Please stand by for realtime captions.

>>I do show we are at the top of the hour. This is Robbin Bull with NCDB. I think we will get started. I want to make sure that we are all set here. Please bear with me. I have my housekeeping script that I usually go through and this is totally off script. [Laughter] I am looking through it, and everything I say is different. I do want to begin by welcoming everybody and thank you for showing up tonight. We do appreciate it. We are going to do things a little bit differently tonight. We do have everybody muted currently. But what we would like to do is have everybody introduced themselves. Since it is a small group, you are able on your phone to use the star symbol and the number six to take the mute off your phone. That will also mute your phone line when you finish introducing ourselves. So what I will do is have you alphabetically through the chat pod introduce yourselves. Just take a minute to do your name and where you are from. Is there anything else you would like, ladies, presenters?

>> If they are a parent or like a professional because I do know we have some professionals joining.

>> Okay. If you can then go back on mute and then we will go to the next person. We will start the recording after we are finished with those introductions.

>> We will also do question and answer session at the end. Also, you will be able to put questions in the chat pod as we go along. We will talk more about that in just a little bit. So I will start with Aimee.

[Introductions edited out for privacy.]

>> It sounds like we have gotten everybody at this point in time. I will go ahead and start the recording and then, Sheri, you can take it from there.

>> Welcome to the third and final webinar in our three-part series on interveners. I am Sheri Stanger am I am the director of outreach with the CHARGE syndrome foundation. We are pleased to have you join us tonight. I welcome back Sally and Linda who will discuss interveners, how can parents advocate for interveners services for their children. Linda is the director for the deaf blind programs at the skyhigh Institute at Utah State University and Sally is the mother of an adult son with CHARGE syndrome and she has worked in the field of deafblindness for over 30 years and is currently the legislative liaison to the national coalition on deafblindness. Tonight's webinar will focus on the rights of children and youth who are deaf blind to have interveners services as guaranteed by the individuals with disabilities education act and the Americans with disabilities at ADA they will share information about navigating the IEP process and guidance will be provided for parents who want to obtain services of intervener for their children. This webinar will be recorded, and it will be archived for future viewing. So please do be mindful of your comments in the chat box. It will be seen by anyone viewing this webinar, so we do ask that you please refrain from writing personal or sensitive information. The charge send him foundation is a not-for-profit organization that provides support to individuals with CHARGE syndrome, their families and the professionals who support them. Our vision is a better world for people with CHARGE syndrome and we gather and develop and maintain and distribute information about CHARGE syndrome and promote awareness and research regarding its identification, cause, and management. Providing webinars is a another way the foundation furthers its mission to lead and partner and improve the lives of people with CHARGE syndrome locally and nationally and internationally through outreach and education and research. If you like what you see tonight, and you believe the work the foundation does on behalf of children with CHARGE syndrome and there's -- families is important, please consider becoming a member of the foundation or make a donation through our website. The presenters request that the question-and-answer session be saved until the end of their talk and that it be done through the chat box. Please keep your phone on mute. If you write a question in the chat box please note that the response will occur during the question-and-answer session, and Megan from the national Center on deafblindness will assist in reading your questions out loud. We thank you for your support and for joining the foundation and our presenters this evening. Enjoy.

>> I am Linda Alsop and I will start off. Just to give you a little information, Sally and I will tagteam tonight so we are kind of doing a duet so I will say some things and she will say some things and we will go back and forth and hopefully that will flow a little bit easier. Also, thank you to both of you introduced yourself. It helped us to know who is on the webinar and I am excited that we have a parent on the webinar who is in the process of what we will talk about tonight and that is writing a request and talking with the district on intervenor -- intervener services for her child. It is good for those of you who are in that position are thinking about being in that position, hopefully this information will be useful tonight. We tried to make it so it is not quite so dry. It is a lot of legal information and we will try to make it not to drive but if any of you have questions, of course, please put those in the chat pod and both Sally and I are available for a phone call and email. We wanted to put a few review slides in.

>> This is a definition of a intervener, a person who works consistently one-to-one with a child who is deaf blind and has training in specialized skills in deafblindness. Again, the difference in somebody who just works one-to-one with a child who is an eight and somebody who is an intervenor -- intervener is that training in specialized skill. And we will talk about what that looks like and I will refer again to that tonight.

>> The role of intervener is threefold. It is to facilitate access to environmental information. As you remember, in the first webinar, we showed how environmental information does not flow naturally, so there is a disconnect and barriers there to the flow of information so that is what does one of the roles of the intervener. Communication is a key piece and we will be looking at that for the legal issues related to communication. And to develop to maintain a trusted and interactive relationship that promotes social and emotional well-being which is a research based role now and we talked a little bit about that in our first webinar.

>> So with that being said, we will start with -- right away with the law. For those of you that may be new, IDEA has been a long around a long time, since about 2004. It has had a little bit of change to it and we are hoping for some more in the near future but basically it is the individuals with disability education act and it is a complex and lengthy law. It is very long, but it ensures specific rights for children in special education. It is all about these children's rights. And that is the key. Again, if you're a parent, these are the rights that your child has. And for summarizing the areas, one of those rights is a free and appropriate education space and you will hear about that and should hear about that and it requires

that a child get special education and related services at public expense and it also means that that child has to have the educated and general education curriculum and general activities as well as special education. That says they have a right to all instruction in the educational system. And it guarantees appropriate evaluation which we will talk more about and it also talks about procedural safeguards. And we will not go into that at length, but you will get those from your district. It also talks about, and I will start at the top, a IEP. Every child has a right to the IEP. This is for children ages 3 to 21 and it is a written statement. Again, that is developed and reviewed and revised, and it is a and -- an ongoing document. It states that special education and related services that must be provided to the child. That is a legal document, once it is developed and have to be signed. And we will talk more about that. A least restricted environment is another important term to be familiar with and that just means that to the maximum extent possible, that means as much is possible, any child with disabilities, any child in public or private institutions or facilities, they are supposed to be educated with children who are nondisabled. In other words, they don't want restricted environments where they are around other children, were normal educational activities aren't occurring and where the curriculum is not the same. We talk a lot about least restricted environment related to intervener -- interveners. Parents need to know they participate in all decision making. You are the most important advocates with children with disabilities and it is important for parents to remember that, that you participate in all of it.

>> Again, if we look at what IDEA is, it ensures a free appropriate public education to all children with disabilities and it requires that a child have access. I have bolded these access pieces because that is a key piece that you will want to use in all of your conversations about your child so they have a right to access the general education, the general education curriculum and activity and specialized educational services. So access is a really key term, and especially for people who -- children who are deaf blind, it is very relevant as you remember from our first presentation, they don't have access. They don't have the same access as other children just because of the disability or lack of consistent auditory and visual information. So when our children go to school, there environments are restrictive by nature of the lack of access to information. So that is an important piece. IDEA talks a lot about it and there are many references to access. ADA, the Americans With Disabilities Act, talks a lot about physical access to buildings and other access. As a parent, you should become very comfortable talking about what access means for your child because that is what the law guarantees.

>> Now, we have a little bit of that ground for IDEA and we can talk about -- background for IDEA .

>> Just to piggyback. I always think of a child in a wheelchair, they have access to the school and ramps and elevators, etc. Kids who are deaf have access to education through interpreters and other means. In your mind, access, we said many times and there is a reason for this, try to use that word as much as you possibly can and get it into your vocabulary so that when you are talking about your child, you want to always think about access. To me, that is the answer and where you will get a intervener for your child.

>> As you can see, I am the I in IEP. Every child who qualifies for special at must have an IEP and they are individualize. If you have any thoughts that maybe yours has been copied from somebody else's IEP, and if it doesn't sound like a child, please let somebody know. It is a legal and binding document. By understanding your child's IEP and taking an active role in it, you can ensure that your child receives the education services that he or she is entitled to. And to piggyback again on Linda, it looks really dry and this is dry information. But if you can come out with a handful of terms and things from this webinar, we will be happy and I think that will help your child get what they need in school. If you don't feel confident going to a IEP meeting alone, ask a friend to go or your husband or spouse. As sad as this is, Sheri mentioned I worked for 30 years both professionally and most of that was with the Minnesota deaf blind project and I would go to these meetings for IEP and this sounds kind of sexist, but the people sat up and listened a lot more when the dad was involved in the IEP meeting. It is really sad to say, but if you can get your husband or your spouse or partner, to go, that would be wonderful. You can also bring an advocate with you, a trained advocate, who could find out about who that person might be in your parent and training information which we will talk about later.

>> These are the important parts that we pulled out of the IEP. These are the ones we thought would be helpful when you're talking about and -- the intervener for your child. There is a lot more than the six areas but these were the six that included language that talked about access for your child. We were hoping, my dream, was to show a IEP document so we could say right here is where you will do this and then on this page you will talk about access on over here we will talk about related services but unfortunately it seems like every school district and every state across the country has their own materials. So we were not able to do that. So hang in there. This is dry information, but it is really

important. These are the critical areas, evaluation, consideration of special factors, present levels of performance, annual goals and short-term objectives, accommodations, modifications, and aids and services, and related services.

>> Linda and I will talk you through these important areas.

>> So the evaluation. This is the foundation of the process. If you think that you build a house, you have a strong foundation and without that you have a house that falls apart. So think of the evaluation as being a foundation. And a full evaluation is done before special education services begin and they must be done at least every three years. I can't stress how important the evaluation is. I always request in the evaluation summary record -- report before the meeting and I would take my yellow highlighter and I would go through that evaluation and anywhere that it said Andrew needed something, I highlighted it because you build the actual goals and object tips from your evaluation. For example, if it said, and he is profoundly deaf and he is legally blind and has vision in one eye and is legally blind. So examples of what be on his evaluation was, Andrew need sign language within 2 to 3 feet, or Andrews reading materials need to be provided at X distance depending on his eyes. So those are examples of what he needed. When you're talking to the IEP team avoid the word want because as parents, we want a lot for our kids. Of course we do. Remember, this is a legally binding document and a legal process and the word that they use is need. So again, you will go through the evaluation and look for all the words that say meets your child's needs and such and such and when you are talking to the team use the term my child needs rather than what I want. Again, Linda talked about appropriate public education and these needs will be the basis that the IEP team needs to develop the appropriate education for your child. You want to emphasize because of your child's vision and hearing loss he or she doesn't have equal access to the visual and auditory information about peoples and things in the environment. It is needed for learning and interaction and education and the environment. Just copy that statement. If you can't memorize it, like obviously I did not, just take it with you.

>> So IDEA requires that parental input must be considered in the evaluation of your child. They need -- they should be asking you about your observations in different situations for your child. It also requires that the evaluation is administered by trained and knowledgeable personnel. Think about on your child's team, who is that person or those people. It requires that evaluation be conducted in the language most likely to collect the

needed information about your child's strengths and needs. So, for example, if your child uses sign language, the evaluation must be done using sign language.

>> And then make sure that this information is included in your child's vision and hearing loss and I have seen IEPs where it was not mentioned and unfortunately the parents showed me a past IEP before the new one came up and there was no mention of that hearing. If that is not in here, good luck getting services. Obviously, you need the information about vision and hearing loss. And then what is evaluation saying about communication? And communication is obviously linked to a child and their cognition. If they don't have communication than the evaluation can't be valid. I used to say in the beginning years, all through Andrews educational life, I said I don't want his IQ tested because he doesn't have the language and the knowledge to be able to show himself what truly is in his little head. And right here, you will see a picture of a great document that was developed by Charity [Indiscernible] and it was all about communication and learning and you should be able to find that online anywhere.

>> Again, think about building a house. If your house has a good foundation, it should be a good building. And the basis of that foundation is the evaluation.

>> I will jump back because I noticed that we left off -- we had a few words on this piece in the evaluation is administered by trained and knowledgeable personnel and this includes somebody trained in deafblindness. That is an important piece and they have to have expertise in the child's disability. And so that is when one of the problems we had in the field is not having a lot of evaluators who now deafblindness, but that is something to ask for and that is something to expect so I know we just left the word off on that and I wanted to bring that back.

>> Let's talk about classification. That is something that is done and sometimes it depends on the district, every three years, I know a district now who is doing it every year. It just depends. Just some perspectives here. If you look at how many's students receive special education, it looks like about 13% of all the population of children grades K-12 and if you look on the left you will see that deafblindness is this black color and look how tiny that is. It is over on the left. You can see that of the 15 major classifications or the 13 that children are eligible for, deafblindness is teeny and that gives us a lot of issues and sometimes

districts are resistant to put in deafblindness but it is very important that that be part of the discussion and be something that the evaluation will help with.

>> We know as far as defining deafblindness, we talked in the first webinar about that definition and how it is not a good definition and really more of a default and it just says where the child cannot be accommodated and a child in a class for hit -- hearing or visual impairment for multiple disabilities. We said that every state has a different definition. We also talked about the definition that John put out and this is one that I constantly use as I am consulting and working with teams and we talked about how there is no compensatory stands and even though that is not a formal definition in your state, you can use this as part of your conversation with the team saying, my child has some vision, yes, but it is not strong enough to compensate for the lack of hearing. My child has some hearing, yes, but maybe not, but if yes, to compensate for the lack of vision. And if the answer is no to either one of those, the child, no matter what the child is classified, they are a deaf blind learner. We don't have a lot of time tonight to talk about some of the issues with classifications. Again, if any of you were in the middle of that please don't hesitate to contact us. We can help. Where I see some of the big issues is with the child who may have and auditory processing disorder and the child responds to sound and everybody thinks that child hears and he turns from across the room. Everything seems good enough. The hearing seems good enough for the vision -- or the vision may be good enough and therefore they hesitate to put that classification there. I would recommend just from experience that that is something that you want to see in your child's IEP and because that term will carry over through the years and help you in terms of services and information. So, again, there is more to say on that, but just know that is an important piece. There is help to define that and talk that through if that is needed. Again, evaluation leads to that, so that is where the hearing document, the vision document, all of the evaluation documents are going to support the access through vision and through hearing and what other places if there are other disabilities coming into play. So that evaluation is very important so you can refer to that if there are any issues about classification at that point.

>> Back to the IEP. Again we put this up front and on some IEPs it is upfront and some I have seen on the back at this is part of the law that the IEP team must consider five special factors. Those have been there for a while and the first one of course is behavior and if the behavior impedes the child's learning, then you have to go into positive behavioral intervention and if the child has limited proficiency, if not an English speaker, you have to consider that. It is the third and fourth bullet that applies most to our children and one is

blind and visually impaired. You have to look for braille. They have to discuss if that is needed or not. The fourth one is when I refer to all the time, because you have to consider the communication needs of the child. In the case of a child who is deaf or hard of hearing. They have to consider the child's language, communication needs, opportunities for direct communication with peers and professional personnel in the child's language and communication mode. That is a very powerful statement. As a parent, or as a professional, you can say how are opportunities for communication with peers and personnel going to be guaranteed. In my child's communication mode, whether that is sign language or using assisted technology and whether that is signaling, there also has to be opportunities for direct instruction in the child's language and communication mode. That is a very important piece as well because we may have a child who need sign language, but the teacher and others don't use sign language, especially tactile sign language. So many children who need tactile sign language, nobody around them knows that. Again, that will lead you into the need for a intervener because that is one of the major roles of the intervenor -- intervener. This is a very important statement. I want to highlight some of these to make sure you*those and if you take notes you can use those later. Then there are the present levels of performance. This cannot be rushed. Sometimes teams will hurry through this because they want to get to the goals. This is important because you have a chance here to give your concern and I have to look at evaluations and they have to talk about your child's strength, which sometimes is not well discussed or well acknowledged if the child is struggling in school or has a lot of issues going on. Also, the function of classroom performance has to be. So, again, if it is not there, you can ask, where is the functional performance data including the academic development and functional needs. You can ask for that because that guarantees it under the law.

>> Levels of performance must include this statement as well. How does the child's stability related needs impact his or her performance and participation? That is the key piece and that has to be stated in the IEP. Again, for children who are deaf blind, we would say, my child's educational performance and participation is not at the level of other children and can't be successfully accomplished because of combined vision and hearing loss. So that is an important statement to emphasize. Again, that has to be whatever the impact is on the educational performance, that has to be stated.

>> A major need then is the access to information and educational environment. Again, why you need to make these points, if you are going through this process, is that each of the goals and objectives have to address these needs. So there is a correlation there. If you talk

about access, you talk about communication right up front, and when you look at the goals and objectives and the support, you can refer back to those. Again get that access.

>> Now, we won't take time to go through this whole list. But in the parent booklet that we referred to before and the link, this is a booklet that has been put together that has a lot of this information in it relating to the law and these are very valid questions can be asked again related to your child's needs. Of course, right up front has to be what is going on with my child's vision. My child only has vision in the left eye, that will affect everything else going on. If my child only hears minimally, that will affect access. So how will that be provided? That is a need. And the information of that vision and hearing that does not allow for, that is something to ask. How will it be provided to my child, and how is conceptual learning going to be provided. You get the idea again. We are talking about the disability, and you are asking the district, how are you going to provide these things or these things must be provided to my child to connect them to allow them to learn and to provide access. Communication, this is really important. Who is going to communicate with my child? My child has a certain mode and how is my child going to have information and how is my child going to be able to request something, to ask for something, to get help. How will my child talk to others and who will understand my child? These are very valid questions. Again, when you talk about communication development, which should be part of the IEP, then you say how is that going to happen and how is my child going to develop in their communication? Who will be doing it? What methods are going to be used? And all of those are very important discussions to have related to your child's need and these are listed in the booklet. We are just barely touching on them. This is a big piece now. When we were first doing intervenor things years ago, the social and emotional well-being piece was a little bit more on the warm and fuzzy side. But with the brain research, what we know now this is absolutely evidence-based. If you ever run into somebody who does not take this seriously, then you need to refer them to the research because the research knows now that in order to learn, a child has to feel safe, has to feel motivation, has to know what is going on and can't be under stress and has to be able to -- the brain has to be able to process what is going on. So again, they have to have a relationship and they have to solve problems and all of these things are important to learning. Again, these are all very important questions. You can give these questions to the team of the parent. You put these on a little card, and again, parents can take them in and to say these are questions that we want to address and you can say that in your parents concern. That is something that is there on the table and that gives you an opportunity again to be knowledgeable and articulate about what your child's needs are.

>> Okay. After that, after you establish all of that, it is when you set the goals and objectives. This is a struggle. I work with different teams doing IEPs, the goal writing and objectives writing can be all over the map. So you can be guided on this, but the goal setting has to be setting specific and measurable and relative -- relevant and attainable. They have to match again what is identified in the present levels of performance. So if the need was addressed and identified for say access to auditory information, if any of the goals are set, that has to refer to that so the goal can say something like given the support of an intervenor, the child will respond by localizing sound and that could be a goal in his auditory area. But it has to reflect and be written so that it reflects the reports of the student can be successful with that. Don't hesitate to ask questions if the goals don't correlate. Again, and all of the goals, there has to be that access piece or your child will not be successful.

>> The other important thing is that your child has a right to make meaningful progress.

>> This is a very important thing. This is especially relevant because statistics have shown that children who are deaf blind don't make a lot of progress and they can go year to year and the goals are the same and I have worked with a number of groups that every year the IEP just looks the same over and over. Again, this is not in keeping with the law. And what is exciting, we just had a court ruling a year ago. The Supreme Court issued a unanimous decision that provided students with disabilities the right to more than minimal progress. Again, minimal progress is something challenged in the Supreme Court. So quoting that, IEP programs must be appropriately ambitious in light of the child circumstances, just like any other child has to go from grade to grade in the goals may be different but every child has to have the chance to meet challenging objectives. Now after this court decision was done, then the department of education weighed in on at. Again as important to see what the Department of Education said. What Betsy DeVos said, the Secretary of Education, they said they have to reconsider the plan if they are not making progress. So if you are in that situation where your child is not making progress, they have to think about that and deal with that. So to quote her, all children must be given an opportunity to make real progress in their learning environment. They can't be passed along from year to year without improvement. She said they must be provided the support needed to empower them to grow and achieve ambitious goals.

>> If you are in the middle of this, you can take this and use this because this is the Supreme Court and this is the Department of Education. This applies to children who are deaf blind, just like other kids with disabilities. You have to guarantee that they have the support they need to make meaningful progress.

>> Next on the list of the fundamentals is accommodations, modifications, and supplementary aids and services. This is another area of the IEP. They are provided in regular education classes and other re--- related settings to enable kids with disabilities to be educated with nondisabled children, which Linda mentioned earlier, to the maximum extent appropriate. It also refers to accommodations and modifications to the curriculum and to participation in nonacademic services and extracurricular activities. So think of going on field trips and think of after school activities. That is where that would be put in. Supplementary services can also include direct services and support for the child. So we look at a intervener as a direct service and support. So the intervener can be determined at this time as an accommodation or supplementary service.

>> Again, we will go back to the needs. All the needs that you highlighted. So the needs of your kids drive the services. If a one-on-one paraprofessional or eight is assigned to your child, which we hear more often than not, but does not have the skills to be a intervener, then the services can't be provided to meet your child's need. So how do you change that? You get that person training. Training is needed for that paraprofessional or aid so the intervener services can be provided to your child. This need is for a trained intervener or the need for intervener training should be included in the IEP. Basically, you don't want a warm body with your child who does not know anything about deafblindness.

>> Okay. We thought we would share an example. This is language that was developed by a team cost of this is language that is in a child's IEP and I have shared this with other teams. So modifications are being used but just as an example, you can write something to the effect, in order to have access for learning interactions and accomplishing goals and objectives, and remember that child has to be successful, my child requires a credentialed intervenor or a paraprofessional taking intervener coursework through a credentialed intervener training program which leads to obtaining the national credential. Again, remember, this was written and the wording that a parent took into the IEP team, and this is now in the child's IEP because training has to be emphasized. This parent further added, there is always the potential for personnel changes like a intervener bleeding or the

intervener having an extended year and their district would make a good-faith effort for a future paraprofessional staff to be either a credentialed intervener or paraprofessional taking coursework through the training program leading to the credential. She added that piece because of staff changes in things in her district. Now something to this effect is doable. We have seen it written in and it is certainly within the rights of a parent to ask for this because some districts don't want to recognize the training that a intervener needs. Some districts, this is reality. What we deal with in our advocacy efforts, some districts will say, that here you have an aide who has -- we have given you an aide and that is adequate or it will be some type of minimal workshop with that aid and that is adequate. Again, that is not adequate. So the second webinar deals with that but it is something that should appear in the IEP related to what type of training you want. You want a trained intervener and not just a warm body.

>> Now, there are two approved intervener training programs that lead to the credential. I just put that in there to remind you from our last time we talked that the University is here and that at Central Michigan University and that are -- those are all programs.

>> Finally, this is the last key detail we wanted to talk about, the related services. This is another area that you can use to talk about a intervener for your child. So related services, they are specifically connected to special education instructions and are those needed for the child to benefit from special education programs. Related services must help your child advance appropriately to obtain goals, to be involved in and make progress in the general education curriculum. Be educated and participate with other children with and without disabilities. So we are saying that interveners can be designated also as related services or supplementary aids and services. In the law, in IDEA, it is written that these services can include but are not limited -- then there is a list. It maybe 10 or 15 things and you can see it includes each therapy and occupational and psychological services and etc. Unfortunately, many special educators don't get the part of the law were it says it can include, but are not limited to. So parents hear statements like, well, I don't see intervener listed on that list of services. Or we don't do that here. But we would like to change that. Many people are working very hard for the passage of this act that has been in the 113th and 114th and now the 115th Congress. We are very excited. It has been introduced in both the House and the Senate and we have two supporters in the Senate and 40 some supporters in the House of Representatives. We are working with three groups of students in this a bill and they are students who are deaf and students who are blind and students who are deaf blind. So there are three sections of the bill. The section, we will just focus in

on the intervener portion of the bill and there are 40 pages. This is pretty pages of information. Basically, there is a statement that says, improve results for children and youth with deafblindness by ensuring that intervener services for students who are deaf blind will be listed as a related service. Children who are deaf blind should receive one-to-one services from interveners who have training in specialized skills in deafblindness. Again, we don't want a warm body. They play critical role in the provision of a free and appropriate public education.

>> So you have probably seen information out there about this and you now know that intervener is main -- mentioned in this bill.

>> So what do we do if the district does not agree? I husband and I worked hard to avoid being abrasive and rude and in their face, knowing that we might he in a battle or 2. But ultimately, our son was in their hands, and we always worried about having their attitude on us rub off on how they treated Andy. So we cajoled and informed and my husband and I took turns playing good cop and bad cop and we got involved and we tried our best. We knew that most things in life, as most things in life, relationships matter. So we fostered relationships when we could and we supported teachers and educators in schools when we could, and we were in turn supported by them. Sometimes, that just is not enough.

>> What you can do if you are having trouble and the district doesn't agree with providing intervener services, as you can call a meeting and try to work it out with the team members to come to a compromise. These steps are going more formal. You could ask for mediation, which is a more formal approach to resolving disputes between parents and schools. They are voluntary and they are facilitated by a mediator who is skilled and impartial to resolve the dispute. The state will select the mediator and they bear the cost of the mediation services. And the next step is to file a state complaint. Contact your state director of special education and request information about how to file a complaint. Finally, you can go to do process, which is used as a way to resolve a dispute between a school and parent a hearing officer. It is more formal.

>> Each state has their own way to resolve differences and for more information go to your state parent training and information center. Don't use that link on this slide because we did not update it. You will see it in a slide in a few more slides ahead. Another parent

resource is the Council of parent attorneys and advocates and the website is on the screen.

>> Just so you know, every state has an organization and they are funded to provide attorney services to families in children's with disabilities -- children with disabilities. They pick and choose their cases. I have talked to mine here in Utah and I have talked with some in other states, and they could be a good resource for you. That is an option. If you feel you want some some poor -- support and what to call that group and they can talk with you on whether or not they can represent you. But that is a good group to be familiar with if you are at the point where you are in due process. Realistically speaking, there are due process cases going on, even as we speak. There are cases going on and have over the -- past few years related to intervener services, related to training for those services. And it can be very daunting to families. It is not exactly thrilling. I would say that for those who have found the support they need through advocates, their attorneys, for help, they have had a lot of support to move forward. There are very good results that have come out of those. Those are cases I have watched or been involved in. Just the fact that sometimes parents are educated and they do know their children's rights and they can talk about their children's rights. Many times, that is a very strong statement to your district to say, we do know this. We do understand this and we know our child's needs and we know what the law states, and we are going to continue to be respectfully demanding until we can accomplish that goal. Again, if you want more information about that, please let us know. We can share and give you resources, but I would say, generally, the ones that I have seen over the past few years have resolved in successful outcomes and in improved outcomes for the children who are deaf blind.

>> Some common questions, we wanted to address this. I have had these questions come up. In fact in due process hearings or special ed directors have asked these questions. So I thought we would just take a few minutes on this. Question number one is how many hours a day does a child need a intervener? This is like a classroom aide and do they rotate and are they for certain activities or not for others. The answer for that is how many hours a day does a typically developing child need vision and hearing? In order to participate, how many hours a day does a child have the right to access? So that is again a question that comes up. And it is not a negotiable number of hours. It is that intervener who communicates in your child's mode of communication and if they are not with the child, how is that being provided. Otherwise, your child is disconnected at that point. So that is a question that will come up and there is an answer for it and again, the right to access is not

quantified in hours a day, throughout the educational day. And more than one person, your child's intervener, again, that comes up where there are districts where there may be aids that are already a morning aid or afternoon aid or somebody goes to lunch and then somebody goes somewhere else. What I have seen again in my own personal experience is that only is this possible if both or whatever are excellent in that child's mode of communication. Because if you have more than one person working with the child, and they are not both trained, again, you have the child trying to -- I don't know if it is a good analogy, talking Chinese in the morning and Italian in the afternoon because the communication is so different. That is the key. Generally, I don't recommend it. I will tell you, is a train interveners, sometimes there is more than one in a setting. They work really hard to stay on board and be very skilled at the child's communication.

>> Next question, what happens when a intervener is absent ? That is one of those mechanical colleges to call questions that comes up. Of course the recommendation is that others in that child setting, can they be able to communicate with them even if they are not fully trained as an intervener, there should be an enter -- relationship the child has with the teacher or another aid and somebody who can come in so it is not just one person who has a connection to that child. In Utah, they try to provide substitute interveners. So sometimes the district will have a substitute of backup interveners training. Generally, what we see is if the intervener has to be absent, then somebody else steps up so the child is not disconnected. So that can be discussed in the IEP, and know what happens when the intervener is not there and my child's access is not there.

>> This next question is one that just came up recently in a due process, when can a person be called and intervener and when is an intervener ready to work with the deaf blind child? If we look at traditional training, and interpreter, and say how are they trained, well, they go to school or college or they have their bachelors degree and some of them have their Masters degree. Then they go out and get a job as an interpreter and they may do some interpreting along the way, but until they have a license or certification, they are not considered really formally and interpreter. The issue we have with our low incidence is that it is probably the odds are against us of ever having a cadre of interpreters ready to go, if somebody determines that a child needs a intervener. So we do recommend that the child be assigned and let the 10 -- intervener be assigned and be enrolled in a program and be studying as they get to know the child and again we have data that shows that it works in that interveners learned skills quickly by learning and a child does make progress. If this comes up, that is one thing we have worked on, try to have language that expresses what

makes a person a -- and intervener. Some districts use the term intervener and training so that means they don't have that credentialing. Again, that depends on the district.

>> Is a paraprofessional with training okay? I have seen this for a number of years and I would say no, it is not okay. Because this is a model that has been used over and over, and we don't see the same results and we don't see the same outcomes as if they are a trained intervener. I want to address this quickly for one of the parents who mentioned her child has an interpreter . That would be another question and my child has both an interpreter and a intervener and I will in the interest of time there are logistical issues with that and I will be happy to talk to you more. We have seen that configuration in cases and things have to be set up just a certain way in order for that to work. An alternative is that I have interpreters in my program that RTE have interpreter skills and are getting intervener training so they can do both. We have some interveners to take interpreter training at the same time so if you want more information on that I want to acknowledge that is an important question. I will be happy to give you information a little more because that could be viewed as a logistical problem, trying to do that.

>> Okay. Resources.

>> There are many resources out there, but we are trying to focus on interveners . The first one will provide good information for you and if you don't have time to go back to the webinar and you forgot some information, you can go to the first one and find a lot of the same information, and the same with the families guide to interveners which is on that website under the resource section. If you need more of the legal help, you can contact a parent center, but I do have to warn you, they probably won't know about deafblindness. So you have to combine your knowledge of deafblindness that you picked up along the way with their knowledge of the IEP, the whole process. So this is the current address so I will give you a few seconds to take a look at that or just copy it or Google the name.

>> These resources are specific resources that are one or three pages I would say that actually talk about -- they are all from the PACER Center, which is a parent training and information center. The first one -- again, they have hundreds. But I pulled out the ones that would be helpful for you in understanding. Why is an evaluation important and what does it mean. The second one is a place to start and understanding the present level of academic

achievement and functional performance and Linda mentioned those. The third one is called from needs to services. It is a nice chart that you can sit down and list all the needs and then there is a second column where you can ask the team what can they do to help your child with those needs and Linda talked about the special factors in this goes into more detail about them and if you weren't able to provide today because of limited time. Effective communication for students with hearing and vision and speech disabilities in public schools, this is very helpful. What these are, they will give you the terminology. You can go into a IEP meeting or discuss with the teachers so you come across knowing what you are talking about. This is rather than just read through them. I will let you go back and look at the archive if you would like to [Indiscernible-low volume].

>> And then as Linda mentioned earlier, feel free to contact us by either email or phone and Linda does intervenor training throughout the state and I am a parent of Andrew, who I have to say that we were introduced to interveners when he was a baby and I never dreamed it would take this long to get the term recognized because it seemed like such a no-brainer to me and Annie Sullivan and Helen Keller and a intervener for my child who can't see or hear but we are making strides. Going back to Andrew again, we talked about interveners and again he's 37 years old. So back in the day, people had no clue what a intervener was. They had no concept. So we eventually were able to -- again, we don't have intervener and a list of related services in IDEA. And I encouraged them to at least use the word in his IEP, which they did . They put the word interpreter/tran14 and we provided extra training to that intervener and it was helpful. We are moving along and I know in my lifetime we are going to see this happen.

>> Okay. We are at questions now.

>> Linda, this is Megan speaking. I have been monitoring the chat pod for you guys. First, I want to let you know who may only be on audio and not able to see the slides, Sheri Stanger was kind enough to put in the link to the assessment booklet , the website link in the chat pod. So it is designtolearn.com. That is that booklet by charity Roland and she also put the link to interveners.org so families could access a family guide to intervener . And it is spelled intervener .org sometimes in Canada are they just Canada they use the OR, intervener.org.

>> Imam asked the question whether there are facilities for children for treating CHARGE syndrome because she said her child was very challenging and that was the first question she had to you in the chat pod.

>> Facilities for treating CHARGE syndrome. Do you know that, Sally?

>> Are you talking about educational facilities or medical facilities ?

>> She is typing.

>> Medical facilities. You are lucky that Sheri Stanger is on this webinar. She is the queen of information in all things CHARGE.

>> Sorry. I had to take my mute off. This is Sheri Stanger. I think this is something that I can speak to you about, and I can put my contact information in the chat box. Also, if you go to the CHARGE foundation website, there is a lot of good information there and I will put that in the chat box as well. Also, there is a center of excellence called the charge -- CHARGE center at Cincinnati Children's Hospital in Cincinnati, Ohio. I hope that is helpful to you.

>> Thank you. This is Megan speaking. The next question comes from Julie. She said you touched on this but my state prefers classification of multiple disability and set of deafblindness due to our department of education definition. Is it critical to change it to deaf blind, and if so, what are the key points quite --?

>> Again, we have seen this before. Many states have done this because deafblindness is so low incident that sometimes states don't even recognize it in their state definition. It is very important. What I have seen is that even though they say that you still get services, matter what the classification is, a team will not pay attention to the sensory specific issues without that classification. I have seen that over and over. Some districts will keep the multiple disabilities and then use deafblindness with that. It is not appropriate just to have multiple disabilities, even though we have seen states do that, even though if it is not

in the state regulations yet, and it should be, and you may ask about that. But that doesn't prevent it from being reflective of what your child's needs are. So, you know, the strategy, if you want to give me a call, I can give you some resources for that. It is a long conversation, but you as a parent have a right to insist that the child's needs be reflected. The need is specific to sensory loss. Sometimes in my own state, they will say, well, the multiple disabilities is the most global issue. Or they will say vision loss is secondary or the hearing loss a secondary. That is not relevant information because the deafblindness reflects the sensory loss needs which reflects neurologically what is happening in the brain and that I as a parent, I would recommend that you insist that that be in there. If you need some help, that I will be happy to help you with. But your district may not be bothered by it. They may say, okay, we will add it onto the multiple disabilities. But we do have it in Utah in our state definition, more and more states, including that. It is one of the 13 categories. Remember like I told you. Legally, it is one of the categories. And your child should have the right to have it in their IEP.

>> Linda, this is Megan again. Julie asked a follow-up question about, has anyone been more successful using ADA title 2 effective communication guidelines rather than IDEA?

>> I will tell you that I know of a few cases who have used that, and I can refer you to a parent who has used that. I have also seen it used in a legal due process in a state where one of the attorneys referred to title 2 of ADA as part of their conversation. So, yes, I have seen it used. I wonder if we don't need to educate more in that for families because that is another piece. IDEA is one piece and ADA another piece is a supportive piece and can be used in that. I would say, yes, I have seen it used and it can be used and if you want more information, just let us know. I have a document that I can give you information from.

>> That is great. For those that can't see the chat pod, I want to let you know that Sherry has added the website in the chat pod which is www.chargesyndrome.org. She has also added hurt email, sheri@chargesyndrome.org. And she is also added the phone number which is 8555 Tat -- 855-524-2743. She also mentions that there are comments on the website and there is a session on potty training and one of those documents.

>> I was just going to jump in and say that the CHARGE syndrome foundation is a wonderful organization and resource and it really offers a great deal to parents and one of the reasons

Sally and I wanted to do these webinars is because of the networking and the capability of the foundation. I would definitely recommend any of the parents to be in touch with Sherry and others there for their support and help.

>> Those are all the questions we have so far so I will offer again to have -- ask anybody that has any remaining questions to put your questions in the chat pod, and we will give it a second here to see if anybody has any additional questions for you all. I see that Hillary is typing.

>> Also, I want to make sure that the parents who are going tomorrow, I think, or this week, to request a intervener, I want to make sure she has the information she needs and if she does not, please contact me, and I will give her whatever she needs before her meeting.

>> Great. Thank you, Linda.

>> Hillary says, if we missed the first two webinars, where can I find the recording? Those are being archived on the CHARGE Syndrome Foundation website which is in the chat pod it is www.chargesyndrome.org.

>> Are there any other questions? I will say for the mom who has to go advocate this week, we will all be eagerly waiting to hear what happens. So you better email one of us to let us know because our fingers will be crossed for you as well as our toes.

>> Megan, if I can just add, because I have been doing this a few years and because Sally has been around a few years, I always, and I will say that again, I always see child change and progress occur once a train intervener is assigned and recognized in that role. And this is also when the team kicks in. And when I say always, it is like always. There will be change and that child will change in that setting will change, and whatever effort it takes to do it, you are not alone. We are here to help, but it is very very worth it.

>> Yes. Donna Snyder said thank you so much to all three of us and she enjoyed the webinar. I will turn it over to Sheri Stanger to say goodbye if there are no more questions for Linda or Sally.

>> I do see one person is starting to type in the chat box.

>> Julie says thank you and I will be contacting as soon as possible about the interpreter and intervener -- intervener dance. I don't see any more questions in the chat box. On behalf of the CHARGE Syndrome Foundation, I would like to thank Linda and Sally for speaking with us tonight. And also for providing important and very useful information on interveners through their three part webinar series. We are very grateful to them for sharing their knowledge on interveners and for all the work they have done to promote awareness of interveners, develop training and encourage best practices in this field. Their expertise is extremely beneficial to the families that have a child of any age with CHARGE syndrome. I also want to thank Megan Cote from the national Center an advisor for the CHARGE Syndrome Foundation for her support and assisting with the question-and-answer session , and of course think Robbin Bull also from the National Center On Deaf-Blindness for hosting us tonight. Thank you for joining us this evening and for supporting the CHARGE Syndrome Foundation.

>> [Event concluded]