Please stand by for real-time captions.

>> Test, test, test, test. Everybody, hang in there for just a couple and then we will get started. I think we will go ahead and get started. This is Robbin Bull with NCD be and I want to begin by welcoming everybody and thank you for coming on this Sunday evening and I will go through a couple of housekeeping items before I hand it over to Sheri Stanger who will kick off today's webinar. As you have seen in the chat pod and we have been talking about, we are to keeping the phone lines are muted to reduce the background noise during the presentation. The question and answer session will occur at the end of the presentation. However, you can write your questions in the chat pod at any time during the presentation. It will be monitored throughout the webinar in preparation for that question and answer session.

>> We want to let you know this webinar will be recorded and archived for future viewing. Please be mindful of your comments in the chat box and refrain from writing personal or sensitive information.

>> I will start the recording now. You will hear an announcement momentarily and Sheri Stanger, that will be your Q to start.

>> This meeting is now being recorded.

>> Thank you, Robbin Bull, welcome to the The Charge Syndrome Foundation first of a three-part series on interveners. This is a topic of great interest to many families and professionals and the foundation hopes that it will provide you with helpful information. It appears we have a strong turnout for this event. My name is Sheri Stanger the director of outreach with the CHARGE Syndrome foundation and we are very pleased to have you join us as Linda Alsop and Sally Prouty discuss Interveners: Who are they? Why are they critical for individuals with deafblindness?

>> In this first of three webinars, historical perspectives will be discussed and information will be given about the evolution of intervenor services into a professional practice. Issues will be addressed such as why does combined vision and hearing loss result in the need for intervenor services and what is unique about the role of interveners in educational and community settings. Now a little bit about our presenters. Linda Alsop is the director of deaf-blind programs at the sky height Institute at University, Logan Utah. Extensive expense working with children with combined vision and hearing loss and their families. She asked as a consultant in

deafblindness and actively involved in national efforts to professionalize the Interveners in the United States and she has developed numerous curriculum training materials and resources that are being used by families, professionals and Interveners throughout the country. She developed and implemented the first online higher education training program in the country that trains Interveners to work with individuals who are deaf-blind and establish the national Interveners credential through the national resource Center for paraprofessionals. She works closely with parents of children who are deaf-blind on Interveners advocacy efforts and currently a legislative liaison with the national coalition on deafblindness, promoting passage of the cuts will Macy Bill and supporting other initiatives to improve services for children and youth who are deaf-blind and their families.

>> Sally Prouty is a mother of three including an adult son who is deaf-blind with charge syndrome. She and her family lived in five states from coast to coast in search of quality medical, educational and social services for their son Andrew. For over 30 years Sally has advocated and worked in the field of deafblindness as a parent and professional. Sally was the first director of children's services providing community interveners at deafblindness services Minnesota and the family specialist and coordinator at the Minnesota deaf-blind project. When Andrew was one year old she learned of Interveners and has been a strong advocate of the approach ever since.

>> Sally co-authored parent roadmap, your guide to raising a child with combined vision and hearing losses and the family guide to interveners for children with combined vision and hearing loss. She is currently legislative liaison with the national coalition on deafblindness and working on the introduction and passage of the cuts will Macy Bill in the U.S. House HR 1120 and Senate S 2087. 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 -- the Charge Syndrome foundation is a not-for-profit organization that provides support to individuals with Charge and their families. Our vision is a better world for people with deafblindness syndrome and we gather, develop and maintain and distribute information about charge syndrome and promote awareness of research regarding incident vacation and cause and 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 through outreach, 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 their families, it is important, please consider becoming a member of the foundation or making a donation to our website. Both Linda Alsop and Sally Prouty 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 that the response will occur during the question and answer period. We thank you for your continued support and for joining the foundation, Linda and Sally this evening. Enjoy.

>> Thank you, I think I am to start. For Sally and myself I want to thank [Indiscernible - low volume] for being willing to support this topic and for making it available widely through their webinar series. The dissemination of information [Indiscernible - low volume] is very powerful and families are definitely those that need that information, so we are very, very happy to have the support and we hope that over the next three webinars we can provide a service for all of you parents who are -- and others who may be on the webinar. Sheri, she gave an introduction of me and I will add that it is always the most painful part is to hear ourselves announced or at least describe, but thank you and just before I begin my comments, and we start, just know how strongly I believe in the rights of children who are deaf-blind to have equal access through Interveners and I have been involved in this work for years. There is -- in all the years I've been in this and all the children I work with, I am only more convinced that it is a very, very critical component to educational programming and community efforts with each children -- child.

>> Sally will kick us off.

>> Okay, here we go. This is my guy. That is Andy, born in 1981. In that picture, that is called a body hearing aid. They did not even have behind the ear aids for young children at that time. That is ending in 1980 -- and the in 1981 and he was [Indiscernible] published in the medical journal. And fortunately that led to his diagnosis fairly early on.

>> Before the diagnosis happened, of Charge, he was labeled deaf-blind. My husband Micah Knight noticed that his ears were misshapen and one of his eyes was extremely small and we alerted the doctors and as you all know, that led to a series of appointments, tests, multiple specialists that we sought. The first thing that we heard was your little boy is going to be deaf-blind. Fortunately he did not have the life-threatening parts of Charge , and I don't think he would have survived had he because he was born in a small hospital that did not even have a pediatric unit or obstetrics unit. I was with all the other patients.

>> He was eventually diagnosed with Charge when he was about three weeks but the deaf-blind word stuck with us. It was really hard for us to hear those words, but it really was not -- it really was a blessing in disguise. We were able to start our work right away.

>> [Indiscernible] when he was a couple of years, maybe three years old, on -- and on the right is Andy now and he works for the federal

government. He is currently the mail clerk at the U.S. Fish and Wildlife service and is work for the federal government full time for about 15 years. And he lives in his own apartment, and has his own -- does his own shopping and gets to work with Metro mobility, the visibility transport organization between cities.

>> Really it is what I always dreamed of. And Andy does not meet us very much anymore. It is hard because as you well know you are so involved in their lives when they are young, so Andy is going to be 30 later this year and he is doing very well.

>> I have to start this slide. Actually it was [Indiscernible] with a Charge child living in Minnesota and his parents said you know what? Our kids lives in a bubble and that biblical is only as big as our kids -- and that bubble is only as big as our kids can see and hear. And he is profoundly deaf so he hears nothing. He might hear the vibration of a train coming down the track at him. And Andy is legally blind. He has no vision in one eye and the other I is about 2200, 2400, and depends when we go to see the ophthalmologist and the optometrist.

>> And then you add to that the [Indiscernible] and it is a wonder that this guy can do as much as he can. When you that Andy -- we did not want to have him grow up isolated. Inside this little bubble.

>> We wanted him to be independent and if he was going to be independent, he needed to go learn and if he was going to learn he needed to access information. And communication.

>> There was just not enough hours in the day for my husband, Mike and I to achieve that on our own. The only way that we learned was to -- through a trained person who could compensate for his vision and hearing loss and that was Interveners.

>> Next slide. Here is Helen and Ann. The only person I could relate to that deaf-blind term was Helen Keller. I'm sure you have all heard of that and thought of that with your children. Of course her famous companion Annie Sullivan. When you that Helen was successful largely because Annie Sullivan brought the world and communication to her. We wanted to do the same for Andy. There were not enough hours in the day for us to expose them to all the information and concepts that his older brother learned so effortlessly.

>> The deaf-blind diagnosis drew us to people in Canada, John and Jackie McGinnis, near Toronto. They were early advocates for an educational support model based on Interveners. We learned everything we could from them. We communicated with them through letters, in the old days. And they wrote a book so Mike and I read that book cover to cover and I don't think we understood half of it but we kept reading it thinking okay it will click.

>> Really, deaf-blind this is not complicated and I think we make it complicated. The diagnosis of deafblindness is really difficult to hear. But it allowed us to get started to meet the early needs of Andy.

>> Okay. What we want to do is kind of late a little bit of groundwork. Some of you may already know this but for those who do not, or do not already, we want to get on the same page when we talk about deafblindness . We will be discussing some definitions of and a little bit but if someone were to ask you what is deafblindness, there are many, many answers that can be given and as I worked in the field, I found that simplifying it was always the best.

>> We think about information, and that is where we start, related to combined vision and hearing loss. We all have to have information. We rely on it. We have to use it to function. With our typical vision and hearing, we get all the information we need. Visual auditory, outcomes of information without even much effort and sometimes more that we want, but it comes very effortlessly see -- to us. What happens when there is a loss of vision or hearing? What we know is for children who have issues related to either one, we know that the natural flow of information does not occur and that there is a shift in how the information flows.

>> Pieces of information can be pieces, incomplete, distorted, unreliable, but the point is it is not complete. And it is not necessarily consistent.

>> If we look at children specifically with hearing loss, many of you have worked with those types of children, and we know that they have to rely -- excuse me we will do vision loss first. Have to rely more upon their hearing so children who have vision loss, they become very adept to using their hearing. And their brain, the way the brain works, it even compensates and more neurons are assigned to hearing so hearing becomes a compensatory sense. For those with vision loss. Because it can, is strong enough to distribute.

>> So a child with a hearing loss, and what we have to do is rely upon vision. To compensate for the lack of auditory information. Are those of you who worked with deaf children you know how good they are with their vision and how they can pick up and scanned lots of visual information that can even fool you into thinking they are hearing more than they do. What happens is there vision will compensate.

>> And so if we are trained in vision loss or hearing loss as professionals, we have that distant sent that we can use to compensate for the other one. So what happens here is the child that has both, we see that neither of those distance senses is strong enough to completely and adequately compensate for the lack of the other. That

is the key here, that we do not have a [Indiscernible - static] sense and that is kind of a bottom line way of describing deafblindness. Other senses in place, touch is in place, olfactory sense is in place and the stimulators, sometimes and sometimes not. But basically we do not have a strong sense that will operate by itself.

>> What we have for deafblindness is that it is a disability of access to visual and auditory information that we all have, we all get from the time we are born, about people and things in the environment, that our children who are getting it's eyepieces, and are not getting that complete picture either auditorily or visually.

>> So we can talk about it as a disability of access. We all know also as with your children, it does not necessarily offer total deafness and total blindness. We have many, many combinations of degrees of deafness and degrees of likeness and we have lots of variations. And because of that, we kind of get caught up sometimes and trying to decide if our children are deaf-blind or not because it may have a lot of hearing so people think they are fine with a lot of hearing or they think they are able to have enough vision or they may in some cases have some level of each. But again the problem is the lack of ability to have a strong compensatory sense that is consistent, that is not distorted, that is reliable.

>> That is the key here, related to how we can think about deafblindness at a basic level. Let us look at the definition quickly because you have that in your space.

>> There is a federal definition of deafblindness. Here it is, deafblindness means concomitant which means at the same time, hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

>> That is the federal definition. Your state may have its own definition of deafblindness. In my situation in Minnesota, where we currently live, there are probably more than -- definitely more than one definition. One is in the education department. Actually that when actually mentions Charge Syndrome which I'm thrilled about and the other vocational rehabilitation and know that your state will have a definition of deafblindness . They may just use the federal definition. And they may have their own definition.

>> If you are involved as many families are, in the discussion with your IEP team or with others, as to whether your child is truly deaf-blind, you can go to the federal definition, and you can go to your state definition. And that may have degrees of vision or degrees of hearing loss. In Utah, our definition has a functional wording in it which is really good, but as I sat and work with teams and they have

been debating this, I always tried to come back to the basic question that John McGinnis posed and Sally referred to in the beginning, again we can ask two questions, does a child have enough vision to compensate for the lack of hearing? Is it strong enough? Would vision he has or he or she has, is it strong enough? And does a child have enough hearing to compensate for the lack of vision?

>> If we can say no, to both of those and if we cannot be totally sure that vision is compensatory our that hearing is compensatory, what we are looking at is a child, no matter what label we might attach, we are looking at a child who needs alternative programming, specific programming in order to be able to learn and function.

>> Sometimes that is helpful with children in order to keep the discussion more of a practical discussion. That may be helpful as you parents consider that with their own child.

>> What is it about deafblindness that is unique and results in the need? Why is it that these children who do not have that compensatory sense have a unique issue? There are many things that make it unique, but the learning is really at the heart of it, and it is important that you understand it and articulate this, with your team and with people who work with your children. Let us look at typical learning.

>> When we look at typical learning, most of what we learned, we have learned a bit through hands-on experience. We did that a lot when we were young. We had direct experiences where we were touching or handing or feeling but really directly involved in the learning. Secondary learning is like what we are doing now, where you are listening to Sally and I talk and present information and that happens at school, in college, happens at the movies.

>> That is secondary type of learning.

>> The vast majority of what we all learn typically is incidental. That term means that that is automatic learning, occurs without any effort, just flows to us. For example I just heard a pipe turn on, in my office, and I heard it turn on. Is it relevant? Think goodness it is a sound I know but if it was an unusual sound I would be alerted to be unusual and that is incidental information. That is the way most of us learned. That information that we get.

>> That is how school systems are set up and that is how I was taught as a teacher of death children to teach -- of deaf children to teach this way because they had vision to compensate for their lack of hearing.

>> That is look at deaf-blind learning and how that is different and so significant. I will click it all on because we have to kind of think of it as a triangle inverted. We have to say that into dental --

say that incidental learning is not a good vehicle for learning because it is based on the flow of information. Visual and auditory, very incidental. Is not going to occur very effectively.

>> Kids may get some incidental, but it will not be consistent or it will be difficult together -- to gather. Secondary, as you get older, they can do better with this but especially with younger children, we do not rely on that educationally. Our children who have the combined vision hearing loss, the direct learning, in some cases the only way that they will learn effectively.

>> That is what makes it very different. It has to be hands on. It has to be experiential. It has to mean something. And so when we look at educational programming, for these kids, we have to realize that that is different from the typical cited and hearing children. Even children in special education, many that are in special classes, if they have vision and hearing and compensatory sense, they are still able to gather information so this poses unique challenges to most educational settings because they are not designed to provide intensive amounts of hands-on learning. Sometimes it is in the early years, in some schools where some people were involved generally but generally education is not prepared for this and teacher development programs, they are not taught how to teach this way. I was a teacher of the deaf and I was not taught how to teach in this fashion with this inverted triangle that we are talking about. As parents, you can articulate this and use this to help people to understand the needs of your children. Let us talk about why, again, what we are looking at in terms of information flow.

>> This is a picture of a young girl who is just sitting there, and information is coming to her and she really does not have to do much but sit there and if we look at the flow of information, there are seven steps that are involved in all of us getting information.

>> The first thing you will notice there is receiving. We receive information and if we have to pay -- attend to it and there is a sound or I am seen something, we have to attend and then we have to gather it in and interpret it and decide what it is.

>> Let me go back.

>> Here we go.

>> Then we gather, we interpret it, we may synthesize it and generalize it and then ultimately remember it. Though seven steps, they are really important for any information we receive in order for it to get registered in the brain and for us to learn. If we look at this and we think about it, the key, the gate, so to speak, is right here, for receiving.

>> If we look at deafblindness, it is a disability of receiving. And so we know if we do not Kate yes, if we do not take care of this pace here, we will not be able to rely on these other things occurring. Okay, next one.

>> Again, if we look in here is kind of a representation of the bubble that Sally was referring to. This information is all around, but it is not accessible. On the child's hand, and all these things that need to happen are not going to happen because the -- of the receiving capacity. So what we need, in a general term, eight general delivery system for these children. There has to be a way to deliver information and it is usually tactilely and it can be other ways. But the point is, there needs to be a way to deliver information, to deliver communication, to help deliver learning.

>> On the other hand, there has to be also away for receiving so there has to be a receiving system. For someone who is there to receive with the child is putting out and many of our children we know are communicating through behaviors, other types of examples, but we may not be or no one is there to receive it or no one is there to understand it.

>> When we look at this, we are looking at the needs for way too deliver and a way to receive information.

>> If we say now what do we do about this? If we are talking about the very bottom line of access to information, what then do we say or do about it, right? What is the effective beginning intervention? We are not dealing with every strategy here. But we have to cover the basics. So basic deaf-blind intervention has to connect and there is a disconnect so we have to do the opposite and we have to connect these children to the world.

>> We have to provide access to clear and consistent visual and auditory information. And other information, tactile, other types of information, basically we have to be aware and make sure that this delivery system is happening.

>> Then we also have to provide support, because what happens is we know with the brain, if there is no communication going on, than the brain does not learn how to do it and the child cannot learn how to do it. So we have to put a big emphasis from the beginning of communication.

>> And then we have to look at the social and emotional well-being of the child. And we have to be thinking about that and we do not have time to go into that in depth tonight but there is a lot of research now about what happens to the brain, to the child, when we do not have social and emotional well-being.

>> That information is available, but it is definitely a research based mission now.

>> I am sorry, I am having issues the battery on my mouse because it is low. Give me a second.

>> Can you move this forward because my mouse will not work.

>> Okay, let us look at what this delivery system looks like. We have the term the came out of Canada, the Interveners, persons who consistently work one-to-one with a child who is deaf-blind and who has specific training and special like -- specialized skills in deafblindness and this person is a intervenor and you may see it with that letter OR, but in this country you use -- we use ER and that is basically the definition of a Interveners, one-on-one, training and specialized skills.

>> If we look at the role of the Interveners it is threefold and a make sense, what we talked about, access to environmental information, the Interveners is there to do that, think about it, and deliver and make sure it is happening. Interveners also have to facilitate and develop and the use of receptive and expressive commission -- medication skills. We know over and over people are setting -- communication skills. We know over and over people are setting up [Indiscernible] [Indiscernible - low volume]

>> The Interveners is also there to develop and maintain a trusting relationship, to contribute to the social and emotional well-being. If we look at that role, we say, you know, I have presented in enough places to know that even when I presented to adults, about the role of the Interveners, if they don't argue any of these three things, we know that all adults and any Sullivan herself had to do [Indiscernible] [Indiscernible - low volume] she had someone with her and she had to have someone to go with information and feel safe and be able to feel good about what she is doing so that is the basic role.

>> Okay Sally. So many of you probably have your kids in school and have a paraprofessional and you need this information to deal with the school district to show that Interveners and her professionals are different.

>> We have a chart here with Interveners on the left side and paraprofessionals on the right side. And you can see that both the Interveners and paraprofessionals work under the direction of the classroom teacher. Both the Interveners and professional abide by agency and district policies. Not we will start seeing some differences. While the Interveners is working one-on-one with the student who is deaf-blind, similar take a process that Linda was talking about with intervention and a paraprofessional usually works

with groups of students but can work one-to-one when assigned by the teacher.

>> Interveners must have comprehensive and specialist training in deafblindness . Paraprofessional usually does not. Interveners has skills in the blank you -- [indiscernible - static] sensory loss, deaf-blind instructional strategies and how to create independence rather than dependence.

>> Paraprofessional has varying levels of skills depending on the assigned experience and training. Interveners prepares materials for one student who is deaf-blind. With whom he or she works with in coordination with the teacher. While a paraprofessional, he or she is responsible for materials in preparation for the entire class, assigned by the teacher. It can be [Indiscernible] preparing bulletin boards, getting ready for activities, not one on one.

>> Interveners is not assigned to do classroom maintenance because of the continuous one-to-one time that is required for the student for deafblindness where is a paraprofessional is responsible for classroom maintenance and assigned bulletin boards and sitting up and cleaning up materials so you are saying to see that there is a big difference between Interveners and paraprofessionals. Interveners usually attends regularly scheduled planning and feedback meetings at the teacher and other -- with the teacher and other team members and with the paraprofessional you really see them at meetings. [Indiscernible] including IP meetings and others who contribute valuable day-to-day knowledge of the student.

>> A paraprofessional does not.

>> Interveners is not generally assigned to additional school duties because of the one on one nature required by the student. Aid paraprofessional may be assigned to additional school duties such as lunch room, bus, playground. You're getting the picture. Interveners facilitates the students connection to others by explaining and leveling the student specific communication system, and acting as a bridge like any Sullivan did to Helen, to the world and creating a safe and supportive and betterment that encourages decibel intervention -- interactions. Paraprofessional typically is not required to facilitate communication connections between students and others.

>> I heard a lot of arguments against Interveners. When Andy was growing up. We lived in a lot of different states. We heard a lot of stories and also in my work at the Minnesota deaf-blind project and meetings and having parents what they been told and it is a lot of them and this is the response. Mid-one, if your son gets a Interveners, all the parents of special needs kids will want and Interveners. There children could benefit from one on learn learning

tools but you have to remember that Interveners are meant for kids who are deaf-blind because they cannot access information the way other kids do. Remember the arrows, inland the slides that she showed and we were talking about the bubbles, they just cannot act as it in the classroom. Children toward deaf-blind need a way to access information, communication and the world. And Interveners provide this. Another argument we heard was, we cannot give your son or Andy Interveners because it will isolate him from the others. Whereas just the opposite is true. Andy did not know conversations were going on in the classroom and sign language because he could not see them. Over the years and these Interveners provided information to him that allowed him to better participate in others in and out of the classroom. If he did not see that you medication, he did not know it missed it. Interveners are trained to know when to step back and encourage communication among the peers and encourage them to comment.

>> I once called a Interveners ambassador for friendship. Interveners are a bridge to others and not a barrier.

>> This is a big one, in Minnesota we really have a nice system developed. When I talk to parents and other -- in other states and they tell me administrators tell us we don't have Interveners that we don't do that here. We have to look back, step back, and because deaf-blind this is such an extremely low incidence of disability, oh school districts may have never had a student who is deaf-blind but over the last 10 years, there have been -- just hovered around 10,000 kids across the United States who have -- who are conscious and -- and the educational system is being deaf-blind and and hundred 24 of those are kids with Charge. As a result, administrators and educators probably have never been exposed to a child with combined vision and hearing loss and unique vision or unique learning needs.

>> And they never heard of an intervener or what they do. And basically it comes down to education. Every single school that we moved to, we started talking about Interveners and we started educating the team about what Interveners could do and basically Interveners is an educational right that provides and facilitates access to the curriculum in the school environment. That access word is really important, you guys. It is written all over special Ed law, I DEA.

>> Use the word access, and I found so many times that -- actually Andy's teachers coach me and they said don't go into the school and say I want this and I want that for my son. But use the word provided an I DEA and I started talking to them about Andy not having access to curriculum and no access to peers and you medication. And it make such a big difference. And then I want you to know that kids teams are not qualified to teach our kids. Deaf-blind kids are often [Indiscernible] never met a deaf-blind student before. And they have never met or they never met one like the student they're currently serving.

>> Teachers have degrees in special education, hearing impairments and hard of hearing, those are typically people who work with her kids. And they need additional training in order to be able to modify their teaching approaches to serve kids who are deaf-blind.

>> Frequently your told and I cannot believe how many -- how much time I wasted my hearing just wait, just be patient. While all the staff members try to put into practice an educational program. There is a scarcity of training programs in the United dates that address deafblindness.

>> And then finally this is another big one, we heard your son will become too dependent on Interveners. Like all of us, we need information. We are dependent upon information to function. Information and interaction that Interveners are trying to facilitate actually helps her kids to become more independent. And they do become dependent and his dealing with interveners as part of the process of building with us and a positive relationship and you have to know that this is definitely the time when there was no alternative plan training for Interveners.

>> He was a guinea pig and so are the people who were on Andy's educational team so once we felt secure and comfortable, we that Mikey increasingly became more and more independent.

>> You have heard some of this and now let us talk about the good things and what the impact as to what Interveners have. We have probably more quotes than anybody has time to read. That we would share just a couple with you. This is Brenda Willits from Utah. You can see her son there. She said I've seen the importance of having a well-trained skilled Interveners with Brady and had one on one aide and he just hasn't made the progress with that. As he's had his Interveners he's made progress in communicating and making choices in social interaction with his peers and in access while the environment that's going on around him and he is happy. His Interveners is bringing information to him helping him learn about his environment concept development and the things that he just doesn't learn incident to -- doesn't learn incidentally like other children do. At school it's fun to because his peers to communicate with him and love it. They love to come up and his intervener will help them to communicate with him and then he can communicate that to them and it's open up a whole new world for him.

>> Okay. Here is Andy. This is actually what Andy says. I had an intervener in school to help me access educate -- communication what was going around with beeping if I do not have an intervener I wouldn't have that. I think an independent -- i think an intervener help me when I was going up because more independent because now I live in my own apartment female bills and I do my own shopping and I

travel independently to work. I think it is important for deaf-blind children to have interveners for a variety of reasons. And I have independence.

>> No comments from interveners, again, [Indiscernible - low volume] we would be happy to share those. I picked two of people that I've worked with as Interveners and this one says, last year at this time I did not know what a Interveners was I was asked to work with a deaf-blind student as a one-on-one at the end of the year. This year her parents fought her to get an intervener and asked me if I would take the position. I excepted and started classes for interveners in my deaf-blind student has come a long way. Her behavior before she was given an intervener was sitting at her table banging her head or pounding in frustration. She would lay her head down to sleep often. Some of the student -- staff assume she was always just tired or not wanting to cooperate. One staff member made a comment that my student didn't need an intervener. Instant my student has made such progress. She is excited about her day and has access to the communication she needed. Awareness for these children is so very helpful and important with access to the medication and to environment these kids light up. The second one is one that we are trying to develop a case study of. This is a student that is now in high school and making tremendous progress but when I started working with his intervener he was considered very low functioning, and a functional skills classroom and he was he would fight it hit and I had to constantly encourage the intervener to hang in there. She had a lot of grit. Little by little she [Indiscernible] with the use of other AP is now breaking the barriers and showing interests and learning faster than anybody else. His teacher called me to say I don't know what to do, I tried to plan for my time with him, he can grasp everything and surpasses everything so what do I do? So I talked to this intervener on Friday to see how they are doing and they have moved him from a functional independent team [Indiscernible] and they are saying he should not be in a functional program but have an academic program. So now they're working to accommodate him, putting him back into an area because they found him to be very bright. I have to tell you that I have seen this over and over where our students appear to be -- there is not a lot of potential there, they are under expectation, it is low, and when we put this delivery system, the intervener in place, the one who has the skills, huge change for the student we start seeing who they are. And they surprise us all the time without fail.

>> We have many more examples again that we do not have time to share.

>> One we have looked at, couple of outcomes, we will not spend a lot of time with this but this is something that one of our deaf-blind project people did in getting some information back when they had trained interveners and you can just look at that quickly to see 100 percent increase in their [Indiscernible] medication of the children and having intervener with training and the had increased time in a

calm space and more exploration and increased [Indiscernible] [Indiscernible - background noise] By 50 percent and you can see the other percentages but always an increase in always improvement and this is just over a few months period. This is not a long study that we -- that was done.

>> We are going to try to to go quickly again through some other testimonials. And then move on to some of the history. We will try to go through them fast. Linda, wondering if we should skip those and go right to the history.

>> They are all there and we would just be reading them.

>> Okay. We can jump to history and come back if we have time?

>> [Indiscernible - multiple speakers]

>> We can come back and the testimonials are good.

>> Yes, very good.

>> We will come back to that. We did not want to bore everyone with a history lesson, but it is important for you parents understand that this is not brand-new. This practice has been around for a long time. There are different reasons why your state may not know about it. But there has been a lot of effort over the last, what, 30 years or so, trying to get interveners recognize, trained, and our role -- goal is to have them professionalize. The first when I put on here was 1984, which was Sally's effort there in Minnesota.

>> Actually, Linda, that is Utah, Linda.

>> Is that Utah?

>> Yes, okay.

>> I apologize.

>> Yes, in Utah we had a gentleman by the name of Tom Clark who worked on bringing the intervener model back from Canada and began the program here.

>> Click, that will work.

>> 93, Minnesota, right? Sorry.

>> [Indiscernible - multiple speakers]

>> 1993, Sally's effort in Minnesota. And they began with legislative dollars that brought on the Interveners work in Minnesota. Just to

jump back to 1984, if any of you are interested, Utah has a long history of work and now there are legislative daughters as there are in Minnesota to support Interveners with children who are deaf-blind. There are some systemic supports a can be provided but I have to say, [Indiscernible] you need to know that parents were intricately involved at every step of the way.

>> I cannot over emphasize the importance of you as parents and what is done, what professionals are what we are able to do, it is really, truly the parents that make the difference. So Utah, it was apparent that got us started and we worked with the parent group to get going. In Minnesota, Sally was right in the middle of that, as a parent.

>> Is I'm clicking I will say when we moved to Minnesota, when you there was program port deaf-blind adult and we went to our deaf and hard of hearing services division at Department of human services and said, hey, did we do something for kids or maybe they would need services when they are adults if they get it when they are kids and they listened. Community intervener program was formed.

>> In 1994-95, about 10 years after the ride, are intervener initiative, in Utah, again it became and initiative that we had the state of education on and included our legislative analyst. There was a lot of lobbying that went on [Indiscernible] and over $1 million being appropriated in Utah, for the education of kids were deaf-blind, with the interveners. And again before parents were intricately involved with all the lobbying about. 1999, Texas Medicaid waiver began and Texas again has a history of more than just the Medicaid waiver. They got a waiver for children who were deaf-blind to have Interveners as adult but they also now have other legislation that specifies the needs of Interveners and community settings as well as educational settings.

>> 2002, we officially formed the national Interveners task force to try to bring states together to begin to look at this so that it was not just Utah or Minnesota or Texas trying to get things done. We also publish the first paper basically to discuss what the Interveners was and [Indiscernible] helped and my cell, and we were just when we first started the paper, I have to tell you, we heard that it would not be well-received, but it was. That was reason enough, I think, the understanding, nationally.

>> [Indiscernible] 2003, we develop competencies, task force, people got together from the field and put together training conferences for Interveners. Next after 2003, we had development of the online program that we have. That was through our federally funded grant of the if iPSC grant that we were able to get funding to develop an online Interveners program through Utah State University and we work with three other higher education programs to get the curriculum put into place and so that was a big effort from 2005-2007 and that was

the beginning for the one that takes place today. 2006, national deaf-blind Interveners initiative parent group was formed, let you -- just let you know it is N D BII and it is a distinct just group of parents and other parents are encouraged to join and we have to parents from Texas and Sally is in the group and we have other parents who joined us from other states and that group has done some lobbying and they have been in Washington lobbying and they continue to strongly advocate in their state so that is our parent connection, that was formed in 2006.

>> 2007 we came up with the booklet interveners in the classroom, guidelines for teams and I can hold it up and it has the comparison that Sally was talking about. This is available for any team and we -- Interveners use it and and administrators [Indiscernible] if anybody needs a copy of it, you can let us know.

>> 2008, competencies that the task force put together were officially approved. Approved by the Council of exit -- for exceptional children and now FIPSE competency [Indiscernible] special education partner is recognized with Interveners by putting it into their proposal request, that was the first time that the federal government wrote it, in a paper and sent it out. That was a big thing for us also.

>> 2009-10, we sent packets out all of the country, again and effort from a task force to share information with states and special directors and state run projects.

>> 2010, national intervener credential was established. Again one of the things we knew and were told was that if we ever want to have the Interveners practice to be valued above the classroom eight status, that there needed to be some standard, like a national standard, like interpreters have and teachers have, there has to be a standard of skill and knowledge so that people will have that piece of paper that says government training, and I am now a skilled intervener. We have and still do have people [Indiscernible] who do not have training and that has been a problem so we worked hard to try to begin to put a system in place.

>> This book, Sally mentioned in her thing, families guy to Interveners and this is a group of parents that got together, myself, to talk about the IEP process and how to look at the process, how to look at each part of the IEP process and advocate for Interveners services during the process and that booklet is available and online at intervener.org.

>> 2013, national intervener Association began, and that is the group of Interveners that are coming out now and we will talk more about the training in the next webinar and we will talk about that association and show you who is there and we have about 100 Interveners there that have the credential in the country and so this

is a professional organization so that they can begin to advocate for themselves, just like the interpreters have their organization an organization now working very hard to get up and run this and they are lovely people.

>> Now 2014-16, when the Ellis Cogswell and Annie Sullivan Macy act started and I will turn the time over to Sally and let us do one more quick Sally, ultimate goal for online is [Indiscernible - multiple speakers] ultimate goal is to establish Interveners as a profession and if we need to professionalize the practice and we are trying to establish them as related service providers under IDA just like interpreters and all MM specials, all there so Sally will talk about now our efforts to get this done.

>> Back when I was saying, we don't do that here, if we get Interveners listed in the assistant related service providers and parents can show them and the administrators the list and say here is Interveners . So basically as we said in the introduction, Linda and I have been working with the national coalition with deaf blindness to help implement the Cogswell Macy Sullivan act and this is our third Congress, 115th Congress, we have had it in house,'s current Congress, House resolution 1120, this is the first year we have got it in the Senate, yes, was Senate Bill 2087.

>> Basically, Cogswell Macy includes three groups of kids, first kids who are deaf and hard of hearing, than kids who are blind or visually impaired and than kids who are deaf-blind. So it is a long document, if you go in and look at the entire thing, but basically the part that we want to focus on right here, this presentation, as we are adding Interveners to that listing of related services and this is also written in the document the children who are deaf-blind should receive one-to-one services from Interveners who have training and I shall a skilled and deaf-blind is. Interveners play critical role in the provision of a free and appropriate public education, commonly known as FAP E because they provide access to information and the children need to learn in order to -- in order to learn and develop concepts and facilitate their communication development and interactions in their preferred mode of communication and to promote their social and emotional well-being. We will be talking more about the Cogswell Macy act in the final webinar.

>> Just a free -- if you resources for you, there is intervener.org. Under that there are resources, families guide that we talked about is there. You can print it off or contact us for a copy. Deaf blindness and the role of the Interveners and we have it on there twice and sorry about the typo. That is there. Comparison of Interveners and paraprofessionals and the guidelines for teams that we also have a Interveners and deaf blindness Facebook page and we would love if you get on there and like the page, we probably have about 3000 likes now.

>> Almost.

>> Almost. And we have a lot of international followers on the website so we try to pose information we try to put videos up, and we are trying very hard to use social media more. To get the word out, to have people be able to talk to each other and network with each other.

>> Again, feel free to contact us with any questions. And any of the testimonials we have, you can look back on this, [Indiscernible - background noise] And see what it said and then [Indiscernible - background noise] I have a document that I mail out so if anybody needs [Indiscernible - background noise].

>> At this point I guess the next thing or next question is, are there questions?

>> Sheri, should be read the questions or how do you want to do this part?

>> I and Megan Cote and I will take turns reading some of the questions the questions that were posted and there but if you and I suspect there may be some or as we are talking. Let me start with the first one. One is pretty basic question, Bridget asked, will these slides from your PowerPoint be provided to people to print? I would love to share with special education director of my district and I know that this webinar is going to be archived on the charge foundation website. Will there be a link that people can use to access your PowerPoint?

>> The answer to that is yes, we will clean up our couple of typos and then we will make it available. Sheri, if you want we can send that to you and you can make it available, does that work?

>> That would be fine. I assume maybe Robbin Bull might help us with that.

>> Yes, you are welcome to use our power points. And the others that we do in the next few webinars. We would be happy for you to do this.

>> Great. The next question comes from Bernadette, have the outcomes of the study mentioned, percentage of increase or decrease of behaviors, been published?

>> To my knowledge, no,. The only published study that was done, was done in 1989 and that was the early intervention study on Interveners that was then here in Utah. It is old now but I still will send it out. Those findings [Indiscernible - low volume] [Indiscernible - static] in Virginia so you can contact her and get information. She was collecting data Bossi was there in Virginia, and collecting data from her work. You might contact her for more information on that.

>> We tried so hard to get several studies. We have written grants, funding for that, but we are still waiting for that. In the meantime, we still see all the same results and we know over and over that it works. We will continue to move forward even without that.

>> Great. Now I think I will have Megan -- Megan Cote asked the next couple of questions.

>> Sure. Good evening, everybody. Next question comes from Sheri, it says an argument by school district against and intervener, what takes priority? The federal definition or the state definition of deafblindness ?

>> I would say it is not a matter of the definition, because a child does not have to be labeled anything to show the need for services. The technical answer is, the child does not have to be labeled deaf-blind in order to me the Interveners in depth like services. We have gone round and round here in Utah with that. It is nice if the district will acknowledge that and have that there, but the federal definition is not a functional one, and you can see that it is really looking at the -- where the children are educated, and if they cannot be educated in what kind of [Indiscernible - static] the default definition, I would say most states try to fall back on their own definition or I have been asked to share Utah's definition with others.

>> That is really more about that piece and then moving on and try not to get too hung up and that with your IEP, talk about war about the axis piece and that is guaranteed under federal law. That access to it is guaranteed, so that is what you can emphasize.

>> Great, next question, comes from many Lambert, and it says what happens when my district tells me that our state Department of Education has said they have never heard of Interveners ?

>> Sally, want to tackle that or you want me to?

>> I think we both can. What I would say is it is time to educate. It is time to make relationships with as many people in high places as you can. I would start with your deaf-blind project in your state, and make a note. This is not the way I was raised or ever thought I would ever do but you just need to start meeting with people and knocking on doors. One teacher claimed, I can Sally Crowder, you are respectfully demanding. If you can be respectful in your demands, you're most likely to get what you need for your child.

>> I would say educate and I'm sure Linda has more to add.

>> I would say hello, many. Many is now a new student and a program

and I would say that is powerful knowledge, knowledge is power it really is and when you understand these issues, when you can articulate those and begin to know what the law says, then it is really going to help you, but we hear that all the time and I hear that from other saying we have never heard of it. So just because they have not heard of it does not mean that it does not exist. Then it is up to us for educating them an estate project can help in your state or we can assess, whatever, but that is just kind of a preliminary -- expect that from time to time and then move on.

>> Thank you. Next question comes from and Stephenson. Is there a good way for parents of newly identified babies with Charge Syndrome to connect with parents and families who are further into the process?

>> I assume you mean -- i assume Ann means into the process with Interveners ? Spike she is typing -- she is typing.

>> [Indiscernible - low volume] Charge network of families [Indiscernible - low volume] important vehicle. I know Sally networked with other people with Robbin Bull on -- and also people Charge but we're also trying to network with families [Indiscernible - low volume] not connected to the Charge foundation. So if you want to contact some of those [Indiscernible - low volume] Sally we can certainly direct you to other families who will help you in kind of help talk it through with you.

>> She did comment she said mostly to connect with other families. Their baby is completely deaf and has severe vision impairment and are very overwhelmed.

>> Okay. They are certainly welcome to contact me, and I would be happy to talk to them. Sometimes it sounds like this might not be a parent -- ann if you're not a parent sometimes it would help if I contact them because we all know how overwhelming it is to get one more name [Indiscernible - low volume] and I would be happy to connect and they can also write a comment on the Charge Facebook page and asked those kinds of questions and I think they would get a lot of support from parents in the country who have children who have Interveners.

>> If I might chime in, this is Sherry Stanger Richter of outreach with the Charge Syndrome foundation and if any families want to connect with other parents, they can register with the Charge Syndrome foundation@ChargeSyndrome.org and they can also contact me directly and all of my information all my information is on the website and I am happy to connect parents to other parents.

>> The next question is from Sarah caught on, just a comment never could get Kentucky to acknowledge Interveners role and had to use the threat of lawsuit to accommodate a one on one signer by access to

interpreter because he is deaf but this strategy worked. Any comments on that?, Sally or Linda?

>> [Indiscernible] unfortunately a lot of the progress, in many cases the progress that we have seen has involved some type of legal or due process. That is just a reality. We will be talking more about that in the third webinar. Give more information about what the legal issues are and the specifics. It is what it is. It is not unusual for families that have to really step up to the plate and decide to say this is the right our child has and we are going to need whatever we need to get it done. We will talk more about that in the third webinar.

>> This is Sally, we had to play the game. Andy -- it was clear that pretty soon that Andy was in the classroom with deaf-blind students with one teacher who assigned everything but Andy did not have access to the board or the bulletin board or access to the materials other kids are making so finally I would say -- i think he was in third grade when we finally -- the best we could do at the time, this is also 20 years ago, was to get an interpreter/intervener just so they knew there was something special about this interpreter. We heard that, we don't do this year. Once they saw the benefit, then everyone had the one-on-one interpreter/intervener, much more willing to realize how wonderful it was for Andy.

>> Great. This is Megan speaking. Next question comes from Sylvia and asked how soon can a child benefit from an intervener?

>> That is really a key question. How soon will the baby benefit from information? One of the things always go back to, I say the typical child, the brain is developing, the brain develops based on information flow. So there is no such thing as too soon. The sooner the better. They need to benefit from information so it may be with some families having the parents know how to be Interveners , because the Interveners is really a skill set, delivery system. If Interveners are not available in many intervention programs, parents and others can be trained into how to get the information and do early communication with the child.

>> You may not have the body there or that person there, but we need to have intervening going on right from the beginning.

>> Great. Next question is from Sharon and she asked, I am interested in an intervener certification. Where could I get the information for such online courses?

>> We will provide that information in the next webinar but in the meantime you can go on intervener.org, and there is a flyer there that talks about the training, [Indiscernible] University. Also there is a training program through Central Michigan University that we will be

describing in the next webinar and you can go on their website. We are promoting various [Indiscernible - low volume] and if you cannot find it just email me and I will send the information to you by an email.

>> Great, Linda, Sharon also put in the chat pod, could I see Sally Prouty contact information again please? I can put that in the chat pod below. I think Robbin Bull is typing it right now.

>> Right.

>> Our next question comes from Emily Bannon, I am from Canada, could you detail more about the differences between an intervener in Canada and an intervener in the USA?

>> Really a good question. Loss most of the differences are -- [indiscernible - background noise] Most of the differences are systemic. And the mechanical issues, I've worked with Canada in the 30 years of my work and I was a mentor with many people in Canada, so we have had a good imagistic relationship intervention. It is the same. The training, what they do, the communication, those are the same. The differences you see is in Canada right now, they have the George Brown program there. Was people [Indiscernible - low volume] organization there in Canada. Here in the United States, training goes on at two universities and we have a national credential that is there. The other thing that is a little bit different, they have separated the Interveners to work with congenital deaf-blind and those who work with [Indiscernible] train and that [Indiscernible - low volume] so they have more of I guess a conversation going on between those two communities and Interveners try to be accommodating to both of those .

>> And so not a lot of differences. They have used our competencies, Wendy drafted their -- when they cut -- when they drafted the competencies and they work with their system and date decided they do have competencies. They have a lot of collaboration [Indiscernible - low volume].

>> Emily made a comment and she said I am and the GBC program so that is why I was asking, thank you for your information.

>> We will skip down to the next question. It comes from Sylvia, under part C, who provides the intervener?

>> Part C in Utah, that is where our intervener program started. It started intervener intervention and that is where funding started under the federal public law [Indiscernible - low volume] 42 and that is where I began to work with interveners and Utah has had early intervention with Interveners , until the last few years when because of different political issues, other issues here in Utah, [Indiscernible - low volume] deaf-blind decided not to do them anymore.

>> One of the things that is of concern is that we do not have a strong Interveners model in early intervention. We have worked and have seen it but it is not being [Indiscernible] across the quantity. That is an area that we need to do a lot of work on and try to provide a lot of support [Indiscernible - low volume] training and support to families in early intervention. But that is an area of need.

>> Linda, this is Megan speaking. Maria from Kansas said to follow-up with some of the questions, and this is sort of an echo of what you are just mentioning. She says, part C, do not have Perez to take intervener classes. Similar to what you were talking about.

>> [Indiscernible - low volume] one of the reasons we are trying to professionalize this, when they say they do not have Perez, they do have services and they do have interpreters and they do have codes and people who work under occupational therapists and physical therapist. So we are trying to shift so that even under part C it can be viewed data intervener is a service provider and can be part of that [Indiscernible - low volume] team and part of the family and that is the work we have to do.

>> Yes. This is Megan again. Sylvia says I'm in Souther California and have eight-month-old Charge baby and the family is using total communication. Do you have any thoughts about or add onto that? Not a question but more like a comment. But do you have thoughts about total medication? Bookselling, why don't you comment quick but anyway you can get information into our kids, the better.

>> So total communication is awesome.

>> I would say, Sylvia, information about brain development and what is going on with the brain, and the children return, the work that they are doing about medication, it is really critical to the family to understand. What they are doing is they're doing the medication, so if you need more information on that, I will be happy to send that to you.

>> I see that Sylvia just type something in, who do I contact about getting training about intervener for the family?

>> I assume, Sylvia is asking that necessarily the intervener formal training through the University?

>> Correct? But yes, she wrote yes, correct.

>> Okay. Well if they would like to start on the intervener.org website, that would be a place to start. It can be overwhelming and they are overwhelmed with that child with Charge but that would be a nice place to start and NCDB website and certainly could contact

them, right?

>> And your California deaf-blind project, [Indiscernible - low volume] familiar with intervener work and I think would be very willing to work with you on that, Sylvia.

>> There was also a comment from a previous question, with Maria from Kansas, some part C staff are interested to take the intervener classes. She says, thank you.

>> Thank you. Again, education, knowledge, it is really the key. I wish we had a pill that we could all take, and we could get it, and we would understand it. But this is a hard thing for us to have recognition in hearing and shifter thinking and understanding this alternate learning. But once we do that and once we put this process in place, for the interveners and parents who have training, through whatever works at that point, that we start to think and see things happen and things to change so it is not impossible. What we know is that these kids are smarter when we intervene and they are valued and I see that over and over and I have to say right for my heart, we talked about that we -- talked about that re-for. Estimate talked about that before and something that is just not right and every time we see intervention put in place, and then we can start same wow, we did not know the child thought that way.

>> [Indiscernible - low volume]

>> That is just something that we know from experience over and over again. I cannot stress enough how important it is for you parents to understand this, to get educated, and then to not [Indiscernible - low volume] in terms of getting -- not to delay getting the assistance for your children and we hope our next webinar can meet your need with that.

>> I have to support what Linda just said. As a parent of a kid with Charge, our kids look funny. And our kids on paper, they are a disaster. But we all know that her kids with Charge, they haven't vision and they charge on. -- they have ambition and they charge on and we have to instill that into the educational team. And our Charge kid will show them and prove to them that they are good learners.

>> There is one last question and I think this is perfect timing because we have time for one last question. Megan, want to read the last one?

>> Sure. It is from Amy, she says would you recommend and intervener for all kids with Charge syndrome or are there cases that could go either way?

>> This is a hot question. In my early years, I would say absolutely,

every child who has vision and hearing loss needs and intervener. I cannot tell you how many times I was yelled at in meetings saying, legally you cannot say every child needs one particular intervention. But now I have come to know that -- and now I do say if a child has combined vision and hearing loss and there is no compensatory steps, yes, that tile needs and intervener.

>> -- yes, that child needs and intervener.

>> Wonderful. Would you like to add onto that?

>> You got it.

>> It looks like that is the last question in our chat box. I see Ann is typing. I will wait a few seconds to see -- it is a thank you.

>> The presentation. Since we are hitting the hour and half mark, I think we are just getting a bunch of thank youse and the chat box right now. I think we will and the question and answer session. On behalf of the Charge Syndrome foundation I would really like to thank Linda and Sally for speaking with us tonight. There expertise in this field is extremely beneficial to the families that have a child with any age with Charge syndrome. I thank them for their time, their continued support, and advocacy and I would also like to thank Megan Cote one of our special advisors from the national Center on deafblindness assisted me with a question and answer session this evening. Please join us for the second webinar in this Interveners series on February 25, 2018 , entitled Interveners , what training is required and how can the need for Interveners services be determined?

>> Please watch for our next webinar registration blast and thank you for joining us this evening and for supporting the Charge Syndrome foundation.

>> Thank you very much.

>> Thank you. [Event Concluded]