

**Event ID:** 2116327

**Event Started:** 5/19/2013 6:55:04 PM ET

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Okay, I am showing we are at the top of the hour. I am going to go through some housekeeping items. I want to begin by welcoming everybody. Once I go through the housekeeping items, I am going to start recording the webinar and turn it over to Sherry Senger who will introduce tonight speaker. First I would like to mention that I will be muting everybody's phone lines so that we don't have to worry about background noise and things like that.

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You can on mute your phone by pressing -- unmute your phone by pressing star-six. You can enter your questions into the chat pod and we will present those to Dr. Denno at the end of the session. Anything you put into the chat pod will be public information and will be viewable by everybody. The cautious about personal information about children that you do not want to have public.

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The first step, I am going to mute everybody's phones. You will hear some announcements momentarily.

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[ Silence ].

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All guests have been muted. You can on your line by pressing star-six.

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The next step is to begin recording and you will hear an announcement about that as well. Then, Sherry, you can unmute and begin your presentation.

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This meeting is been recorded.

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Okay, we -- being recorded.

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Okay, we are good to go. Welcome to the CHARGE seminar. My name is Sherry Senger and we are pleased to help you -- to have you join us as Laurie Denno discusses the top 10 strategies for promoting Positive Behavior in children. Laurie Denno is a board-certified behaviorist and licensed mental health counselor. Laurie has over 30 years experience in working with children who have developmental disabilities. She has worked with public schools, private schools, vocational programs and a rehab programs. She works at the Perkins school for the blind and is also on the faculty at Simmons College. Her primary interests are CHARGE syndrome, Delft blind and mental illness.

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This will be recorded for future viewing, so please be mindful of your comments in the chat box. It will be seen by anyone viewing the webinar. As you know, that CHARGE foundation is a not-for-profit organization that provides support to individuals with CHARGE and their families. Our mission is to gather, develop, maintain and distribute information about CHARGE syndrome and to promote research about its identification cause -- identify -- identification, cause, and research.

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If you like what you see tonight and you believe that the work that that the nation does on the behalf of CHARGE children and families is important, please consider making a donation through the website or becoming a member. We thank you for your support and for joining us and Laurie Denno this evening.

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Hi everybody. Thank you Sherry for the lovely introduction. Before we get started, I would just like to say how honored I am to be invited. Also to tell you that at about 12:00 this afternoon I fell off of my bike. If I mumble a little bit -- moaned a little bit well I am moving around, forgive me. I have no skin left on my left elbow. In any event, I want to talk about the strategies for promoting positive behavior. One of the reasons I have selected this topic is because it is so much easier to teach children to engage in appropriate social behavior than it is to try to get rid of troublesome or undesirable behavior after it is entrenched in a child's repertoire.

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So, I have some general information that I would like to share before I go into the top 10 points. Then, I will go through the 10 points and hopefully we will have some new information that will help you make information -- decisions about your kids.

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First of all, I am a behavior analyst and most behavior analysts believe that behavior is learned. So, behavior is learned by interacting with the environment. Behavior is very much contextual and is influenced by both what comes before it and what comes after it.

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So, every kiddo that we will work with comes from a unique environment. The context is only there's an is not like any other students or child's. So the support plan we would like to write for a specific child is unique. That is one of the thing that sets behavior analysis apart from other areas of treatment. We believe that every child needs to have something designed for them.

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We all know that children with CHARGE syndrome have many challenges with sensory impairment. So, if behavior is learned with sensory impairment, sometimes you get really challenging behaviors. So, as we all know, behavior difficulties for the individuals with CHARGE can be compensated due to learning and sensory challenges -- complicated due to learning and sensory challenges.

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You need to be really aware of the learning and the sensory challenges at home and at school. Some behavior however is not learned. In that category, I put behaviors that are things like tics, obsessive-compulsive disorder, test -- Tourette syndrome, and some self stimulatory behavior. This behavior is not learned in the same way that other behaviors are learned, but they can still be strongly influenced by the environment.

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The first one of my top 10 things to do is to be consistent. That involves having people in your family make a decision about what is important to the child and to the family. Then, what points do you want to focus on first and then make a plan that will work. It is important to pick 2 things at a time to work on at a time. Otherwise you become frustrated and the child becomes frustrated.

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One thing that is important for consistency is to have all family members to know the plan and follow the plan. To know what areas you were working on and what you are going to do in specific situations. This is not an easy task. Our -- all grandparents want to love up their kids and they don't want to follow a plan and plant -- and follow responses with children. It is important. Consistency is also important between school staff and home. When talking about schools -- talking to school staff about what important things you are working on at home, help them make the same decisions at school so that things are carried across both settings.

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As we all know, kids with CHARGE syndrome needs lots of structure and predictability in their lives. Just for a couple of reasons. Many of the students we know have anxiety disorder. So, not knowing how things are going to go and not having a predictable schedule can increase anxiety and add more difficulties. Another thing that is really important about consistency is that if kids can into the page what will happen next and the structure is predictable, they can be more comfortable in their learning

environment and will be less likely to engage in other kinds of behaviors, maybe to avoid a learning situation.

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It is important to remember that when you are teaching new skills and learning new skills that it takes time. That is especially true for children with hearing and vision impairment. So, being patient is crucial. You want to pick those things that you want to work on and then put in time and effort. Your patience will be -- will pay off.

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Sometimes when you have a child engaging in undesirable or inappropriate behavior, in the moment, you just do not know what to do. It is perfectly reasonable to walk away and give yourself some time and space to think about what is going on with the student or the child. What is the best response? Walking away is a great skill and I highly recommend it.

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It is very important I think to be positive with children. This is probably easier to do than the consistency point. Try to put into your mind to tell the child what to do. It is so easy to tell the child what not to do such as stop running, stop yelling, put your hands down. We all do that. But, if we can tell the child, we are in the supermarket and you need to walk, you will get way more mileage -- mileage then if you tell the child what not to do.

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It is also helpful to have positive, descriptive feedback. [ Indiscernible - low volume ]. When I'm talking about descriptive feedback, I'm talking about the example that I just gave. Such is saying, oh, you were walking, that is terrific. You want to label the behavior that the child is engaged in so, they know specifically what is the good job.

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Using social feedback and praise is really an important thing to start with children at a young age. You can really tap into their in -- their desire to please adults. When children want to please adults, you can get a lot of mileage and good behavior by using social feedback. [ Indiscernible ] more complicated reinforcement systems.

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The only roles include that you need to be immediate. Research says .5 seconds after behavior is the optimal time for giving feedback. So, it is pretty quick. Feedback reinforcement should be frequent, especially when you are teaching a new skill. You want to praise every time the child engages in the behavior. You want to make the reinforcement as positive as possible. That means, you may do social feedback with tickles or special treats or access to a special activity occasionally. Also, being positive

with social feedback needs to be consistent. So, children will expect to get positive feedback for specific behavior. [ Indiscernible - low volume ].

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I have a rule that I call the 10 to 1 rule. One should try to give 10 units of positive feedback for every unit of negative feedback or correction or reprimand. We don't like to use reprimand at all, but sometimes they slip out. But, 10 positive statements for one negative or criticism statement is a good rule of thumb.

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Using positive feedback can also be used to decrease undesirable behavior. It is called teaching alternatives. So, if you have a child that is engaged in undesirable, and egg -- unacceptable, unsocial behavior, you can use it said to -- you can use it to reinforce the behavior that is opposite of the undesirable behavior. It takes a lot of creativity on the part of parents and teachers, but it can be and ask -- a powerful tool. It is not one that think -- that -- it is not one that people think about much unless they have been trained.

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It is also important to focus on the strength of your child. All of the kids cannot do what we want them to do right away. Giving them feedback for what they can do successfully will be helpful.

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So, point 3. Have behavioral expectations. We all have expectations for our kids, but we don't really present them in an organized fashion. I am going to suggest to you that you will do something called roles, reminders and reinforcement to increase acceptable behavior. It will be really helpful.

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I don't think you need a lot of rules, but you should write them down so that you remember what you are working on. 3 is plenty for any situation. For letter kids -- little kids, it may be too many. You will know your own child.

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Always state the rules in a positive manner. For example, I have rules for being in the supermarket which would be, you will hold my hand, you will use a quiet voice while in the store and you may have one cookie in the checkout line. You will notice they are all positive. It does not say there is no running in the aisles or do not pay for cookies. It is all positive statements about what the behavioral expectations are for the situation.

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Again, you want to use descriptive positive feedback when the rules are followed. Even if you have to remind the child to follow the rules. Remember, one cookie is the rule.

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Listen to your reminder and follow your request and give them positive feedback for that and you will be much more successful in the supermarket.

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I think it is important to remember to be successful -- respectful to children. I think sometimes children can say no. They cannot say no all the time, but occasionally, it is not going to cause any harm. It gives children some ability to control their own environment.

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I think it is really important in the family that behavioral expectations be the same for all children in the family. That does not mean that all of the children need to be -- to do exactly the same thing, but if you have an expectation and your family that your children will do chores, then all of the children should do chores. Even if it is a tiny chore like taking your plate off of the table and putting it onto the counter. Or putting your dirty pajamas into the hamper in your room. There are simple things that all children can do.

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Children with disabilities, things are hard for them. I think it is important to them to have the same behavioral expectations that all of the kids have.

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It is important to offer choices about when, where and how they do things. If they have a sense of control, do you want to take your bath now or after dinner? Do you want to play with your dog, or do you want to color -- doll, or do you want to color? Allowing children to make choices can be helpful.

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It is important to pick your battles carefully. It is so easy to get into a power struggle with a child, especially if they are willful pillar -- willful. Sometimes you can let things slide and no harm is done, but again pick your battles carefully.

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Sometimes you need to compromise. It can be a good solution to a standoff in a power struggle. You can step back and say, this will not work. You can go halfway to meet child. It also teaches important skills for later in life such as negotiation. A lot of the kids are great negotiators.

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Also, not following the rules can teach a valuable lesson are natural consequences. If you don't wash your hands after lunch and get your coat on, you will not be ready to leave on time to go shopping. Not that is a nice -- not that it is a nice thing, but if you cannot get yourself organized, maybe people will leave without you and you will miss the opportunity to go shopping. It sounds a little harsh, but it can be helpful in many situations to let those natural consequences happen.

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A lot of times we make exceptions for kids. I know at the school where we work, we often label those special occasions or special exceptions. So, children don't expect lots and lots of special treatment. Your behavior also influences the behavior of your child. I think it is important to have your own good behavior. One of the things that I am always talking to the staff about is not to yell across the room to get people's attention. Pretty soon the kids will be yelling across the room to get your attention. It can get loud and key audit -- chaotic.

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Another natural rule of thumb is to be an authoritative parent and not an authoritarian parent. Because I said so is authoritarian. Authoritative is to speak with content -- confidence. Children raised -- will respond to that.

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If you do have a negative consequence, it is important to follow through. I don't do any programs with negative consequence, [ Indiscernible - low volume ] consistency is important for follow-through.

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Communication is important. It is especially important for children with hearing and other learning challenges. Communicating at the child's functional level and in the prior -- primary mode is important for a -- important. Learning to communicate effectively with our kids [ Indiscernible - low volume ].

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Make sure that you know your child's for capillary and core needs with the school or preschool can be helpful -- and coordinating with the school or preschool can be helpful.

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Giving direction in short clear sentences in the child's field of vision. I know that you want to have an enriched communication environment for all of the students. In fact, we sometimes use way too many were and we don't really hear the message or the request.

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Again going back to telling the child what to do. It is an ongoing theme in this talk that is very important. Thinking about your communication style and remembering to tell the student or the child what to do

and not what not to do. I think it is important to recognize each child's strengths and limitations and try to coordinate again with the school. I think it is important to have a strong relationship with the speech and language pack colleges. Children are not just going to -- pathologist. Children are not going to just learn to communicate. It takes a lot more work on everybody's part to teach them to be effective communicators.

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I think it is very important to anticipate the child's needs, but you need to expect the children to ask for what they want. It is so easy to just anticipate because we are trying to be really good parents, but we want children to speak up or sign up for what they want.

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It is also important to teach the children to ask for a break or for time to relax. When they are presented with activities that may be difficult, often when presented with those kinds of activities, children will engage in avoidance behavior. That results in behavioral difficulties. It is much better to teach them to delay and activity for a brief amount of time by asking for a break. It will avoid other troublesome behavior.

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When I say that actions speak louder than words, I am talking about the actions of parents. I skipped one, sorry.

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Do not try to talk your child into being good, or expect anybody else to do so. I often have parents ask me to talk to her and tell her to stop doing that. That is not really how behavior analysis works. As I said earlier, it really is a function of looking at the whole environment and seeing what comes before the behavior and after the behavior and looking at the context of the behavior in order to make decisions about the right approach.

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Therefore, actions speak louder than words. The way you are before troublesome behavior and after troublesome behavior will change the behavior. Not just talking to the child about the behavior.

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We can't say anything nice, say nothing at all. When your child or student is engaged in a lot of inappropriate or troublesome behavior and you don't know what to do, sometimes it is good to walk away. Or, just be quiet until you can figure out what is the appropriate response to that situation.

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It can also be helpful to use a script with your child when you are discussing less than desirable behavior. Saying something like, remember yesterday when we were in the supermarket and you fell on the floor and were screaming? The next time I go shopping, you are not going with me, but we can try the next time. Just stating things in a matter-of-fact way so that it is no big deal. You are in fact telling them what the expectation is and what the consequences.

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A schedule is a really important thing. It is very important to follow a daily routine that has consistency and predictability. It makes life easier for the parents and the children as well. Sometimes it is difficult to figure out how to make a schedule for a student or child at their functional level, but you need to consider a lot of options. You can use words, pictures, symbols and organize a to do list for students who are a little older. All of those things are helpful.

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You want to teach to build and -- teach in building changes and cancellations. I do this with older children. I chant -- I schedule a cancellation so we can practice a cancellation and thinking of something else to do when something is canceled. We have arbitrary changes so the children can learn the changes okay and go forward. You can teach the children to accept any predictable and thoughtful way as opposed to when there is an actual change or cancellation. Sometimes you cannot make a good plan around those.

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You can also use a schedule with the behavior support plan. It can be very easy to do if your child has [ Indiscernible - low volume ] organize structure plan. A lot of times you can overlay a behavior plan over a schedule [ Indiscernible - low volume ].

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I think it is important for the schedule to follow the regular flow of the day. Save some time for down time and a long time. That is one of the things we neglect with our kids. Just to have time to chill out and relax. I also, with older children, teach specific relaxation skills. Sometimes children with CHARGE syndrome can become over stimulated and they cannot get themselves back under control. You can teach them relaxation strategies [ Indiscernible - low volume ].

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Of course you want to teach play skills and have some fun with kids. But, like many other children who are deaf-blind, you have to teach the skills specifically and often step-by-step. At the beginning, it is not so much fun, but at the end [ Indiscernible - low volume ]. I think it is important to plan for regular sensory integration activities. Not being an expert in that, I cannot speak to it specifically, but I know that deaf-blind children have a lot of sensory integration needs in general. You can plan that into your time and that can be very helpful for some children.

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I think it is important for all children to help around the house. That goes back to having behavioral expectations for all of the children. You will be surprised that I do a lot of assessments for children and -- the things that they can do and they things they cannot do, and a lot of the children that I work with do not know how to clean the dishes after the meal or throw their clothes into the hamper. Those are things that should be included in the day from the get go.

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At the end of the day, I think it is important to have fun. Hopefully everybody has time for that.

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This relates to what I was just talking about, but a child should be able to do for herself. People night -- people need to have the children participate in their own lives from an early age. If it is possible, they need to help around the house by feeding the dog, getting the mail, watering the flowers and other chars -- chores.

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One would also want to teach activities of daily living like handwashing, face washing at an early age. Because, remember that we have children with delays and that means it takes longer, so you should get started early instead of thinking -- for teaching a child to wash his hands, it may take three weeks or a month, but it is good to get started early on.

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Expect the child to try and then help only if necessary. Try eating is really important. It is good for self-esteem and helps to make you an independent person and give a sense of accomplishment. Even if things are hard, trying is something.

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Of course, we want to use a lot of social feedback and praise for doing it right yourself and being independent. That is what everybody wants for the children, when they are older to be independent and self-sufficient.

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One thing that we forget when children are young and they have so many therapies and needs and people in and out of the house, it is really quite chaotic. But, I think it is important to give children sometime to spend alone with tollways -- with tollways -- toys, fit -- a favorite object. Just downtime.

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Things to avoid. First and foremost, I think punishment is something to avoid. Punishment will suppress behavior, but only when the punisher is present. When the punisher is not present, the behavior is likely to come back. I am not a fan punishment. Punishment also has some big side effects. With punishment, children often show [ Indiscernible ] responses. They may become angry, hate you, cry and cause more trouble than the behavior that they are being punished for.

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Mostly, punishment is not teach new behavior. Punishment suppresses behavior, but does not teach new behavior. So, it is not a very efficient [ Indiscernible ].

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Personally I think reprimands should be used sparingly or not at all. Other things to avoid include shopping for the magic solution. I think people here about and read about some new diet I'm at there be or advice that could be helpful for their child -- new diet, therapy or advice that could be helpful for their child.

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There are many fads and pseudoscientific treatment and you need to be careful and be an educated consumer.

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Another thing to avoid is the phrase, she will grow out of it. If you believe like I do that behavior is learned, the behavior is occurring for reason. That reason is probably going to be maintained and it is unlikely that children will grow out of behaviors. It is much more likely [ Indiscernible - low volume ].

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Another thing to avoid that happens all the time is saying, she is fine at home, or she is fine at school. Remember when I was talking earlier, behavior occurs in context. The behavior at home and at school is different. Again, I think it is important to try to put your hand across the bridge to the school or the home so you can have some sort of a consensus and plan of why a child [ Indiscernible - low volume ] and what you might want to do about it.

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It is very easy to make a lot of excuses for children with multiple disabilities. They certainly have many challenges in life. It is also really important to be a little objective about why things are happening. I think everybody looks for children, especially children with multiple disabilities, that they are doing the best they can. So, making excuses is not really helpful. Think about what we want to teach and how to teach it.

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Another thing to avoid is blaming others. There is a lot of blame in special education. Again, I think a team is critical with open communication so that people are all working on the same thing and in the same fashion.

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Another thing that happens often with CHARGE syndrome is playing. CHARGE is not the blame for everything. Kids can have the regular old bad behavior of any other kid. It is important to look carefully at the situation so that we are not blaming the syndrome.

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Another thing to avoid is being the martyr. This role often falls to the moms because the moms often stayed home to take care of the child when they are small. They do everything and take on all of the responsibility and coordinate all of the medical people that work with the child. I think it is important to speak up and ask for help and to share the burden across the family.

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The last thing to avoid on my list is giving up too soon. It is important to remember the delay, the developmental delay, takes a while for all children to learn skills and abilities an acceptable social behavior. So, don't give up.

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One thing that I think, especially in this day and age, that people can do is to educate yourselves about the behavior in children. You can read a book about applied behavior analysis, functional analysis of behavior, behavior management. I have the books listed on the next slide. You can take the class through a college or through a parent group. There are many classes for behavior analysis at the college level. For a small amount of money, you can get a broad educational experience with a lot of information.

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Of course it is always important to network with other parents. I think that that CHARGE Facebook and listserv have been helpful in people connecting and sharing information.

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You can talk to the staff at the school about resources. A lot of times teachers have a lot of contacts outside of the school or in the community that can be helpful. There is always the CHARGE foundation that has unlimited materials and information. There is more and more all the time.

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So, these are some of the books that I have on my slide to help people educate themselves. The first 3 books on the list, The Good Kid Book, Parents or Teachers, Living with Children are old books. They are

mostly from the 1970s and 1980s. They are well written and straightforward. They are easy to read and pretty straight forward. They have wonderful tips for working with children who have behavioral challenges.

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The Relaxation book is specifically for children with developmental disabilities. It is a great textbook and a good how-to book on teaching relaxation to young children with disabilities. It has been in print for probably 35 years and it is still one of the very best book. It is also great for the moms, dads and teachers who need relaxation. It is a great book.

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The next book, Functional Behavior Assessment and Intervention in Schools is more for educational settings. [ Indiscernible - low volume ] kids who are troublesome.

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The next book, Solving Child Behavior Problems at Home and at School, Solving Child Behavior Problems at Home and at School, is not a book I have read, but I was looking through a catalog recently and it appears interesting. I think that would be a good addition.

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The book, Applied Behavior Analysis is a textbook that the certification exam is based on. It is a textbook that is really expensive, but you can buy one on Amazon about one third off of the regular price. If you are really interested in learning about behavior analysis, everything is in this book.

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The last book is Freedom from Meltdowns and is for children with autism. I know many of these children do not have autism, but Thompson is well respected -- is a well respected behavioral psychologist. He has published thousands of articles and edited hundreds of books. It has a very neurological -- neurobiological approach to the disabilities. I like all of his stuff, he is a wonderful writer. I picked up a copy of this book, and as I was reading through it, every place it said autism you could put in CHARGE syndrome. There are all kinds of excellent tips for preventing and dealing with meltdowns. We know that our children how meltdowns. So, this is a great book.

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All of these books, with the exception of the textbook, are relatively inexpensive. You could probably order them online in about five minutes. I would suggest that you pick a couple of up and look through them.

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I think it is important, as I said earlier, to talk to the school staff. If you are having behavioral difficulties at home, they may not know that much about CHARGE syndrome, but they probably know a lot about behavior. More and more academic classes for special educators are focusing on the behavioral issues. So, people are getting more and more educated about this.

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One important thing that I have learned is not to try to solve problems for teachers. Just listen and brainstorm with them. I think the interesting -- I had an interesting experience with adult services. A parent was contacted because the daughter was having a lot of behavioral difficulties. The mom came in and we were talking about different things she could do. She said, I noted -- I know what to do to make this better, but you need to stand behind us and support us. The mother thought that she knew how to solve the problem and that she knew what to do. That was the best conversation I had had with a parent of an adult child and adult services. She really did think that every time people called her up was that we wanted her to fix it. What we really wanted her to do was to stand by us. It was a helpful lesson.

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So, when people from the school call, they may not want you to solve the problem. That may not be what they are thinking.

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I think it is also important for parents to speak up when they are having a problem so that the staff can help you. Everybody has different skills, thoughts and ideas regarding a child's education. [ Indiscernible - low volume ] is really important.

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One should and -- one should expect high-quality education. Some people struggle with this. It can be done.

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I also think it is really important for parents to educate themselves about the materials, homework, communication and the strategies that are being used at school. They can carry those things over at home. You can have the best educational program in the world at school and those skills are not necessarily generalized to the home setting. You can talk specifically about the environment in which they need to occur. Having the parents on board with the educational component at home can be very helpful.

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As I said earlier, the children that we work with are very complicated. They have the learning issues, they have a hearing, vision and balance issues. So, their behavior can't -- the behavior problems are complicated. I say to you that because of the complicated troubles, you should get expert help. I was

suggest a board certified behavior analyst. The board has a website which is listed here. You can plug in your zip code and get the list of all of the behavior analyst that are within 25, 50 or 100 miles where you live.

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I am lucky because I am in Massachusetts [ Indiscernible - low volume ]. I heard from a student of mine a few weeks ago that they have 17 in Vermont. Depending on where you live, you can get names of people.

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Now, a good BCBA will not necessarily know anything about CHARGE syndrome. You can teach them what they need to know about CHARGE syndrome and death-find issues. Essentially behavior is learned the same -- ---blind -- deaf-blind issues.

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Sometimes I think we made CHARGE syndrome to special and people do not know about it. If you need help at home, you can also asked the school. A lot of school psychologist now are trained and functional behavior assessment and behavior support plans. That was not the case years ago, but it seems to be more and more prominent there may be somebody in your school system who could help you out.

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A lot of times you can get help from a mental health center and quite often there is a Children's Hospital near your home that will have resources. They also have support people. -- Support people and staff at a hospital.

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You can also call organizations to serve other kind of developmentally disabled children and they may has resources -- they may have resources available for you as well.

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A lot of people who teach special education or psychology have experience with behavior analysis and behavioral issues and [ Indiscernible ].

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So, those are the 10 things that I think you could do to help prevent behavior problems. I have one more slide that I would like to share with you. This is specific to individuals with CHARGE Syndrome. We have noticed over the years that a lot of kids have what I call interfering repetitive behaviors. These are behaviors that include repeating -- repeated question asking, having have something finished before they can move on, checking the cupboards to make sure things are in the right place, he having doors

opened, having doors closed, having lights on, having my soft. All of those kinds of behaviors. -- Having lights off. All of those kinds of behaviors.

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It does appear that they are probably neurological and not necessarily learned. Although, they can be influenced by the environment. It appears that the children are driven to complete the behaviors. What happens is that parents or teachers have enough of the behaviors because they interfere with work or activities. When they try to interrupt or get the behaviors to stop, often that is when the children become aggressive or engage in self injurious behavior. It is the aggression and the self injurious behavior that cause the biggest problems at school and at home. But, it is the repetitive interfering behaviors that are the root of the problem.

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It is important to get a good assessment of what is happening before troublesome behavior as well as after troublesome behavior. The aggression and self injurious behavior [ Indiscernible ] traditional behavior support plans. The behaviors are treated directly. In that case, psychiatry can often be helpful. It is an important distinction to make. It is important to look at the fruit of the problem -- the root of the problem before you jump to a conclusion about [ Indiscernible ].

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That is the end of my overall presentation. I hope people have lots of questions.

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[ Silence ].

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Thank you very much for an excellent presentation Laurie. There are many interesting questions, so I will pose some to you and then Sherry Sanger will follow-up with some more.

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Amy asks, if the child is having a tantrum, which you asked them to calm down, or what would you suggest?

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I would want to know what happened before the tantrum started, and what people have done for tantrums in the past? If I did not have a lot of information, or could not get it quickly, I might just wait until the child was done. I don't usually interact with children during tantrums. They can't [ Indiscernible ] anyway.

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Good. Melody asks, how do you handle a child who wants to control the situation. She clarified that down, she said that my daughter hates to be told that she needs to hurry up and finish what she is doing. That is when I see her wanting to control the situation.

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I think in that situation, it would require some specific observation to see exactly how it goes. I hate to not answer a question, but the complicated -- it is a complicated kind of issue. I think it would take a thorough want -- a thorough analysis to figure out what is going on. I have seen many of the children that I work with who are similar. They might be a little bit on the perfectionistic side and want to do things in a specific order and in a specific way. If you tell them to hurry up, it is really annoying to them. There is all sorts of collateral behavior that is fallout for that.

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Very good. Another interesting question. What if a child is fixated on one thing and does not want to do anything other than the one particular thing, or play with the one particular toy all the time?

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In that case, I may take that away and use it as a reinforcer -- they take that way and use it as a reinforcer. Or, I may make a schedule for the child that would include a variety of activities. Then, plug in playing with the toy as part of the schedule. That may be the option.

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Or, you could put some rules around when you can have the toy and cannot have the toy. Having those kinds of changes, probably the child will not be happy and have some meltdowns and 10 term behavior. -- And have some tantrum behavior. You want to think about what you can do to get to the other side of those tantrums.

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Very good. Here is a very interesting question. What if a child knows what he or she is doing wrong, for example like pulling out a Jew to, and does -- AG tube -- of G2 -- a G-tube and chooses to do the behavior.

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This is where you need to get an expert involved. They are doing a behavior for some reason. Maybe it is to get attention from the behavior -- from the parents or to avoid something. It could be a variety of different reasons. It is a serious and scary behavior. I have had children [ Indiscernible - low volume ]. You probably want to get an expert involved to help you understand what is going on with that.

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Excellent. Sue asks, what if the child is indifferent to praise?

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If you have a child who is not interested in social feedback as reinforcers, then you need to come up with something else. All kids have something that they like. It might be some sort of a sensory activity, it might be snacks, MIP toys. -- It might be toys. If you can't identify a couple of activities were toys that you can use as reinforcers -- can identify a couple of activities were toys that you can use as reinforcers. You can [ Indiscernible ]. Again, I would suggest getting an expert involved. There are some wonderful things called reinforcer assessments that you can use. There are different kinds of activities and snacks that kids might like. You can actually do a hands-on assessment and come up with some ideas.

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Great suggestions. Martha asks, can -- how do you get the school not to use punishment or the removal of recess as a means of punishing the child for behaviors that are caused by the child losing control?

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That is a hard question. I would think that I would try to get -- again, I keep saying this and sound like a broken record -- I would try to get some expert help. Maybe if the school had some other alternative for being able to do something a little more proactive. I would think about something like a point system or a token system where a child could earn recess, extra reserves -- recess, special activities for engaging inappropriate behavior. I don't like to use punishment and almost always use punish -- almost never use punishment. [ Indiscernible - low volume ]. This may be another case where expertise can be helpful.

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Wonderful. Josh asks if it is okay to blame CHARGE for some behaviors? He goes on to ask, how do you know if it is CHARGE or if it isn't CHARGE?

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I think you need to do a careful assessment of the behaviors. I think that as I said earlier, most behavior that children engage in is learned behavior. So, you need to take into account their learning issues and their sensory issues, but -- all kids learn behavior the same way. If you have a child that has a disruptive or unhealthy behavior, they are probably doing it for a reason. The way to work around that is to figure out the reason and then teach them something else.

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Very good. Sherry, I will ask this last one by Mark that and then if you want to pick up -- Martha, and then if you want to pick up.

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Sure.

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Martha says that it takes 6-7 weeks for a child to change and learn appropriate behavior. If this is so, how do you get the consistency from all involved for that length of time?

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I don't know where the 6-7 weeks comes from. That is certainly not the research literature that I read. So, I cannot speak to that. I think it takes time to change behavior. It depends on the power of the reinforcers that you have available for the child. What behavior you want to change. The question that hits the nail on the head really hard is it is hard to get a lot of people to keep -- to be consistent over a long period of time. It is the crux of the issue to get everybody on board doing the same thing to make the change happen. It is a very difficult job. I will not say otherwise.

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It is because people are used to responding to troublesome behavior in their own way. For some reason, they respond to the way that they are reinforced. So, trying to provide them with other alternatives and to overcome their own learning --

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Okay. This is Sherry. Before I go to Amy's question, I just want to be sure that melodies question was answered about ADL. She asked what is ADL under the [ Indiscernible ] heading? I know some people responded in the chat box and I just wanted to make sure that that question was answered.

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What is the question?

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ADL under do for her says -- do for herself living.

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That is daily living such as washing your hands, brushing your teeth, brushing your hair. Those are all things that you would want to work on as the child is able to. It is not really appropriate for little kids.

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Great. The next question is from Amy. If behavior is neurological, can it be solved?

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Behavior is not neurological. A lot of behavior, expect -- in fact, most behavior is learned. Learned behavior by interacting with the behave -- with the environment and people in the environment. Very little of behavior is neurological. Although, as you have learned, you have neurological changes in the

brain, but it does not start their. It starts with interacting with the environment. It is how people respond to you and how you respond to people and that's how you learn behavior.

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We have Paul asking that when you say psychiatry can be helpful for SIB, do you mean medications?

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What I meant to say, who knows what I said, psychiatry can be helpful in working with people and children who have repetitive interfering behavior. That when you interrupt that behavior that they engage in self injurious behavior or aggression. Many, not all, that many of the children I work with are involved with psychiatry because they have a diagnosis of obsessive/compulsive disorder which is treated with medicine. Once they are well treated with the medicine, the aggression and the self injurious behavior decrease. If they do not go completely to zero, you can use other kinds of behavior treatment to decrease those behaviors.

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Okay. Aaron asks a question that I know that many parents ask. How do you encourage a toddler to keep his or her cochlear implant on when he/she does not want it on at all?

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I would make a schedule and put the cochlear's on during specific, highly preferred activities. I we do a little desensitization program where I would gradually increase the time that the child wears the cochlear.

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Okay, we have another question from Amy. My child seems to check out with cell stem behavior. When trying to redirect this -- self stimulating behavior, when trying to redirect this is when we see behavior.

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That is common. I am not a big fan of allowing children to engage in self stimulation. Though, we ask so much of the kid, especially when they are small. We asked them to pay attention to a lot of things and do a lot of things and to try and try really hard. I think they get overloaded. So, a little cell stem, -- self stimulation, although it is not a good thing, it may be helpful. An -- other activities may be objects that the child can use alone or with the parent that are self soothing and provide downtime. It could be rocking, swinging in a hammock, rubs. You could get information from an occupational therapist about some techniques that are self soothing.

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Okay. Aaron asks another question. Is it common for children that you see with or without CHARGE , to go through month-long phases a particularly negative behaviors and then all of a sudden stop doing those behaviors? For example headbanging or spitting food out?

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Usually when a child does it behavior for a specific amount of time and then suddenly stops it without treatment, it always makes me wonder if there isn't something else that has changed in the environment. I don't know anything about the particular situation, but spitting food out may be because it is a different texture were kind -- or kind. Maybe there is a different taste.

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I have seen kids who suddenly stop doing behaviors, but not very often. There is usually an environmental variable that you can [ Indiscernible ] if you do a thorough assessment.

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Let's see, the next question is from Paul. Does OCD behavior peaked at a certain age? Does it tend to be progressive? Is it amenable to behavior modification?

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3n one -- three and one -- in one. Particularly developing people who have obsessive-compulsive behaviors, when they were as young as four or five. They continue to have difficulties and often they became more difficult as they got older. I can't say that is the course for everybody, but I have seen several adult friends who have described that to me.

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Although some people are much older I suspect, I think generally people are thinking that those behaviors are from a younger age. What was the other question?

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The other one was, does it tend to be progressive and if it amenable to behavior modification?

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I don't know if it is progressive. I work with a psychiatrist who always says that it waxes and wanes. They get worse in times of stress and better in times of nonstress. So, I think they know a lot more than I do and I suspect that is probably the case.

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Some obsessive compulsive to behaviors are amenable to behavior treatment. Our behavior of Troy's for -- behavior of choice for developing children and adults is medication assisted by up for each/avoidance behavior -- assisted by approach/avoidance behavior. They will engage in those behaviors and then a coach helps them resist. It is a gradual desensitization they were -- procedure. There has been a fair amount of literature published in that area that has been pretty successful. I think it is awesome -- often paired with medication.

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Okay, we have a question from Sue. Have you redirect or change fixations that go to the dark side? For example, would much rather look at a saw character than Cinderella? Do you deal with it or let it past?

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That -- pass?

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That is an interesting question. I like saw the walls better than Cinderella myself. -- saws-alls Better than Cinderella myself. I think I would keep my eye on it and try to encourage other interests with social feedback, praise and other reinforcers. I don't think I would make -- reinforcers. I don't think I would make a fuss about it.

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The next question is, what if the child is engaging in [ Indiscernible ] behavior in order to get out of the particular situation? To take the child out of the situation or not?

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It pins on the child and the situation. I would look carefully at the such -- it depends on the child and the situation. I would look carefully at the situation. Maybe the situation is to overstimulating, too hard, or maybe it can be broken into smaller steps. There are a lot of things that you can do to make the situation more appealing. I also might add a powerful reinforcer for staying in the situation were completing the activity. Maybe teach the child to take short breaks. There are a variety of things that you can do.

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It sounds like another situation where getting expert help might be a good thing.

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Okay, we have a question from Melody. Our nine-year-old daughter breaks her glasses about six times a year when she is in a moment of frustration. I have heard of other CHARGE kids that do the same thing .

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That is true. There are a lot of children who engage in destructive behavior when frustrated. That is across the board, not just children with CHARGE. One might want to think about looking at the environment and how to structure the environment so the kiddo is well supervised. Maybe thinking about situations where the child is likely to be frustrated and decreasing the frustration or the glasses wearing at that time. It is a situation where a thorough assessment of the environment would be helpful.

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Okay, one more question and then I will have Laurie read some of the others. Also, I have been told that medications lots of times aggravate the situation in case with CHARGE syndrome.

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I'm not a medical person, so I can't really say very much about that. Except that in my experience, I have seen children who have been very helped by using medication and other children who are not helped by using medication. A few kids probably who had exacerbation. It was highly and a large -- highly individualized.

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Okay, Martha has an interesting question. Is it appropriate to ask the school environment to be accommodating to the child having a break with quiet activity, even if it interferes with the schools teaching schedule?

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I think he would have to look at the schedule carefully and plugged in the breaks -- plug-in the breaks at the most convenient times for the educators. The teachers have a schedule and they like to follow it. It is very difficult in many classrooms to make a lot of extra accommodations. But, if they can see the benefit of the accommodation and see that it might prevent other troublesome behavior, sometimes people are willing to make those accommodations.

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Aaron asks, do you encourage to say or sign no toward bad behavior, or do you just ignore it?

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I personally do not use no. Unless the kid is running into the street. No does not teach new behavior. I am much more likely to state the behavior that one would like to see and then reinforce the behavior.

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Very good. Mary asks, have you had any experience with toddlers suddenly preferring to be lying on their back all of the time when they were previously liking to set up or practice walking in there -- their trainer?

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That is PT stuff that I don't know much about. I would ask what they could do? I we get a PT involved in that. From a behavioral standpoint, if the child is -- there is a possibility that the child is avoiding the activity that the activity -- the activity that the PT is requesting. In that case, I may use powerful reinforcers for completing the routine. As far as the PT itself, I think you need to rely on the experts for that.

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Very good, there are just a few comments now on the chat about writing accommodations in and IEP. -- And IEP -- an IEP. I think this has to do with breaks. Could you asked the schools about accommodations?

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I think you need to [ Indiscernible ] the break -- style the breaks to the teachers they have to implement them. I think it can be helpful for individuals who work with deaf-blind children to hear about how much effort it takes for a deaf-blind person to pay attention for a long period of time. It is a tremendous amount of work with those kinds of impairments to pay attention for a lot of -- for a long period of time. Maybe even a demonstration of what it is like to be deaf-blind would be helpful for them to understand what it takes to engage and pay attention.

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Certainly scheduling breaks seems like a small thing to ask, it is just not typical acting. People resist things that are not typical. -- Not typical I think. People resist things that are not typical.

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I appreciate this presentation so much. There is time for additional questions if anyone else would like to ask our presenter. Otherwise, I will turn it back over to Sherry Stegner. -- Sanger.

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It looks like someone is typing a think you to Nancy. We will give people a moment to type.

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It says the multiple attendees are typing, give it a moment.

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We have another question. Do you have any calming strategies for when a child is frustrated?

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I am beginning to sound like a broken record. In a situation when a child is really frustrated, I think it is important to look at the environment to see what the frustration involves. Where it is coming from? Try to maintain the environment to decrease the frustration. Certainly using relaxation strategies is helpful. Taking deep breaths and teaching the child relaxation that I spoke about before can be helpful. We sometimes -- at the school where I work, sometimes when children are really worked up, they do well under a weighted blanket to chill out for a little while. With a lot of those strategies, they are found through the OT world. They are up on that sort of thing more than I am. I would check with the notes he -- with an OT. I am more familiar with breathing, relaxation and the weighted blanket strategy.

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We have a few more questions that just came in. Melanie asks, I have heard -- melody asks, I have heard -- I'm sorry, it jumped a way for me. I have heard about CHARGE and problems was self-regulating behaviors, can you talk about this?

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It is not really my area of expertise. I have read a lot of that same stuff. There are some issues and I think some people do become over stimulated. Not all people with CHARGE, some people. People in a busy, active situation and they need to get out of that situation in order to regain control. I am sure that there are children of similar proportion with CHARGE and not CHARGE who have attention deficit hyperactivity disorder that have the same issues.

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I think the research on that is just beginning. So, I don't have anything specific to say, except to say to look carefully at the environment and the issues where it happens and try to restructure the environment a little bit.

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It looks like we have 2 more questions and then we will try to end it there. Aaron asks, regarding whether or not to say no to bad behavior, what if it is something like poking their eye when there is no positive behavior to teach?

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I would direct the kiddos hands to an activity and reinforce them for participating in the activity. I would not say no for that. It is very likely that there is some sensory feedback that the child is getting from the poking which may be reinforcing. I would try to compete with that reinforcement and try to get another kind of reinforcement. Also another kind of sensory reinforcement. Maybe flashing lights or a toy with a little fan or something like that. Really focusing on more hands-on activity.

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Okay, it looks like there are two more questions and then we will end. Shelley asks, my eight-year-old pulls out his trait many times throughout the day -- trait -- trac many times throughout the day and it is a health issue. What would you recommend?

---

I'm going to say that you need to get an expert in to figure out why he is pulling it out and in which situations he is likely to be pulling it out. One thing you might want to do is a really thorough assessment of that before I could make recommendations. You may want to look at the environment. When is he likely to pull it out and when is he less likely to pull it out? What is going on in the environment? What happens after he pulls it out? Those kinds of things. I would suggest that because it is such a serious behavior that you get some expert help.

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Okay, this is our last question for the evening from Judy. What can you do when you know something is bothering your child, but he is unable to communicate what it is?

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I would say, how do you know something is bothering them? What behavioral changes are you seeing? I think you have to be really good detective. I don't know exactly what to say in response to that.

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Laurie, do you think we will stop there with the questions? It looks like one more person is typing.

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Let's let them have their question. I am almost out of voice.

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It still has not come through yet.

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We are still waiting.

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I hope it is not that long of a question.

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We will make this the last question since we just hit the 8:30 mark on the East Coast. What would you do if she is intent or menu want to calm her down and she is getting more mad about it?

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I would ask her to go to a safe place and way for her to get finished. If you are touching her and she is getting more agitated, that is not helpful. I would create a safe place that she can go to tantrum and then interact with her when she is -- When she is finished.

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I see that one more person is typing, if it does not pop up in the second, we will have to and to keep our time frame.

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There is the question, and this will be the last one.

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If we get our son upset enough when we try to help them, he sometimes forgets originally what bothered him.

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I'm sorry, can you say that again?

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I will repeat it. If we get our son upset enough when we try to help them, he sometimes forgets what originally bothered him.

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I actually don't quite understand the question.

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Maybe it is more of a statement, I'm not sure.

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If he gets more upset from PDF -- from people helping him, I think I would likely look at what kind of help and how I am helping and try to make that more structured. You don't want them to be more aggravated. I don't know about what was bothering him.

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Here is another comment, just a comment, trying to make it better initially makes it a works -- makes it worse and then he improves.

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Probably less is more in this case. Not interfering too much and waiting for it to blow over and then interacting him -- with him might be more reasonable in that case.

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Okay, that is the end of the question and answer session. On behalf of of the CHARGE Syndrome foundation, I would like to thank Laurie Denno for providing useful information that will benefit our children and students. Thank you for participating this evening. I appreciate your time on this Sunday night. Please remember to support your foundation through membership, fundraising and donations so that we can continue to bring high-quality webinars in the future. I look forward to seeing many of you and our international CHARGE Syndrome conference in Arizona. Have a wonderful evening everyone. Thank you again Laurie Thank you, and has been a pleasure.

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[ Event Concluded ]. -- Thank you, it has been a pleasure.

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[ Event Concluded ].