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Please stand by for real time captions.

>> Thank you for being patient. Can everybody hear me now text Martha and sharing can you hear me? Very good. We are going to get started and I want to welcome everybody. I am going to go through some housekeeping items before I hand it over to Sherry who will be introducing tonight's speakers. As you have probably all realized all phone lines have been viewed it so we don't have to worry about background noise. Your questions can be written in the chat box at any time throughout the presentation and it will be monitored throughout the webinar. There will be additional time at the end for questions and chat pod. This webinar will be recorded and archived for future viewing. Please be mindful of your comments in the chat box and read -- refrain from writing personal or sensitive information. I will now start the recording you will hear an announcement momentarily and Sherry that will be your cue to start.

>> This is Lori. I am sorry to interrupt but to people on the chat box indicate that they do not hear anyone.

>> Okay. I am going to start the recording so they can get started and I will put indications in the chat pod because they are not able to hear me.

>> I will meet myself. -- Mute myself.

>> Welcome everyone to the charge syndrome foundation's second webinar in the 2015 series. This is part of the webinar series focused on topics that the foundation hopes are the greatest interest and benefit to any and all who are involved with individuals with charge syndrome. It appears we have a nice turnout for this event. My name is Sherry and I am the Director. of outreach with the charge syndrome foundation. We are very pleased to have you join us as Martha and sharing success strategies for success that work at home and in the community. Martha is the assistant education director in the deaf point program at the program -- Perkins school for the blind. She has worked with students with charge syndrome for more than 30 years. She has worked with teachers to develop educational programs, communication plans, and IEP is for children with charge ages 3 to 22 years. Sharon is a teacher at the deaf blind apartment that Perkins. She has worked with children with charge syndrome and their families. Chair -- Sherry and special interest are cheap -- teaching strategies literacy and communication. This webinar will be recorded and archived for future viewing. As Robin stated earlier please be mindful of your comments in the chat box. It will be seen by anyone viewing this webinar so we ask that you please refrain from writing personal or sensitive information. As you know the charge syndrome foundation is a not-for-profit organization that provides support to individuals and their families. Our vision is a better world -- world for people with charge syndrome. We gather, develop, maintain, and

distribute information about charge syndrome and promote awareness and research regarding its identification, 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 is important please be coming -- consider becoming a member or making a donation through our website. Both March -- Martha and sharing asked that the question-and-answer session be saved until the end of their talk so if you write a question please note that the response will occur during the question-and-answer period. We thank you for your continued support and for joining us and Martha and sharing this evening. Enjoy.

>> Thank you very much it's a pleasure to be part of this wonderful family, all the people that support charge, and we know that family support their kids every single day. Sharing and I join you this evening with some ideas that will help -- we hope will work. We have enjoyed working with their children and students over the past several years and we have met many of you at the charge conference. We look forward to attending again this year to share ideas. Tonight we have been asked to help you understand strategies that work because Sharon and I both work in the educational environment our goal tonight is to share ideas that we have heard from families and to understand better what might help you as you share your ideas with us. We are going to set the stage we have many things we would like to talk about with teaching strategies the primary agenda is to talk about school-based strategies that we know as professionals and share them with you so that you can implement them successfully both at home and in your local community. We will also talk about the challenges that children with CHARGE face and hopefully some of these strategies will actually help your students and children to be more successful. We will touch on communication strategies and share with you what parents that we have met with like the children to learn as they grow up and become young adults. Most of you know this but without the foundation should be set that when we talk about children with CHARGE we know that they have many challenges every single day of their life. These are not in any particular order that we feel that communication -- if they can learn better communication skills than everything else will fall into place. Obviously medical will not fall into place but if we look at how we communicate with us -- with these children we hope that teaching strategies will help develop their ability to express their needs better, which might have an impact not only on their behavior but on their need for sensory input. We know that access to vision accommodations is really important. We know that children with charge have some significant visual issues. You know that as well as we do. We know that in a school situation the professionals need to be aware of where the [Indiscernible] exist within these students so that they will access communication in the right-field. We also know that in more recent years children have had many more successes with cochlear implants as well as [Indiscernible] and other types of hearing aids. We hope that this will give children more access to the hearing world is much as possible. We have met many children with charge syndrome who have a wide range of cognitive and intellectual ability. We have some little mentions that -- munchkins that we know will grow up to be very confident learners. We know the charge conference that there are many students that are highly capable and go on to college. There is a mixture of children with in the range and we look forward to talking about strategies that might work with all of the students regardless of their cognitive level. We know that many children have significant physical challenges and access to communication is really important in that area. If you

have a child in a wheelchair with CHARGE syndrome that they have easy access to their picture communication board. To sign language and the right visual field and if they are using switches that they are located in the right area so that they have accurate access as well. The sensory means we need to refer to our good friend David Brown we talk to she talks about sensory needs far better than we do but when we look at teaching strategies we want to understand better what those needs are and give our students the possibility of expressing what they need through communication so that they generally feel better about themselves. Medical is a comment that we are just going to make. We know that many of your children have significant medical issues we have several students in our program I have significant medical issues and we know that research within the charge foundation warned more people are finding out more information that can help your children be better -- be help beer -- healthier from a medical point of view. Lastly, behavior. We hope that we can teach our children better ways to communicate and that can help their behavior show more promise. We believe that communication is the key to behavior. I am sure that if you were talking with us live right now you would say my student -- my child really just throws things when they get upset. They are communicating really nicely about what they want or don't want. We have students that have significant behaviors that can be accommodated if we pick up choices for them to make decisions about what they would like to do. We also know that behavior can be -- our students can be very much in charge of themselves and one of the strategies that Sharon will talk about is the art of negotiation. Everybody gets a turn to express what they want.

>> Just an overview of how we think about communication. We know that the use of total communication can be extremely help full to all students with charge syndrome. Total communication stems from the work that we have done and the world has done for students who are actually just lines. -- Deafblind. We know that many of these children use speech as their primary input that sometimes the use of sign language, simplifying Scott gestures, facial expressions Pictures, photos, objects, line drawings, print braille, and more recently assistive technology all combined together to help your children become better communicators. We know that there are students -- your children not only use speech and that is a lovely thing but we also know that some students who need access to sign language also benefit greatly from a visual system. Many of our students that we have met if we can sign to them but also give them for example pictures or [Indiscernible] they have much more success in being able to not only understand language but be better users of expressive sign. What we know -- there is so much that we don't know and there are some things that we do know. One thing that we know is that students can generalize strategies across environments. We work hard in our program and another other programs work really hard to help your children learn something at school that they can bring to home. One of our questions in terms of generalizing strategies is can you share with us some examples of how this works for you in the home situation and if you are able to type that into us in the chat that would be awesome. As you have ideas what works in terms of generalizing strategies, how do you do this at home, what is it -- successful for you. The second question is consistent use of communication and expectations. If you could share with us what works for you and if you could give us some examples that will help us be able to talk more specifically at the end about strategies that we might suggest -- what I'm doing right now the other question is the specific use of strategies that are used between home and school. We know that your children can have more success between home and school then they will be probably not a little bit happier. -- Probably a little bit happier. They will be more supported

by the strategies that can work and the relationship between your child's teacher and you might be strengthened because there's more consistency of strategy. We think that one of the challenges that we have with our kids and your students is that we have to be consistent across all environments. We also know that many of your children need consistency, not only as strategies that -- but how they learn in general. We also find challenges in making sure that we are all on the same page and parents have great opportunities to share with us what they now because you live with your children much more than we do.

>> I am going to go back to slide. Through our work with parents with children with CHARGE syndrome these are kind of hopes and ideas that the parents have shared with us. As they have hopes for their children one of the things that we hear a lot is that they want their child to become a very -- effective communicator. If your children have a better way to communicate they are going to be more -- they'll be happier and maybe their behavior will decrease because they have a better way to express what they want and how they feel. Many parents would like their children to be social. That is part of growing up. One of the goals that we have working with the parents at three -- of the parents can be social in their home community obviously a fair social we become more of a group. They will have a neighbor had Artie and never say to us how can we get Sharon to be able to go to that party and have a good time. We might come up with some strategies that would work for your child to be more involved and I think last but not least is the idea that your children will become a good self advocate. When we think about strategies we think about choice making. When we think about a three-year-old with charge syndrome we think about an opportunity that we can give them in order to say what they want. They might say what they want with your behavior but the goal would be that we get them pictures and they can point to what they want so they can begin to know that they can be very powerful with communicating their ideas throughout their school day and in their home. If you have ideas that have worked in any of these categories we would like to have some discussion points so that we can better talk about strategies as we got there -- further into our presentation.

>> One of the things Sharon and I think of often when we are writing an IEP is what strategies -- I'm sorry. Biscuit to slide. We are -- I skipped in-flight. One of the things that are in Portland for us to think about is a strategy where materials and toys are age-appropriate. One of the answers we would like to have from you is what are your children Mike. Do you think they are age-appropriate to you wish that your child would like something that their siblings like to play with and what strategies when we use in order for them to come -- to become more part of their sibling group. It seems like they have much more access now to technology and we have heard lots of examples about children playing with their siblings with their iPad or doing age-appropriate games on their iPad. We are feeling that tech knowledge he has really done a lot to do with it to -- to motivate some of these kids because they can be leisurely and watch their videos maybe they can watch homemade videos that they have done together and create an iPad library that is not only age-appropriate that might be motivating. Our sense from working with so many kids with CHARGE is that the best thing that they like is watching themselves. The answer of what is motivating is that they like to look at themselves and they will watch themselves in a video over and over. We would like to know what excites your child in terms of what happens at home and do they like a variety of things? Do they tend to pick the same toy all the time. Both answers are

fine we are just curious. In terms of learning and natural -- natural environment we want to know where your child learns best. We have had experiences where the child learns best in the family room other children go to the playground, we know that some students watch what is happening at the playground and maybe six weeks later they decide to participate. We would like to know what natural environments are the most successful for your children. In the home and in the community.

>> What is your childlike? When we think about activities and we write IEP's we always like feedback from the families to tell us what is your childlike. There's probably nothing more insulting to a child than we give them something that they don't like and we know we -- that they don't like it and they are rejecting something because we've taught them self-efficacy but it would be better if we can understand what your child. Things are so that when we write an IEP we are including things that the child likes both at home and in their local community care products --. Are the favorite places that your child likes to go? To us that is important and when we offer them choices we want to make sure that we are developing pictures so that their favorite things get put in that picture set. One of the things we also find really important to think about is that when you are making this last think about who is your community and your family. When we talk about strategies we are making sure that we include all in the neighborhood. For example, the babysitter, neighbors, maybe grandma and grandpa come every weekend and we want to make sure that when we look at strategies that the whole family -- the family system get included in the discussion about what we are going to do. Sharon will talk about negotiation. How is grandpa going to learn to negotiate with sharing in terms of deciding what they will do for an activity. We know that the negotiation and teaching strategies that work in the community should also work in the homeschool. As we talk about more examples we want to make sure that we are including the community at large and very specific members of the community related to your child. Strategies that work. These strategies that Sharon will be talking about have worked for years and years with children who are defined as deafblind. We have found a lot of educational strategies from that field and we know that for children with CHARGE syndrome many of the children are actually considered to be deafblind some of them may have simple hearing loss. Some of them may have simply of vision loss. We tend to use the strategies for children who are deafblind with the ultimate goal of using strategies that can be generalized between home and school. We know that the generalization can sometimes be difficult. We also know that a parent will say to one of us I can't believe they are doing that at school. Why are they not doing that for me at home. Hopefully this evening Sharon can share with you some of the ways that might work. We also know it can be the other way around where parents can say -- they are really good at this. They play with their siblings but at school their level of play is very different. We always want to understand why and we want to understand if we can make that better by again using consistent strategies between the home and the school or community programs.

>> I am going to talk about strategies and ice -- I see that students putting the comment about -- Sue is putting in a comment about her child when they are out of social activities they do really well if they have an interpreter available. Being the teacher I am always asking about what works if you have the intervener and the interpreter what is it about having that person there that makes the child successful in a social situation. The first one that comes to mind is the child have access to communication. The second thing for me that comes to mind is that the child has one on one attention and they have

somebody who is there sort of go to person who can sort of answer the questions and be the go-between from what is happening in the situation to -- to be the bridge between what is happening. What pieces about working with that interpreter or that intervener can we duplicate so that when they are not there they can make sure that the child is successful. My question to you to is what about that does he or she really -- what is the core of the strategies. We will talk about some of the strategies that work. Blow -- we will really think about that and see how we can duplicate that. It might just be a personal preference and that is a strategy that we are talking about. Sometimes for some of our students here at school we know that they have people preferences and they would rather be doing something with the assistant rather than me or vice versa so to think about that. I thought we would think about teaching strategies in general. When you hear the word teaching strategies and want you to think about things that you do naturally at home. Every parent uses strategies whether you call them strategies are not. The first thing that I was thinking of was started with the beginning and middle and end. For our kids charge syndrome we need to re-create the activity, they know it's going to happen, I say this when I'm talking to parents and other teachers that really what is important sometimes is not the activity of self but the important part is having a really clear beginning so that the child knows this is starting right now you do the activities and how do we do the activities so that it ends successfully. Especially for some of our children that do not want to end a favorite activity they might want to be done much sooner on a nonpreferred activity so how can we really think about that. Some of the strategies do not stand alone they really intermixed with each other we will be highlighting and giving you examples of all these different strategies that we go on. The next one is choice making and I think this is so important. It is really giving empowerment as Martha said to our kids. So many times I think about I really think it's important to us making as a natural way that you can incorporate kids having a little bit of power. From choice making in the morning. What you want to wear? Maybe not the whole closet because it might be 40° and they decide they want to wear shorts and a bathing suit top and you are thinking well that's not really important. Maybe it is a limited choice and you want to wear jeans and your blue shirt or do you want to wear jeans and a richer. Think about small things like that. Every day we make the choice such as what time you're going to wake up in the morning what we're going to wear how we're going to have access and how do we incorporate some of that for our children with charge. Had we let them have more choices and more involvement in what we are doing. By giving them more choices we are bolstering communication skills we are practicing a lot of communication skills we are showing the respect that they have a voice and that is really an important point. The next one is an organization, structure, and routine. In my experience and you can tell me if I am right and wrong but I think that so many of our kids with CHARGE Syndrome crave structure and routine. They want to know that things are going to be predictable. They want to know that it happens in a certain order. They really want that routine the problem lies in that their organizational system may not be the best to ask for or to cope with structure. They wanted but they don't know how to go about getting it. Because of their organizational skills internally. This is where things like having calendar schedules on a weekend when you are -- on a Saturday you wake up and you say this was what we will do today. After we had breakfast you can go out and play in the yard you can decide if you want to swing a ride your bike or play some soccer with your brother. Those kinds of things doesn't have to be like school where you have to go at 9 o'clock we do reading and 930 we do math it doesn't have to be like that it can fit to your own family style but having a structure asks for a little bit of chaos for many of our students. Partial versus

full participation -- I mean this as I is your child required to do the whole part of an act to be or task or only part of it. Think about it as if they are playing a game with their siblings. Maybe they cannot play the whole game. Maybe they can only play part of the game. They can either be -- I love the idea of having a partner and playing any games in partnership. That way they are doing part of the act today. Maybe they can only play for a certain amount of time so maybe they will play at the beginning maybe there will be -- okay you can play for five minutes or 10 and you work from partial participation to greater and greater amounts of time. Accessibility. Martha talked a lot about this thinking about their vision, motor, and auditory needs. When we were setting up for this webinar Robin was setting up with us and we practiced and we had to look at the lighting, was the lighting right, would it be good for you guys, would it be good for us, what could I see, what did she see, after this webinar take a look at your house and think about the lighting. It does not always have to be the brightest lighting. You know your kids vision much better than you do. But think about what needs to be highlighted when they go to their chores to get out of their close. -- Out there close. Is it like going into a dark hole and you cannot see what's in there? Would it be better to lay it out on the bed where there's better lighting? Think about those things in terms of accessibility. For prompt levels that is really how much you want to help your child. How much help is too much and how much help is not enough. Just held them verbally or sign language or maybe you have a list of things or maybe there's a list of things that you have to do I think what works better his hand underhand rather than hand over hand for example I will put this in my WebCam. Rather than grabbing her hand like this you are putting your hand underneath and maybe were still doing most of the task who here amongst us would not do anything that's not motivating. If it is not motivating you will not do it. If you don't get paid for your job most likely will not be doing that job. You want to do something that is having motivating and cavities and having more success for all of her children. Having clear expectations that the child understands so that you are not on one page and they are not on another page so you were thinking why don't we do this for 15 minutes to do some respite for a young man has charge syndrome and we always have to clear expectations of what is going on. Their expectation is for every time they go to Donald's. My expectation is we are having hamburgers at my house and he hears the word hamburgers is going to Donald's. We have to make sure we're on the same page for that kind of communication and that is really clear because otherwise we all have a serious discussion going on because our expectations were different. Many of you know this is my favorite teaching strategy. This is what we all do all the time. We are negotiating. One more can you work for 10 minutes first this than that remember you look at this later on if you do all of these kind of things negotiation is a natural part of life and I find it is a really powerful stuff for my students that have CHARGE Syndrome. You might have the communication skills to do that. It is really a powerful tool. If you think about that you are always negotiating. I wanted Chinese dinner tonight and I was thinking of Italian how do you negotiate that point. Age-appropriate activities we would like things that are maybe a little bit below their age level. Like to select activities that are age-appropriate so that if they are for sample -- they like to [Indiscernible] when you are 13 years old if you like filling little blocks out of the container it's not really age-appropriate. Think about washing the dishes. That is the perfect filling and dumping activity. You have to fill the cup of soapy water it's the perfect filling and dumping. Try to put it in something that is age-appropriate. Predict that just makes sense for every kind of teaching in the whole wide world. Teaching activities whether naturally occur. You would it make putting in your bedroom. You check and make putting in the bedroom. If you are repotting a hostile plan to do that on

the kitchen table and that's where you do it that's what happens. That is your natural environment. If you go outside and do it outside in the garden of the back porch that's the natural environment. Thinking about it for you guys what environments in the home to you use and do you think of using the environment as a teachable moment. Is a place that you could teach something to your children. That's a question that I have for you. To think of those places as places that you can teach your children. The last one is modeling which I think goes to also turn taking. We have to be good role models for our kids. So many of our kids watch and learn and like Martha says it might take them a while to watch and then they finally have their turn and they do it because so many of our kids don't want to fail at something. They have a full understanding of what's happening that's what being really good role models and having your other children be good role models for them is really help full. I love to use it in my room and I catch a kid doing something really great. I say are you being a role model for Joey because he has a hard time with that and you were being such a great role model doing that. Pointing out when they are doing something right and they can be part of the modeling process as well. Going to look at a few pictures of some of the kids here at our school. Doing some things. Here's some skills that are kids work on. Here's money skills for shopping and right away I teach about this -- I think about the teaching strategies we are using here's a young man. He is a teenager shopping age-appropriate. It is age-appropriate. He has to work on money skills and counting and all of the school type of skills. Working with money is a lifelong skill anything that I think is lifelong or can be used as they go into adulthood that to me is a red letter day for you can do something and you can take that skill and use it. It is motivating. This young man loves money. He was earning money, getting money, spending money in order to buy something you have to know how much money. You have to know how much something costs. You have to know how much you have and in the end might be going actually out and doing the shopping the next one is this is an age-appropriate I know somebody here will record versus young woman. She loves Mexican food and cooking. Feminist teaching strategies where she loves guacamole. That was anything to make. Shoes reading her recipe and following all the directions. So we have a beginning, middle, and end. The students in this activity were all part of the decision of what to make an Mexican was one of our favorite foods. We made it in our classroom.

>> Sharing, was there any negotiation with the other students? Or was everybody on the same page?

>> In this case they all deferred to this young lady. Negotiation was not a part of it for this particular recipe. Sometimes we have to work on that it was not always her turn to choose. That is where the negotiation came in. For this they all actually really enjoyed Mexican. When something else came up sometimes we had some really weird food combinations. One time a young man wanted to make coleslaw. We negotiated to have a mishmash recipe day. In this next picture the students are out and Mrs. -- and they are doing some fine-tuning in barrels so we incorporated so many things. Going out in the community, communication skills, beginning, middle, and end. We have to negotiate what we were going to plant with only a certain amount of arrows. We had to vote in a room if we were going to do vegetables, flowers, how many vegetables, how many barrels with vegetables and how many with flowers. Here is what we had done. This is our second year doing barrels. Before that I had done modeling about how to dig a hole, what you had to do, the whole thing, and here they are able to execute what we were doing and what they are planting. They are teaching in a natural environment.

There are so many -- you can think back on that list and you will all have that copy of the presentation that you can think about what strategies work very well and I am hoping that this is getting you thinking about your own children and -- I can do that or I already do that with my child.

>> Here is another fun it to the. These guys are all buddies. One of them had a special birthday. He turned 18 his mom had him decide who he could invite, he wanted to invite the whole program. His mother said no because the hall would only fit so many people. They had to negotiate how many people he could invite. Could they come from a large Portuguese family so they have a lot of family they wanted to decide who they could invite for his friends. They had to learn what to do at a party had to act at a party and the young man whose birthday it was he was getting a little bit anxious she asked his teacher to go over who was also at the party to tell him the order what is going to happen so that he knew that first everybody was going to come than they would eat the food, after the food he would have his cake and singing because that's what he was really looking forward to. Had to go back and use some of the strategies that you use in school to make his party successful he had to know the order of what everything was going to happen at the party. He had to know what to do at the party. The other guys had to know that he could not just the their. You cannot just there and draw and not talk to anybody. He had to look around maybe ask somebody to dance. May be good talk to somebody else. Meet some different new people. Those are kinds of things that we have to think about. Was a age-appropriate? At Sewickley -- absolutely this is a young man at my house. I was doing respite. Here's the negotiation. He comes home with me and he wants to do -- he wants to be on the computer and he wants replaying his DS game. That Fitchett agenda. My agenda is that I have two pops at home that need to be walks and fed and let out. That is part of his responsibility when he comes to my house. He does love them. What we do is negotiate when we will go for a walk which one he will walk, which one I will walk, how far we will go because he would just like to go once around the block. That takes about five minutes and that is not a long enough walk for the docs so I have to negotiate on their behalf. Then what we will do at the end and the reward is -- they get the reward and he gets the reward because he gets to be social and pet them and he is giving him a cookie.

>> For that example I have a question for you. In order for this young man to increase the number of walks around the block is there a way that you would suggest to families -- did you count with him so he knows we would go one more time? What language do to get him to understand the expectation?

>> He will -- he knows time and he wears a digital watch. On his watch we do a time thing. That works really well for him so I will say if we start walking at 330 I will say you have to walk until 345. Because if I do laps he walks faster to get the laps done so a time thing works better with him but if your child -- if you want to do something sometimes with kids like swimming in the pool or if they have to do laps around the track I would use number cards and you can just have small cards in your pocket that you could do it or he could just get with them if that works for them. Having that tool works and it takes me out of the middle. Your watch doesn't say the right time to end. Not me

>> Now we will talk about -- this is a play choice. This young lady is eight years old. She has learned that she can make choices. When it was time for her to create a choice pad at home the teacher worked out that there could be several different ways for her to make choices. Initially the first three choices at the

top were what we started with because the choice of all these things was very overwhelming. They would pick which ones make the most sense given the time you have. If a child really likes the iPads and based on the time you have on a Saturday morning and iPad may be something that is a choice when you have more time or you negotiate as Sharon said he can watch a video for 10 minutes and it will be finished. These activities are all age-appropriate they are actually appropriate for folders -- older kids as well she likes dolls, books, Mr. potato head, she likes all of these things. She clearly has more preferences. You may present a choice of three or four. In this presentation she's able to visibly handle the number that is on the page but initially we started making sure the symbols were just large enough for her to see them. We went back to visual access and went back to the number of choices on a visual page. So this is a really important choice making -- this young lady had a variety of set -- sensory preferences. In this case she uses some of these at home. She uses most of these at school. This is another example when you see your child getting a little bit agitated and you are quite sure it has a sensory cost to it than we need to know what works. We worked this out with not only the parent but our occupational therapist and we came up with a list of symbols that this young lady can choose from because we know they are help full. We don't want to add a choice making to something that is not in a work when you are already agitated or desperate for a sensory break. I think that these could also be used. That's essential -- perhaps in a playground. If you know that your child really likes to swing on the swings that go around versus the swings to go back and forth and at a playground you could make a picture sandwich swing do you want to go on. Maybe there is one of the seesaw things that your child really likes. That could be on their. If it is sensory want to make sure that they like those activities versus getting more stimulated but if I think about the choice making that could be available as Sharon points out when her students went to kick the actually had choices of the food they would buy so another activity might be the dad and so and so go to the grocery store and they are making choices based on what they will prepare for dinner -- making sure that they are visually accessible and that your child understands the presentation. Maybe they are going to use objects or words. You'll notice all of these that we have words in the picture of the actual object. We're making sure that it is successful goal based on the child's cognitive understanding. There's nothing worse than asking the child what they want and it is not accessible to them because they don't understand the symbols. We always want to make sure that both at school and at home they are getting activities than an -- they understand. Sharon talked about using a schedule anyone is from the top to the bottom that there is a 12 and three. The student is doing different activities first second and third but because of her sensory needs at the end of the act divination has a little sensory break. She knows by looking at the schedule that there is always an opportunity to have a time to be able to relax. Going back and using her sensory board. We will go back -- using this for her sensory so it is in her schedule. We have found when she can use this at home her mom shares with us that when she is home she might jump on one of those big peanut walls.? Arrest on helping -- or she will go best on her beanbag. She will have 12 or three at home and she can respond accordingly about her sensory break. This is an example of older students becoming friends. They are quite social. I think the motivating part on the right with the three boys is that they are doing community-based instruction. This activity was able to be duplicated by their families once they heard that this was something that the students really liked. They were able to generalize that strategy and be able to do some things with their siblings because they had the repetition ahead of time in the modeling. They could share that experience with the family at home. For some of the strategies that we

talked about related to communication -- we talked about total communication. I think the important thing to look at is one of the ones that I highlighted is the conversation. That should actually say shared topics. That means that I want to talk about something and so do you. If I do not want to talk about something as a parent I will negotiate. It is my turn to have a topic and you could talk about when it is your turn. I know that many children want to talk about the same thing over and over. We get that but sometimes we will take some term taking the negotiate. We would talk about your trip to the zoo and then we will talk about something different. For the younger children in the conversation we want to make sure that there is joint attention. Some of our children with CHARGE Syndrome will look the other way and not pay attention. They have gone on to something else so you end up talking to yourself. That is not the purpose of the conversation. That brings us to taking turns and building strategy to take turns. Sometimes we would think about -- you are going to do this back and forth three times. Sometimes the fourth time the child really gets very excited and is able to say a little bit more than they were willing to the first time around. It is really persistence. We want to keep the conversation going as long as possible. Sometimes the behavior strategy that we used for the same topic over and over is to ask the student to answer the question by writing the answer in a notebook so they can think about the question and answer it themselves. They can learn to use the resources and think about either going back to the calendar if they don't know how to read or they can get the answer in their calendar system. One of the most important things that we believe is that every child should have a calendar it gives the children an opportunity to know what's going to happen. It makes them feel secure that they cannot only know what is going to happen but maybe have ideas about what they would like to do instead. It gives children the opportunity to say -- I'm going to go to the grocery store with you but can I go to the candy store afterwards. There is negotiation and maybe the answer is no. Doesn't mean that you get everything you want that you can have the opportunity to create part of your own calendar Sharon said earlier that it is really good and I think one of the observations that we have had over time and one of the routines he can build in a home situation we also know that sometimes home is not always that routine. Maybe breakfast or something like that and maybe we'll see in one of the flights from before we built in a surprise. Maybe instead of having a calendar system that you put in was a surprise at home you will see what he's going to do. There's also wish to discuss what is going to work group I think it is important for all of us to remember early the pacing and the pause times for response in terms of -- student communication we know that many of your children have really had some struggles and learning communication the weather typical children do. They have the answer but we need to give them enough time and when I started this presentation I talked about visual presentation & language they can answer this sign language that's awesome for them but maybe they need a visual presentation that they can go back and point to what they want and all of a sudden they are able to participate using sign. The visual system can be really helpful for students who are really still trying to figure out the whole sign language thing. It is more concrete for them to call answers when there had has many thought about how they will answer that question. When we are trying to develop communication strategies we want to make sure that our communication was clear and though it we are using language that they will understand. We are very aware that there are students that have sophisticated sign language and a talking about children that are first using sign language and they needed to respond that they also needed to be very clear. Positioning really refers to where are you in the conversation. Are you standing beside your child weather don't see? They won't see the science? Or are you standing in front

of them were you really need to be on the left. We worked really hard to help staff understand and remember that each student with the position is where they are going to be and make sure that it is very successful. This is as an example of a scheduling sequence. You will know that it's a school sequence but it's an example of what you might do at home. We would use a picture or photo of a G-tube if they are G-tube said he will see that there are several sequences in a row some children really benefit from three major act to produce. Some students benefit from wanting to know the entire day as they start the day. It really depends on what their interest is. There are two workstations because this particular student bus to work but at home your child may cover that at to the of doing puzzles because they simply don't want to. If they choose not to then good for them for being able to express themselves. Let them know through self-efficacy that they don't want to do that. Sometimes the answer is just fine with this.

>> This takes us back to self advocacy. The representation on this needs board is I need to use the bathroom, I need to relax, I would like to go for a walk, in this case the student is for a walk because it helps them to that is. At home if the student points to that than the student -- parent is very ecstatic because she is able to recognize what she needs that she needs to go outside, take a break, and do her thing outside. The student might need a sensory break, student might want to drink, maybe they want to have a conversation. In that way the conversation might happen with grandma who is there visiting for the day and the child has decided she wants to spend time with grandpa and grandma. Sharon talks about that as people preferences. This is an example of students becoming buddies. There are two students that are sharing a computer screen. They become buddies periodically at home to assure activities in the home situation. The other teams -- two photos are talking about kids becoming friends by introducing themselves. The student on the right is making an E for her name and the student on the top is looking at her friends picture. The students are in preschool when we took these photos and again we are looking at strategies related to friendships as parents want for their children as well as self advocates -- self advocacy to learn who their friends are.

>> We're back to not thinking about more strategies. We are thinking about behavioral strategies. The first thing to remember is that behavior is communication. Think about what everything comes under. Think about when any of your children were young decried if they wanted mom. If they think about some of our children perhaps I have not developed the communication skills to say what they want. So they tell us what they want through behaviors. For me it is the exciting part about teaching because you have to figure on out what the behaviors are to think about it first think about the behavioral practices instead of saying cash of noticed a tantrum happens every time at 8 o'clock maybe they will say they want their breasts so maybe it's your job and my job to be a detective and figure out what those kinds of behaviors need cash rather than saying you looking at the negative say what you want them to do instead reinforce anything that is good and they are doing something that is right or being a good role model or maybe something that had a young man in my class that he could not be around young children. He walked by one of the preschoolers wonder if he was not screaming and he did that and after we walked by I said I saw that you were being a good role model to the others and I saw that you did not -- you had a nice quiet voice when he walked by. So catching them doing something positive in reinforcing that -- I really wrote -- I really like it when you share your toy with your brother. I really like it

when you help mom put in the laundry. Or when you help staff bring in the garbage can pick up really being very specific because kids know that they are doing a good job. They really want to know what they are doing well. Mood induction we have been teaching for a long time. Think it is a relatively new term that has come out that is really looking at lighting and where the students are at a day in the mid-are they ready to learn. I always think about my kid with charge syndrome and remember how different aspects of our kids and what they need to do. The kid sitting fidgety in the chair one can decide I want to stand up. [Indiscernible] thinking about the mood and what sets the mood for better learning for better communication that doesn't mean [Indiscernible] suffer the art of negotiation comes than. Maybe if they have to sit on a specific chair of the Just be there chair at the dinner table it's not a big deal. Is that sets them in the right mood that we will have a nice peaceful quiet dinner then I say go for it.

Negotiation comes up again. Thinking about that. How many? First that the nests. We're going to end in five minutes. Maybe we need more help we can help you come up with strategies and what causes good behaviors and working with the school system and you and all of those things I think of so I think it is okay to ask that. I know here [Indiscernible] are great and really help us out. I am going to go through some of these pictures because I know we're coming to the end of our time. Using pictures -- I think sometimes rather than myself -- you can have in the negotiation and have it in the picture schedule or anything. That is what is in the schedule. This is what's happening first and this is what's happening second. I think that is really where -- thinking about those. We want you to share now with us what works for you and one of the questions do you have for us. Martha will talk a little bit -- I will talk about some more strategies as you are thinking of those questions. So here's some examples of things we know about when our kids need to know had a little schedule for the day if you don't have a calendar system to so they know what's going to happen. If they need to be organized with their belongings having a checklist. We're going to go overnight with grandma's house. Did you bring your favorite pillow did you bring your pajamas and those kinds of things. So thinking about things and what set it -- what kind of strategy you can use of the item that you need. Frustration with the schedule I like the big red X. If you have something you're going to go somewhere and suddenly you have a flat tire with your car. I think having a big red X and construction paper I cut it out and put it on anything. Think it works really well for a lot of kids. To make a think we skipped one.

>> I have talked about several of these things are part of what we wanted to share with you is these can be a really nice handout for any members of your family or school staff. We're looking at the positive result of these strategies. When we look at the need for sensory breaks make sure that you offer choices for what you think might work for your student and child the beginning middle and end I find that not only is it an educational strategy that helps predict the beginning and the end but when a child understands that the end is coming at helps with moving to the next activity. We spend a lot of time helping parents say when it is over tell them and we can move on to the next activity hopefully. Choice making we have to -- talked about quite a bit. It really comes down to sell the advocacy and that's what we want for your children to become independent and self serving as they can be. We found it really helps children become very secure because they can anticipate what is going to happen. They know it is going to happen next and there is comfort in that X -- especially when it is not calm. If they know a routine is going to come up and I like that reaching them are met -- help them come down. It comes from one routine to the other but they will remember and what's going to happen next. Organizational

skills we are quite sure that this helps children's brains become more organized internally and so they can follow sequences which helps them not only participate in school but they can follow sequences at home and the steps in getting ready for bed with the steps related to what are they going to do to help dad water the plants with motivation Sharon has talked about that. It's clear that there's something that we likely will have a more positive response and people preferences really comes from us learning from families nobody else is going to talk to the child but they were go spend the whole day with grandma and. It's the most famous popular person for that child and we want to give them the opportunity to work with that person. Sometimes at home you might think about scheduling an activity with one of the more grown-up siblings. They will start to think that I want to play with Johnny not to you. That we give them opportunities to give them more empowered. We know that our kids with charged and always get what they want it might help make the activity be more successful for everyone.

>> So I think it is time -- we have one more slide.'s time to hear from all of you -- Jennifer I see that people are typing but nothing is showing up. I have seen that as well. The final slide that we have while we're waiting for questions is the strategies that we are recommending is for lifelong existence in this world. We would hope that parents can use some of these and make them just a little bit happier with the things that you ask them to do everyday. We start with young children so you can practice the skills so we can start a ready with self advocacy it can be a lifelong tool for them for an environment. We think that your children will have much more success. So there is a question. This was an answer to one of the questions about that the person response to. And to allow activities that she enjoys. Work activities needs to have a time limit after a short period of time she wants to revert to activities that she initiated. It sounds like you're using some great positive response and it's related to she is doing what she likes and there's a time limit and I'm wondering if you are telling her overtime are you going to work for 10 minutes and then over the next few weeks going to work for five minutes are you able to help her increase the time and had as she react when she goes back to the act to these that she really wants. Is she happy or is it challenging.

>> I think other people are typing

>> Here is another question. They asked a little bit that they were told that their child has artistic like behavior in the question is is it or is it not actually alters them that is part of CHARGE Syndrome. It's hard to know the real answer without knowing the child but I think that our belief is that the child sensory impairment of the primary disability in terms of an educational study would borrow some of the strategies from the world of autism and I think regardless of whether they can be a little bit artistically prefer just think about them as autistic like we use the strategies that many of these work well with children with autism and I don't think that we can answer the question but we do see kids that look a little bit artistic cash autistic. We were not given the diagnosis but we would borrow strategies that would work.

>>

>> Learning about time and learning to use a digital watch has been huge. Kelly share why it has been huge?

>> She probably cannot hear your.

>> She is saying more.

>> We're trying to finish getting the question.

>> She is talking about the use of a schedule and we know that Andrew is now an expert in using his schedule and my sense is that for children that are so confident with the schedule that helps people film are frustrated more in charge of what is happening and at some point he will most likely develop his own schedule of things he wants to do based on his own motivation.

>> The children like to keep to their own schedule -- no matter how they understand time so many of our kids are doing great with using time since they are on the iPad in the computer you can be on and when it gets to the 1030 and you show them the visual model and were not gets done you have to turn them off and it helps to remind them. Scheduled work really will -- while that way. We know it is also at two -- double of sward you have to be really careful about that it keeps me being honest and true to my word about the schedule. I think that is always really -- I think it is keeping him on track and you on track. It is really help the. It is really great. I saw that Judy had a question about not wanting and I see this with a lot of my students. That they don't want to be wrong and they are really hard on themselves and sometimes they don't like to try so the thing that -- a couple suggestions because it is at home and that we can say for you to practice maybe 10 words are too much if you are only getting two words right. That is happening week after week that would be something that I would go back to the specialist team and talk to them and say can you have maybe five words so he has more of a chance to be successful and then you could build up because at that point -- or maybe the words could be a little bit easier. And we can work for example in spelling if he wants 10 words maybe five of those words are words that he's already have bullet brainstorm of the special ed teacher you are right something is not working that is to ideas that I have

>> The question from poly applicable at the other families respond to that. We have not used the formal speech communication with our students here but that doesn't mean it's not successful so hopefully the parents who have had some experience can respond..

>> This is Lori. So we have maybe one more minute for a last question and then we will have to end our evening.

>> I think that is on -- that is the end of the questions I want to thank you both very much for sharing your time and expertise with this. You provided a wealth of great information and I thoroughly enjoyed it and I can tell that everyone else did so thank you very very much. You can tell that we are almost as passionate as you guys are with their own children. We look forward to seeing many of you at the conference and if not please feel free to comment -- contact us at the charge foundation if you have any

other comments or questions we would love some feedback. Thank you for setting this up press. Thank you to the foundation.

>> Thank you very much. Have a good evening.

>> Goodbye..

>> [Event concluded]