a university, you will see there has to be approval for a certain level of rigor and the instructors and the supervisors have to be qualified and may have to go through a vetting process and the programs have to include monitoring and evaluation of instructors and the -- Beth will be sharing her programs. I have to be evaluated every semester and my students tell me what they think. So the program has to be looked at and watched over and it's very systematic, and there is high accountability for me and for the students.

>> We have to do a [Indiscernible] so we can measure knowledge gained and also the students do better when they have deadlines and we all know that. You give us two weeks to do something and we will probably do it the last day because most of us kind of do better if we have a schedule, a timeline. So we have personalized instruction or mentors or coaches and we have a supervised practice [Indiscernible] that we will talk about.

>> Back to that slide, there are some advantages, some definite advantages of why higher education is important. It's also sustainable. So programs that are at universities are community colleges, the instructors may come and go, but those programs can be sustained. They are not dependent on just one person.

>> And also, a part of professionalizing the practice as we look the other has to be some type of a standard that people work through so there was a recognized standard. For teachers cut a have a teacher's license in our state. Interpreters, they make it a state license but they can also get a national certification through the interpreter training program. So, again, it was important for us to have a standard that states would look to. Many states feel they don't want to create a new certificate for their state, but they will pay attention to a national one. So we worked with several groups. We were finally able to establish the national intervener credentials to the national resource Center for parent educators and Marilyn Likins is the director there and there is her address and all of these interveners get their credentials through that. So now we have a national bar and I will go through all of these to give you an idea of what they have to do in order to get that credential. They have to do a practicum portfolio and they pay just a minimum, a \$100 processing fee and once they get the credential it is good for five years.

>> I will go quickly through these. Any credential, and a national certificate, it is important because it recognizes a certain standard, a quality level of training, a standard of excellence, and it helps with the systemic work. I have had many people ask me, what makes a intervener? What makes the difference? When can a person be called a intervener? This is part of why having a credential helps create that standard where we can say, does this person -- have they met the standard themselves. Then they are intervener and hopefully we will get higher pay and more recognition.

>> Quickly, I wanted you to see this map . This shows where we have credentialed interveners around the country. You can see one through five and five through 10 and 10 or more. We have a lot of Texas and Kansas. We have a lot in Michigan thanks to Beth and her work there . We have a lot of interveners now with this credential who have the training and who have gone through the training and who are available. If you are in a state where you say we have not done much, don't feel discouraged because these interveners, the majority of them were working while they got the credential, so they were assigned to a child, and then make up the training and got their credential while they were working so it was mostly a matter of growing.

>> For the programs available now, I will go quickly through mind and terms -- turned some time over to Beth. Utah state has a program and we have had our programs and 2009. Beth Kennedy did an amazing job. It was amazing to do. Any of these low incidence programs are difficult to get the university level. And we continue to make more effort that way. Just a few quick things about the Utah state program. It's all online and it is asynchronous so I have students who study from all over the country and and with Beth and our program. They can get undergraduate or graduate credit. We now have continuing education credit units that people can take if they wish and we also have an Associates degree program in general studies. We have very few interveners go through that and that is mostly because of finances but it's on the books here and there are very few programs in deafblindness in the country. Our coursework includes interactive discussions and video clips and applications and assignments and power points. So it is fairly rigorous.

>> This is the required coursework and I won't go through it but you can see the practicum is this third class. All students have been intervener coach that works with them during their hands on practicing experience and may have a coach who works with them and the coach is either on-site or is a distance coach. I do a lot of my coaching by distance. But we have many coaches around the country who have had training. So the students here take this course for four credit hours in the second course for four credit hours and they do their practicum for four credit hours and then they are put in the position of completing their portfolio to get their credential. I will turn the time over to you, Beth. Or programs are similar but a little different. So she will share about Central Michigan coursework.

>> Thank you. This is Beth. Like she said, I just started this program in 2016, so my second cohort of students is finishing up their third class. I don't want to get ahead of myself, but

like Linda's is, it is online so nobody needs to move to Michigan. I do have students from within Michigan, as well as around the United States. Most of the coursework is asynchronous. It's just that coaching piece that Linda talked about where that would be happening in real time. So the program has four classes where Linda's has 3. Linda's takes a year and a half and that is three semesters to complete. The CMU programs can be completed in one academic year. So that is where our programs differ a little bit. Here all of our online classes run for eight weeks and so you take DB 101 the intro class for eight weeks and then you take 201 for eight weeks and then spring semester you take the final two classes, one is the intervention strategies and the last one being the practicum class that Linda talked about. It does add up to 12 college credits. One other difference between the Utah program and Central Michigan right now is CMU students began their portfolio right away in DBI 101. So doing preliminary and basic pieces of the portfolio and it fills each class until that fourth class, when they are working hard to get it all completed. And then like Linda's program, you submit a portfolio to the national resource Center for parent educators and that results in this national credential that she is explaining. So the program, like I said, I didn't say much about myself. I worked in the field for almost 27 years so I worked in a variety of positions with kids who are deaf blind and as a consultant for professionals and families to support students who are deaf blind. So I was able to do the presentation so with each class people will watch multiple presentations of me talking about the content that and intervener would need to know to meet the criteria of the national credential. This includes a lot of video clips of students and from what I call guest appearances that are actually kind of talking heads of experts in the field. The content is based somewhat on the [Indiscernible] module the Open Hands Open Access module available on the national Center's website. I have modified content and I have added things and subtracted things. Like I said, I am a presenter for all four classes. So I told you I am an expert in deafblindness and I present in the classrooms. And right now, I am doing all of my coaching myself. In the future, as the program expands and grows, so it may be as large as Linda's is one day. I hope to tap into the expertise of the different deaf blind projects as she has in terms of getting coaches. It's not all on me and accessing the expertise of around the country. That is a little bit about CMU. I would encourage anybody who is interested in learning more to contact me and I can email or talk with you and explain in more detail.

>> I will mention again our perspective here is this is a work in progress that we are not where we were even two years ago and we hope the will be larger in a few years. We are a growing professional interveners who will be available to work with your children. So hopefully you'll see that big picture.

>> Now share with us your great thoughts, Jodie Beavers Well known when is 15 and he has had for interveners starting about the time he was 6. And I feel like we have experienced a little bit of everything and he has had interpreters and now he has interveners and our experience with interveners is that they do so much more than an interpreter can do for our children. An interpreter primarily focuses on communication only. Our students have so many more needs than that. I flick interveners are trained to see the world from the perspective of our students. Because of that, they can anticipate the obstacles that the child will face and develop strategies to help them overcome those obstacles. The needs of Nolan has changed over the time he was six The needs of Nolan has changed over the time he was 62 now that he is 15. And I feel like the interveners they develop a post personal relationship with that student and so as a result of that insight, they always go above and beyond. This is the beyond what they need to. On the screen you can see one of his first interveners. She has done so much to change his life. She not only helps the access school behaviorally and academically, but the biggest thing that she did for him was helped to access his life socially. Nolan always wanted friends, but he could never figure out how to make them or didn't know how to interact with other kids. She worked very hard with him in developing manners. And he would take those manners he was learning with her, and he would apply them in other areas of his life. Just to see that pride in him was amazing.

>> Now that he is older, his needs are changing. He is not as behavioral as a means to be and he is getting older and we are looking at transition. He is a freshman in high school and he has started going to jobsite so now he is not only had school but he is going out into the community and has interpreter will help him access his social experiences at school, but then she also takes him out into the community, and he has to learn what it is to be that behavior appropriately at work sites and his responses and how to be understood. So he is really good receptively. He has a cochlear implant and he can understand the world around him and what is said. That people don't understand him very well. So one of the biggest jobs with his interveners is to help other people understand him and to make sure that he is persistent in getting his point across. They have been so key in doing that. Has confidence hasn't grown amazingly with having and intervener -- the intervener.

>> Okay. One of his favorite things to do is have meetings about himself. So we have had PCP meetings which are person centered plan. Our interveners are always a big part of those plans. You can see on the screen there is a picture of him vacuuming at is jobsite and

also a picture of himself. At the top it says I feel excited about going to my IEP so he is gaining confidence and his intervener is helping an advocate for himself and think about the future. She can talk these things through with him so he is prepared on what he will do. So we can definitely see him growing.

>> Here on this next slide, the intervener is with him at a different jobsite. This one is a picture of him watering plants. In the past, when he was younger, he had huge sensory issues and he would not touch a plant. He was terrified actually of plants. Now we see him and his intervener helped him overcome those fears and you can see that he is actually taking care of and watering the plants that is jobsite. Next to the picture of him watering the plants, there is a picture from his past about -- it says proud touching plant, not scared. It's a picture of him and his intervener and he is touching a plant. So out of all of these little hurdles that the interveners have helped him overcome copy of all the amazing. He is always so proud and happy. He has so much trust for his intervener that I will -- would love to see the intervener programs continue past school age. In Michigan he will be able to attend school until the age of 26 and I know that is not true for every state. I am a little worried about what will happen beyond ages 26 because he still have that need for the intervener and those services are no longer available. I am hoping we can change that by the time he grows.

>> Here is what does it mean to have an intervener for Nolan. For him it has been a life changer. It has build his confidence and it has allowed him access to friends. It has allowed him access to his jobsite. He has become in touch with his emotions. One of his interpreters, when I got started [Indiscernible] for him and he was never very in touch with feelings and he can identify them and himself or other people. So she developed a whole notebook with dividers that have the different feelings labeled and then after he would experience those feelings, his intervener would have them do a picture and they would put it in the appropriate section of the notebook. So just having the interpreters -- interveners be one step ahead of his needs all the time, it's amazing. That is something that they are just not trained to do. If anybody has any questions, I would be happy to answer them at the end.

>> If I can follow up, Jodie, I love that list . When I first read that, I thought what a gift that is. And if you don't mind, I will go back one. I have an opinion, I can make choices. I believe for my experience, and I know everyone would agree, for many of the behaviors we see with

these children, they have to do with not having these things recognize, the ability to communicate or no that they can reach other people. So I think this is a beautiful wish, Jodie . And it's profound what they are giving these students. So thank you for doing that.

>> You are welcome. I would like to add as well that he did not have the confidence before his intervener. So it took a lot of work to have him gain the confidence to do some of these things on the list.

>> Okay. Chris, do you want to introduce yourself?

>> Yes. My name is Christine Jay, and I am a credentialed intervener in upstate New York. I have been a credentialed intervener for five years now. This is me right here in the picture working with my student. But my situation is unique with my student. I started taking care of him when he was a baby. He was just, I think six months old when I started and his mother needed somebody to watch them during the day and I was home with my daughter who was 3. She said, he is deaf blind and do you think that will be okay. I said, absolutely. I would love to get to know how. So I -- know him. I took care of him for a few weeks and it was awesome. We got started that early. And then he went off to a special needs preschool. And my daughter went off to kindergarten and I started working at the school. When he was going to be going into kindergarten you asked me if I would like to work with him, and I said of course I would love to work with him because I knew that we already had a relationship. I knew that he trusted me because we kept in touch throughout the time that he went to preschool. So I said sure. I will do that. We got started. He came to kindergarten. We all kind of looked at each other and we were like we don't know how to work with him. So what we did was we piecemeal is programming and then I had the opportunity of taking these classes at Utah State University. I was thrilled because I really needed to learn how to work with him. What an eye-opening situation. I absorb the material and I went to school and I did this to my whole team and then all of a sudden it was like, I was doing one of my things online and it said, do this not for. I said no wonder he is not advancing because we were all like I will do it for you and then I am like, okay, I went to school that next day and I sat him down and we talked about it and I said, you are going to be doing everything now. He kind of gave me a little bit of a puzzled look and we went on what our day and sometimes he would just stand there and wait for me to do things. And I would sign to him, sorry, your turn, you do. And then all of a sudden he was like, okay and the jig is up. I am going to have to be doing these things. From then on, after all of the classes and everything,

he started to drive -- thrive. He started doing his calendar system which is how his day will go and what he will do next. And what he will do after that. He thrived. He knew the signs. I was even starting to teach him the braille words for his calendar system. He was happy and doing so well. It was so awesome to see. It was all because I took those classes through Utah State University. And then, his programming, it all came together because I turn key to all the information for the whole team and we would have team meetings once a week, and IA would for an hour teach the team what I had already learned. That just made everybody feels so good with working with him because they knew now, okay, this is really how we are supposed to be working with them. When he first came to kindergarten, and it's a little embarrassing, but we had no idea. We would sign to him and get behind him and put our hands up in front of him, and his back was to us and he would sign that way. We did not know that we had to join hand underhand facing him. So that taught us, it made a world of difference for both he and I because I knew what I was doing. And then he, in turn, was learning how to do so many things. We had started community outings and we would go into the community and we would have breakfast and he would have to sign what he wanted and he did use symbols and the hand underhand signing. There was one time, I decided that -- I know his favorite is pancakes. I decided that I will do the simple pancakes on his board. We were there and he was [Indiscernible] and I said the one eggs and he would sign no. Okay. Do you want waffles? And he would sign no. And I thought well it's either eggs are waffles and he kept signing no. No. No. And I said what do you want? Tell me. And he sat there for a little bit, and he had a few behaviors and was pounding on the table. I said you need to tell me. And obviously I was signing all of this to him. And finally, he signed the word pancake and I showed him the symbol and I said this is what you want, pancakes? And he signed yes. And smiling. That really showed me that he could do anything. He could tell me and show me what his wants and needs are. So that made me feel good and it made him feel good as well.

>> If I did not have that training through Utah State University, I don't know where he would be now. It gave him a purpose in life and it gave me a purpose in life. It all worked out for the best. Now I will change roles. I am the chair person for the national intervener Association, NIA. Our mission is to promote quality intervention services for individuals with deafblindness. We promote recognition of interveners at local, state, and national levels. -- Levels. I work with the New York deaf blind project on some things and I will be speaking at the eastern state CHARGE conference in New Jersey in May. We all work together to promote acceptance of the term intervener as a unique profession that requires training and deafblindness. We promote awareness of the positive impact on interveners and what that impact can have on a child's learning, communication, and overall development. And

we are true to that because my student was not communicating and not learning and the overall development was not moving forward. Being an intervener with him, that really worked for him. We provide interveners with support and opportunities for networking with others in the field. We have a Facebook page that we work with and other social media as well that we work with and we advocate through the legislative process for national systems change and had interveners recognized as related service providers under IDEA. And we're advocating and we reach our Senators and Congressmen is Congressmen and women to help with that. And NIA is a professional association that people join to support our work and it was developed by a group of interveners and recently within the past year we have really ramped up our meetings. We are really doing a lot of things and we have been a survey for interveners and the standard database. We gather info on what the pay scale is and how interveners are treated. We wanted to know if everybody attended IEP meetings because there were some that were not the ultimate in IEP meetings and we're working on typical job descriptions for interveners because like when I became an intervener, there was no job description. I was just there professional it was an intervener. We are working on that. So people have a job description to be able to take to their employer and say this is the job description and you need to come up with different things to go along with that job description.

>> The membership, we have the credentialed member who holds the national intervener credential and then we have student membership, which our members who are currently enrolled in an intervener training program. We have an associate, a member engaged in providing deaf blind intervention, but they are not currently a national intervener credential. And we have a support membership which is an individual who supports but is not engaged in serving as an intervener.

>> So that is what I do and I will turn it over to Linda? Are you up next?

>> Sally is up next. Thank you, Chris. She has been dedicated and busy. Thank you. Sally will address our next question.

>> Hello, everybody. She mentioned I am a parent of a 36-year-old who has CHARGE Syndrome and we were told when he was born that he is deaf and blind. We had to learn all about this on our own. So I want to talk you through this. When he was young, very young,

when we met John McGinnis, who is the person who --" we are using on the slide. He says if a child has enough vision to compensate or does a child have enough vision to compensate for the lack of hearing, and in our case, Andrew did not. He is blind in one eye and legally blind in the second type. And the next question is does the child having of hearing to compensate for his lack of vision? Will he is profoundly deaf. The answer to both questions is no. John McGinnis though she started this program in Canada but he did a lot of training with students who were deaf and blind so we learned a lot from him.

>> If you look at the slide, a typical child, most of what they learn is incidental learning. Basically, it is learning so much by just watching what goes on around them. The next one is secondary learning like listening to a teacher or person one-on-one and direct learning is the hands-on stuff that is the one-on-one. So that is for a typical child. Then we go to a deaf blind child. It has to be just the opposite. When our son was born, we thought how are we going to teach him everything that he needs to learn because everything that he needs to learn has to be hands-on and one-on-one. Secondary learning is difficult and incidental learning does not occur. We are so amazed at watching Andrew, what he doesn't pick up better other two kids pick up in the environment when we are at a family gathering together. So it poses unique challenges in most educational settings because those settings are not designed to provide a lot of one-on-one learning.

>> Several years ago, the people you see listed on the right hand of this slide, we knew that we had been successful at some point in our child's life getting an intervener for our child but we know that other parents were having a hard time. So we got together with Linda and it took us years to get this booklet together but here it is. It's a little spiral-bound booklet and walks you through kind of what is deafblindness and what is unique about deafblindness and why does your child need an intervener and how do you get one. So we want to talk a little bit more about that process.

>> People always say how do you determine the need for an intervener or how do teams know and you have to back up and look at the special education law called IDEA . It ensures that we call a free and appropriate public education or FAPE , you'll see that all over the place. Well, the big keyword in IDEA with FAPE is it requires a child has access to general education and the general curriculum activities and specialized education services. My son did not have access. If the teacher was within range, he might the able to see some of her signs or if the other students in his classroom are close to him, he may be

able to see their sign language. He did not have access. This is a key word that I want all teachers to really hang on to and write it down and think about is how your child is going to access a school. You think about a student in a wheelchair. They have access in the classroom because -- or getting into school -- because of a ramp or elevator. You think of a student who is deaf and may have access because they have an interpreter. Well, our kids have access to an interpreter, and that is how I think about determining the need for an intervener, does your child have access.

>> They do provide a critical role in providing free and appropriate public education and the word there is appropriate. It would not be appropriate for your child if they could not see what was going on or hear what was going on or understand communication. So we will get into this a little bit next time in the third webinar about how to actually do that. But interveners can be designated as related services are supplementary agent services.

>> So here we are thinking about some key questions and I will mention this now in case we run out of time. But this booklet is available on intervener.org and inside the book we have 64 pages. On about five of those pages we talk about this information, which is these are key questions. Think about how does my child access visual information. How does my child access auditory information and how does my child going to have consistent access to visual and auditory information and instruction needed for learning and interaction and the educational environment? How will you do that? Is the whiteboard close to them? Will you use an interpreter. You think about access, visual access.

>> And then how is my child going to access communication? What is my child's receptive communication? Just think about my son. He depends on sign language. If he doesn't see sign language, nothing is communicated to him. What is my child's expressive communication mode? Sign language. How will he see or access. Who will be able to communicate with my child and his or her mode of communication? This is something that comes up so often in the meetings I have been to with other parents and my own is they say, well, there is a speech therapist who comes to class and she can sign and we have the deaf and hard of hearing person who comes to class and she can sign and the kids now sign language and the teacher does. But I am telling you now don't accept that answer. You need somebody will be with your child consistently throughout the day who your child has a trusting relationship with. So think of these different ways that your child access is communication -- accesses communication. How is my child going to know what is

happening around them and who is there? How will my child know when he or she is safe? How will my child be motivated to try new things and learn? Kids will turn into a lump on a log if they don't have access to what is going on socially and visually and communicatively.

>> He or we are at resources. I have been fighting a cold for the last two weeks. My voice is going and this is the best it has been for two weeks. I will handed over to Linda.

>> Thank you. We were thrilled that her voice held up tonight. You sounded fine, Sally. We hope you feel better. We want to take a minute before we turn it over for questions for resources and here the resources that were mentioned earlier and it's called the Open Hands Open Access intervener learning module and there is the website on the screen. These modules are stated on their website and they are a national resource designed to increase awareness and knowledge and skills related to intervention for students who are deaf blind and are being served in educational settings. So this is a good resource for parents. I know that there have been some session specifically for parents to work to learn about what interveners are and what their role is and how they work in the educational setting. So this is a good site to go to and you can also check with the training they are doing related to that. Also intervener.org, this is the family's guide to interveners and it's online. You can get the booklet by just contacting us, and I believe it is \$15 and that comes with questions on a laminated card or you can download it for free and it's on the intervener.org website and you could read it there under resources. Also, we have, as we said before, the Facebook page and we encourage you to like that page. We will be doing more and more information on that and we are finding it a very good social medium for us to communicate with people all around the world. We would ask you to join us there also. A

>> So we are at the point where we can entertain questions. We will see -- I am not sure, do you want to help us with any questions that have come to you, Sheri Yes. I will help. Megan will also assist with reading the questions in the chat pod. I will have Megan start off.

>> Don't forget, Megan, you are on mute.

>> Hello period --. This is Megan. We have one question so far in the chat pod that I see more people are typing. The first one is a woman wants to know about a link to find

intervener information. She is in Texas and her daughters IEP doesn't specifically say intervener, just parrot training and the person serving in that position right now will not be the next year so she wants to help the district get a jump ahead on training and is wondering where she got to go.

>> Texas is a wonderful place to be looking for interveners. They have a parent group called [Indiscernible] and may provide scholarships every year for interveners to study. And so we have been actually able to train a number of interveners who are on the job. Other words, I think you said that you are -- your para will not be there next year so you want to prepare for the next year. Certainly visit with the districts about if they had somebody in mind. But I know it's possible to get a scholarship and get financial support for enrolling in the coursework. And most of the students enrolled for the CEU option, which is not as expensive. So I can give you -- we can give you the contact information. This is if you want to email Sally or myself we will give you the contact information. They are a wonderful resource. Those ladies are some. So I would highly recommend them.

>> Are there any other questions? Feel free to put it in the chat pod if so.

>> I will add that what we have seen, somebody talked about the IEP. It specifically does not say intervener. It says para in training. That has been one of the issues that we have seen all over the country. We have had parents step up in their meetings, and again we will talk more about this next month. But ask and request that the term will be in the IEP. Some districts will not. Some parents have been able to get it in the IEP but then they also add that somebody training -- trained in deafblindness -- or somebody who has the national intervener credential or is currently are will agree to take intervener training program for higher education, so that is on the IEP of federal children that it is there because their parents know what to request and what to ask for. The nice thing about that is once you get that IEP, the wording plus the training, the level of the standard you want, that follows the child if the child moves into a new school district or whatever and one citizen there you don't have to fight that battle again. I will tell you that some parents have had to go to do process over the training piece so the district will give them a one on one but then they will not necessarily invest in appropriate training for them. They will come up with other options for training. Again, as parents, when you ask for this, or work within your IEP, it's really important to manage the wording that says you want a nationally credentialed intervener who hasn't either already or will work to receive that. So I just have to add that training

piece is definitely important for you to be savvy about and to specify. I think she also said that [Indiscernible] in the future and I didn't catch what she meant? Did you understand what she said?

>> Linda. This is Megan. I think what she was suggesting is that they were going to be moving to Texas. I put the address in the chat pod.

>> Perfect.

>> Another question?

>> Please give comments or suggestions on how to transition intervener services into adulthood.

>> That is really a big discussion. In many cases, even in my own state, it has been difficult to get interveners recognized in adult services and support for -- service providers are provided here. Texas has done a wonderful job of that. They put the main intervener into their Medicaid waiver. So they have interveners that are funded and recognized through the state [Indiscernible]. Again cat if you want more information on that, if you want to contact me, I will give you more information about what they had done. But many states are still struggling to get that piece with the adult services.

>> This is Sally. I just want to add to that, there is nothing like the power of a parent to get things changed. I know that it took me probably five years from the sitting back waiting for somebody else to do things. I was not used to taking control of situations. I thought the school did their part and the doctors did their part and you are all CHARGE parents and you know that is not the case. So I realized that I just had to start doing things on my own. And my husband and I did. We were not afraid -- well, we were afraid. But we did. We went to the state legislature and lobbied and a few of the different states that we lived in, and we have lived in 5. We have seen a lot of different services. But it really helps to get involved. I know you guys are busy. I have been there. but it really does help to get involved. If you are a member of a group of parents in your state, that is the way things are going to change and I

know they got this Medicaid waiver done in Texas because a parent got involved. Things are not when to happen if the profession goes cold. They need to see you, the legislators need to see you, and they need to see your kids. So little encouragement.

>> This is Sheri. Before I get to the next question, I noticed that she was clarifying her question earlier. She was asking what site can she find that information in California. You had mentioned that for Texas. Is there something similar in California?

>> The person there is Marie [Indiscernible] and maybe you can put in that contact information. The other thing we saw and California is an agency now who is hiring interveners and then brokering them the school districts. It is kind of a new model but they also do the same thing with interpreters and with oh MM people and there is financial support their through that agency to pay for these people to be trained because then they go out and work in the district under the agency's name. There are interveners in California. Maurice would be a good one to help you and give you good information and go from there.

>> The next question comes from Sharon. Is there any financial help to get the interveners certificate, either for you talk or Michigan University, or does the NIA have any information about financial assistance?

>> Okay. There is limited financial help at this point, I am sorry to say. We do have a scholarship that has been funded through the [Indiscernible] drug company and it is for interveners to work with children have where diseases or disorders. So if your children fall into that category with a rare disease or peroxide [Indiscernible] disorders we have sending out from that company to pay for their schooling to become a credentialed intervener and it's exciting to have a company, a commercial company step up and say we will support this. So that is a very exciting thing. We have some interveners to get Pell grants or other vehicles here at Utah State. The other thing is that the CEO options for continuing education credit is only about \$600 a semester so it's very reasonable. So do the daunted by the idea that it is extreme tuition because truly the districts who have supported their interveners in our program have been paying for that CEU option because it's not as expensive as the full tuition. So NIA at this point doesn't have any information about financial assistance to answer that question.

>> Beth, I don't know about CMU, financial assistance? Do you want to take a moment to respond to that?

>> Thank you. This is Beth. I just typed into the chat as well, whatever state you are in, if you contact your state deaf blind project, they may have a partial scholarship and some cases a full scholarship. It's worth corresponding and talking with your deaf blind project. CMU, as I said, you take two classes each semester, one at a time, each one for eight weeks. But the two classes per semester allows for financial aid packages. So at CMU, if you apply to CMU, you can then indicate that he would like to be evaluated for financial aid and as Linda mentioned, sometimes those are grants and sometimes those are student loans, but it is definitely worth checking out to see what exactly you would qualify for.

>> That is a good point about the projects. We have had some state projects, and Megan is one. She was her state director and they were supported financially of her interveners. So there are states that will do that. So as she said, please don't hesitate to check with your state deaf blind project into kind of do some networking to find out because it's doable and we have seen that with over 100 interveners now. It's doable for them to get this education.

>> I also want to say as a parent, one of my husband's famous slogans is all you can do is say no -- all they can do is say no. Ask your school district and ask anybody and you never know. You may get a yes out of somebody. But all they can do is say no. That is the worst they can say.

>> Sometimes school districts will pay all or some of the tuition.

>> I see that somebody was just typing. I am not sure if it's coming through.

>> The question is, do you feel it is best to have someone else be the intervener for your child or is it more worth to try to reach for the intervener program as a parent?

>> That is a good question. We have had some experience with that. We have had parents who take the coursework but we don't encourage them to get the credentialed to do that. I have not -- I have tried training parents and have had parents be involved this interveners, but it has not been what I would recommend at this point because your connection to your child is you are the parent, you are the mother. That is such a special role and to try the service at intervener, and you heard Chris talk about that tough love stuff and encouragement, it's really better and better for you allowed -- for the parent to be trained to get the training so you know to do is what to do at home but to support somebody else in the school system.

>> This is Megan. And Chris said in a chat pod that the New York deaf blind project paid for her coursework.

>> CHARGE Syndrome is considered a rare disorder.

>> That opens that door then for sure. So please contact us if you would like to know more.

>> It is also on the Facebook page, the flyer and information about the scholarship and that information. You can get that there as well.

>> That Facebook page is called interveners and deafblindness.

>> Okay. This is Sheri. I'd -- I was going to say I don't see any more questions. Sally wrote in the Facebook page in the chat box.

>> Is that the name, Sally?

>> Yes.

>> That is the title for the Facebook page.

>> Great. Thank you. Well, I don't see any more questions. We are hitting the hour and a half Mark.

>> I think we will wrap up. On behalf of the -- The Charge Syndrome Foundation, I would like to thank Linda and Sally and Beth and Jodie for speaking with us tonight and for the information you gave us. Their expertise is very beneficial for the families that have a child of any age with CHARGE Syndrome. I thank them for their time and their continued support and advocacy. I would also like to thank Megan Cody cow one of our advisors for the CHARGE Foundation. She is from the national Center for deafblindness and assisting me with the question-and-answer session. I want to remind you to please join us for our third webinar in this series on March series on March 25. It is entitled interveners, how can parents advocate for intervener services for their children. Please watch for our next webinar last. Thank you for joining us this evening and for supporting The Charge Syndrome Foundation. Have a good night, everyone.

>> Thank you.

>> [Event concluded]