

NATIONAL CENTER ON DEAF-BLINDNESS  
CHARGE: THE ROLE OF THE FAMILY IN THE IEP PROCESS  
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HARGE: The Role of the Family in the IEP Process

>> ROBBIN BULL: Okay, just a couple more minutes and then we'll get started.

Okay, I am showing that we are at the top the hour, so I think we will get started. This is Robbin Bull with the National Center on Deaf-Blindness. I want to begin welcoming everybody to the CHARGE: The Role of the Family in the IEP Process webinar for the CHARGE Syndrome Foundation. I do want to mention that all phone lines have been muted to alleviate the background noise. I do ask that you keep your funds on mute during the presentation to keep that background noise to the minimum. The question and answer session will occur at the end of the presentation. However, you can write

your questions in the chatbox at any time during the presentation, as it will be monitored throughout the webinar in preparation for that question and answer session.

We do want to let you know that this webinar will be recorded and archived, and it will be posted on the CHARGE website within a couple of days. We do want to ask that you be mindful of your comments in the chatbox and just be aware that anything that is typed in the chatbox will be recorded and it will be archived, as well.

I'm going to get the meeting recording started, and then I'm going to hand it over to Megan Cote, they will be introducing tonight's speakers. Megan, just one moment as the recording gets started. Just a little bit of a delay, this evening. All right, Megan, if you want to get started, that would be great.

>> MEGAN COTE: Sure. Welcome everyone, to the CHARGE syndrome foundations webinar entitled CHARGE: The Role of the Family in the IEP Process. My name is Megan Cote and I am a board member with the CHARGE syndrome foundation as well as the Initiative Lead for family engagement at the National Center on Deaf-Blindness. I am thrilled that you all have joined us tonight. It's an honor for me to be able to introduce the following three individuals who have graciously agreed to provide their expertise and perspective on navigating the IEP process with you, tonight. They are Kristi, she leads two initiatives for the National Center on Deaf-Blindness, the first being interveners and qualified personnel, and the second being Assessment, Planning and Instruction.

Ricky who is one of the two Iowa CHARGE state family liaisons, and last but not least, Donia, who is a CHARGE state family liaison for Florida. The foundation is thrilled that these wonderful individuals have agreed to present for us tonight. As you know, the CHARGE syndrome foundation is a not-for-profit organization that provides support to individuals with CHARGE syndrome and their families. Our vision is a better world for people with CHARGE syndrome. If you like what you see tonight and you believe the work the foundation does on behalf of individuals with CHARGE syndrome individuals

and their families is important, please consider becoming a member of the foundation or making a donation through our website. The presenters will each take turns sharing and then there will be time for questions and answers at the end. If you have a question, please feel free to write it in the chat pod on the right side of your screen and indicate the question is for. We will make sure to cover as many as time will permit after they have shared. I want to also let everyone know that this webinar has been planned for quite some time. Since the onset of the coronavirus, I know much has changed in the stability of the educational systems with school closures, etc. So the CHARGE syndrome foundation as well as the National Center on Deaf-Blindness is strongly encouraging you that if you're having questions around the impact that the coronavirus is having on access to schooling for your child to directly contact your individual school district, as each district is navigating the waters independently to try to figure out how best to serve and meet the needs of the students in their district.

Without further ado, we thank you for your continued support and for joining the foundation tonight and listening to our wonderful presenters. We hope you enjoy. Kristi, you can take it from here.

>> KRISTI PROBST: Hello, everyone. My name is Kristi Probst. Like Megan said, I work for the National Center on Deaf-Blindness. Before I start, I just want to let you all know that my Wi-Fi has been not being very cooperative. If I happen to freeze midsentence, Robbin is going to be so kind to bring up a picture that she took yesterday. Hopefully that doesn't happen but I will just let you know that ahead of time so it is not shocking.

I wanted to start off by saying that if you're looking for information about what to do for your children and with the school district are expected to do, the US Department of Education did release information on distance learning and how students needs can be met. This is a hyperlink that you will be able to use to go to that website that gives you that information. This is not something that I will be talking about. But I know with all of the changes that have been occurring lately, you must all have questions and probably

have some concerns about services for your children. So we're not going to be addressing that tonight. But there is a fact sheet that has been put out by the US Department of Education and I want to encourage you to go there for information about your rights as parents.

Going to start out by saying the family is the most important part of the educational team. The most important part. They are the ones who are the most consistent both in the life of the student and in the educational progress of the student. The family knows the student best. You know them better than we do. You also hold the big picture for your student. You have the information and experience from all areas of the child's life -- not just what it looks like at school. For instance, you know what it's like at home and with the medical needs and history have been. You know what it's like at school. You know what it's like in the community, when you go to church, to a playground, when you go out to eat. The family also has the personal interest of the student. You want the best for your student, assess the rest of the team. But as the family, you're the one who is vital to the educational team.

When we're talking about the family, you may be the driving force of the team. Why is that? Well, you're the unique source of information for the team. You have information that the team doesn't have. Yes, the team sees your child at school. But some people on that team they only see your child once a year. Or, if they do see them only at school, that's just a drop in the bucket for the child's whole life. So you are unique source of information and you have unique information to share with the team. You bring the voice of the child to the team. You help identify educational goals. You may not be an educator, but you know your child best and you know where you see your child going. You have to be an advocate -- and I know that you know that -- but that's part of your job. You also learn and implement the strategies and techniques that are necessary to help your child learn. You want to help them access the environment, communicate, socialize, and be as independent as they can be. So what you do as a family and is you take what is done at school and you apply that at home, as well.

The family may also collaborate with other team members better support the child in the schools, but also in the community. You reinforce at home what your child is doing at school. And, you enrich this experience by organizing extracurricular activities. That could be participation in story hours or sports activities or going to church and doing things at church. Whatever your family does.

You also share with the school what was working at home. They won't know those things, so they depend on you to share those things with them. And, you also share with school any other critical information that will help the child's experiences at school. If something changes medically, or if you're seeing things work at home that did not used to work. The bottom line is that families and parents are, by law, equal partners on the IEP team. In fact, the law, IDEA, lists parents first as the required numbers on the team. You're first. You're the ones who are most important. You are the ones who have intimate knowledge of your child's strengths, struggles, development. And, because of that, your input on the IEP and that team is extraordinarily valuable. Your participation at every point in the IEP process matters. The school can't develop, change or limit an IEP without you. So you are the most important.

As I was thinking of this I thought well, what could I tell you after I told you that you, the important is most important, I thought about giving you some tips. The first set of tips or things you might want to consider include sending your ideas to the IEP team ahead of the meeting. We do that? It helps guide the discussion and draft the plan. It helps if the team knows ahead of time what you're thinking so you can all send information back and forth to help draft the IEP.

Another thing that's important for every person on the IEP team is to use positive language and have a positive attitude. It is not going to help anyone if everyone is trying to get their own way. But working together with a positive attitude always helps. Another thing is to focus on what will help your child work toward their goal. Sometimes there has to be some give and take, and that's great.

Another thing you can do is include your child as a meaningful participant in their IEP, in their life goal setting and career planning and decision-making. They want to have a say in that and it is their life. So including them is very important. Another thing is make sure you include work-related goals in your child IEP. If it is not in writing, it is likely not going to happen. So you want to make sure that it is in writing.

Other tips or things that you might want to think about our maybe want to bring another family member, a friend or an advocate to your IEP meeting. If you don't feel comfortable for whatever reason, having someone there who knows your child, who knows your family, is also someone who can say the things, help you say the things you want to say or help you just feel more comfortable sitting there. They may not say a word, but having someone there with you can help you sometimes feel more comfortable.

You also want to work at building a good relationship with the other members of the IEP team. You are all working together to get the best outcomes for your child. So having a good relationship will help everyone.

Then you also want to keep your eyes on your and your child's long-term vision for the future. What do you see for their future? Keeping that in mind will help you as you plan your child's IEP program.

But what happens if trouble occurs? If you're having trouble communicating, if the team is having trouble getting along, even? Well, one of the places that you might choose to turn to is the center for parent information and resources. If you don't know about this center, the purposes of it are to work with families... And my computer just went off....

Hold on, just a second. So sorry!

>> ROBBIN BULL: Kristi, is the presentation frozen, or is the phone and the presentation frozen?

>> KRISTI PROBST: My computer just completely totally turned off. Megan, if you want to take over for a second, that would be great.

>> MEGAN COTE: Sure. Hi everybody, this is Megan pitching in for Kristi. We are trying to do the best we can with the limitations on the increased demands of the Internet due to the coronavirus.

As Kristi mentioned, there is this place, The Center for Parent Information and Resources. They work with families and infants, toddlers and children and youth with disabilities age birth through 26, all disabilities. Not just individuals with CHARGE, but all disabilities. They really have been effective advocates in helping parents with navigating the IEP process. And, they partner with professionals and policy makers to improve outcomes for children with disabilities.

We would encourage you that if you haven't yet checked out where your parent center is in your state, to go to that hyperlink that you see at the top that says Center for Parent Information and Resources to see where your local parent center is and get connected to them for support around these types of things. Also, the Federation for Children with Special Needs, they can help you also with finding an educational advocate in your area if it's necessary.

I am seeing a question which is a really good one in the chat pod that says, "Is there a particular age at which it is best to allow your child to have a say in their IEP?" My answer to that question would be as soon as they're capable of articulating things that they would like to work on, or when they're indicating to you what preferences that they're having. Because even if they are a nonverbal communicator, if they are reaching out and showing preferences for particular toys, individuals, or sounds, or whatever, they're letting you know what it is that motivates them and inspires them. And, you can take the information that you've gathered from them and allow them to communicate that out to the IEP team in whatever form or method they can, whether it be you taking

pictures of the child or a film of the child and sending it to the educational team ahead of time, so they're able to view what it is that inspires the child. Or if your child --

>> ROBBIN BULL: Megan, this is Robbin. Can I ask you to stop just a moment? I believe that we have lost our captioner, and your phone is cutting in and out. We will see if we can get Carrie back on, who is captioning. And, I would like to do an audio check on your phone line. Please bear with us as we work on this technology. Again, I think everybody is hitting Netflix right at the moment.

It looks like Megan's call dropped, as well. Ricky, can you still hear me? Donia, can you still hear me?

>> DONIA SHIRLEY: Yes, I can.

>> ROBBIN BULL: Great. [LAUGHS] Very good. I'm glad that I'm still on. Kristi, are you still live on the phone?

>> KRISTI PROBST: Yes, and I just got back in. [LAUGHS] I don't know.

>> MEGAN COTE: Perfect timing, Kristi. This is Megan, I just got back in. Go figure. I apologize, everyone that's joining us. And thank you for holding tight to our technology glitches. Kristi is back on!

>> ROBBIN BULL: We don't have our captioner back, can people type in to the chat pod if you're relying on captioning at this point in time? Okay. Thank you. All right. Okay. So what I am going to do at this point in time is have Kristi, you continue on. It doesn't look like anybody is using it currently. We will go ahead and caption after the fact so we will have it to go with the recording, later.

>> KRISTI PROBST: Okay. Thank you, Robbin. I was just going to say that I totally agree with what Megan was saying, and that, when your child shows that they have



preferences, I think what she was saying when her call dropped was, you could take pictures of them and show them to the team so that they can see what the child is interested in and wanting to do and showing preferences. And, that can help you as you craft your educational program for your child. Megan, was there anything else you wanted to say before we move on?

>> MEGAN COTE: No, that's exactly right. A profound way to show, too, is not even just still photos, but also video. Sending a video ahead of time of your child can also be very, very helpful. They could even come to the IEP and hit a switch to play the video, if need be, so that they can be a part of it.

>> KRISTI PROBST: And when I was in the classroom, I loved seeing videos of my students from when they were at home. Because it often seemed to me that students do things at home that they didn't do at school, and sometimes vice versa. They would do things at school and I would show videos of them during those things at school to their parents and their parents would say, "What? I didn't know they could do that." Video is very powerful and it's a great way to show the team and each other what's going on with the student and what their preference is and things that they can do and things that they enjoy.

The next part here that I wanted to talk about is there may come a time when you have conflict and you feel like you just can't fix it. It's not going anywhere, the conflict is staying and you're looking for help. We really like the Center for Appropriate Dispute Resolution in Special Education. CADRE is a great organization that supports the prevention and resolution of disputes with anybody. They have a fantastic website that has lots and lots of family-friendly resources. And we have just listed a few here like webinars, Quick Guides for parents of children and youth. And then, they also have IDEA, Early Intervention Family Guides. All those are freely available on their website and they're just a great center that can help you if you feel like the conflict is just not coming to a resolution and you're looking for some help.

At the bottom of this slide, you also see a hyperlink and it says Find State Agency and Parent Center Information. This is a place that you can go and get information about your parent center that we were talking about previously. And, Robbin, I do not have access to advance the slides. There. Okay.

We also have two more hyperlinks here that you can use. The first one is titled Where to Turn When You Have Concerns. This is when, this is a place that can get the information about when you have some... well, this is delicate situations, but when you have situations that are surrounding the education program, your child's services, and you just don't know where to go with the concerns that you're having, this is one place that you can go. This is a webpage that talks about when you talk to the professionals in your child's educational journey -- when you talk to the teacher, when you talk to the school administrators, and, it's the different people that you talk to and what point at which you go to those people. It even goes into when you talk to the district administrator, lawyer, student advocate. So this is a website that will give you that information that will kind of help guide you as you're thinking about conflict resolution.

Then, the other one is Strategies For IEP Dispute and Conflict Resolution. This is another great resource that just gives you some information about conflict resolution, understanding special education, but also, just some basic principles to help you move things forward, to help you share your information, communicate more effectively, and really, hopefully, achieve the goals that you're going for.

The last few resources that I have here are 8 Steps to Better IEP Meetings: Play Hearts, Not Poker. It's actually from a great website called Wrightslaw, it's a good website and it has a lot about law and educational law on it. I really like this website, because it talks about using the law to really work on the conflict that you may or may not be having. But also, the concerns that you may have and how to work together to have a better IEP meeting.

Then, the other two ones are IEP Team Meetings: a Guide to Participation For Parents. That's a good website that will kind of give you some information as parents about IEP team meetings and how to effectively be a part of that. Then, the last one is just Frequently Asked Questions about IEP's. Those are all hyperlinks, so you will be able to access those. And now, I'm going to pass it off to Ricky Teed, and I am going to turn off my camera. So Ricky, you're up.

>> RICKY TEED: Hello, all right. Thank you, Kristi, for the presentation. I enjoyed it a lot, and I do relate to both spectrums that you are talking about. You started talking about what an ideal IEP meeting should be and some worst-case scenarios. We had, mine was flipped around where in Kansas we had the worst case, and we moved to the best case we could have hoped for. I will move into my slides. What my presentation is going to be about is what I wish I had known in Kansas, but also what I learned in Kansas that helped me in Iowa.

Hannah is my daughter, she has CHARGE syndrome. She's 10 years old right now and is doing amazing. She is in fourth grade and is in the general education class with about 30 to 45 minutes of pullout time for an ASL class. We've been very blessed here in Iowa to have an excellent program. Her deaf and hard of hearing instructor, she went to college and worked with CHARGE syndrome and deaf-blindness. So she was beyond ready to help us with our IEP. We were impressed with that. She has a great interpreter, as well.

But some of the things that've helped her progress through school, I would say, are her siblings. She has a younger sister about 20 months younger., and that has pushed her to learn things and to keep up. That was a great blessing. Then, an older brother that really watches out for her, as well, and two younger siblings, and they're just fun to have around.

There is Hannah. That was probably a couple years ago on our trampoline. Her smile, her spirit about her is contagious. And everyone that works with her just falls in love with

her. We have really had some great people around us that have supported us. And, Hannah's learning started when she was a few months old. She wasn't even a year old when she went to the Lee Ann Britain Center, which is in Kansas City, and my wife drove there for four years, two to three days a week, and she started with feeding therapy and that's how we got our foot in the door. Then, they increased her services there. That was pretty much her preschool. We considered that preschool for her, which was amazing, because they were all trained therapists, and they would work with her every day she was there. In the long run, it also, I don't want to say hurt us, but it made it more difficult for us to get into the public school system.

In Topeka, Kansas, where we lived when Hannah was born, she had great medical care, so we were happy with that. But when she went into the public school system in kindergarten, she struggled. This was where the worst-case scenario started. This is where we learned everything that we probably needed to know about IEP's and what was right, what was wrong. We are still using that knowledge to move forward, even though we're in a good situation. I would say we are implementing a successful IEP. There's always things that could be improved on. We are happy and, I think what Kristi said is, to have a positive attitude, even though we don't get everything we want, where Hannah is in the right place. And, her goals are being met with her IEP right now.

So, then Kansas, I call it trial by fire, because we were young parents and we didn't know anything about the IEP process. She didn't have an IEP established when we were going into the public school system because she was at Lee Ann Britain Center. One thing that we did know was we did not have to sign her IEP until we were ready and felt like it was adequate for her. But we were being fought tooth and nail on services that the team had identified would benefit her, but they weren't providing it.

So, it was really an interesting situation, to the place where each IEP meeting we had was about two hours long. I remember we had four IEP meetings and each one got progressively worse. It was unbelievable. But one thing that got us through it was that we didn't ever sign it, but that, we had an excellent team supporting Hannah. And at that

point, it was my wife and I, where my wife was more the emotional, reactive type person. So, I learned a lot from just watching her, and she would question everything. I was more to absorb everything, take everything in. I blew up a few times. But when I started talking and some people started listening again, and between the two of us, we were able to get the IEP where we were, we were trying to get it to a certain place. But the final outcome in Kansas was, I got a new job, which is probably not the best solution for trying to solve a bad IEP situation. But fortunately, I got a new job in my hometown, and we moved back to Iowa.

Some lessons learned in Kansas was that the individuals that make decisions must be part of the team. We have, many times, only part of the team there. And the facilitator was trying to establish what the IEP was going to say. Really, if you want to have an effective IEP meeting, you have to have an entire team there, and that was not happening on a regular basis there, to the point where we did not have everyone, so they wanted us to take a straw poll if Hannah needed certain services.

We had someone there that helped us and stopped the IEP meeting and we were done at that time. As I said a few times already, you don't have to sign it until it's entirely accurate. The reason why this benefited us was once it's signed, it's harder to change that if you get it in there the first time. Unfortunately, probably, for a lot of people listening, that's probably beyond where you're at right now.

The one thing that we have advocated for our daughter and continue to do that at every parent-teacher conference or IEP meeting is not to underestimate our daughter. I remember the first IEP meeting for kindergarten, they said okay, we will have her learn 13 letters of the alphabet by the end of the year. I looked at them and said well, what is it for a typical child? They said all the letters of the alphabet. So we had them set the goal at all the letters in the alphabet by a certain time. So that is what we can do as parents, is advocate for our children.

And I am a strong believer that, I don't care how nonresponsive a child is, nonverbal, in a wheelchair, I believe that at a very young age, if we can help those kids overcome those barriers, they will be able to communicate. I believe the majority of the time that children, the people are in there and they just need a voice to be able to let their mind be told. One of my kids, my oldest, who's in sixth grade, has one of his classmates who was nonverbal in a wheelchair. He's going around delivering mail and he get to push a button when he gets to a certain room and he can communicate through an app. So he can speak to people now, and it's really opened up the other kids' eyes that this kid who seems to just be sitting there every day has something to say. I think that's really the purpose of the IEP, to try to take down those barriers and open up new avenues for those kids that are not typical in our education system.

I also put "words have meaning." This is where my wife taught me a lot, as we would go from one IEP meeting to another and they would change the words around. It was an ambiguous word I don't remember what it was. My wife asked to clarify that word and they clarified the word, it meant the exact same thing as what we were saying no the exact two hours before. I think as a team, hopefully you can have that team supporting you and with different strengths, you can move your IEP forward.

Families Together is one of the places in Kansas that helped us. We also had support from the deaf-blind projects when we were going through the lows in Kansas. And really, in Kansas, we felt like it was Us vs Them, as Kristi was saying. The problem was, they know the laws. They're dealing with it every day, on a regular basis. And, we were a novice in the IEP process. So we try to bring the support with us, and we were trying to ask the questions that needed to be asked even though we did not know much of what was going on.

Kristi had mentioned a few tips, and I had one tip that I wrote down. Tip number one would be to have Kristi be part of your IEP team. It sounds like she, I enjoyed everything she was saying about those supports and everything. But unfortunately, she probably doesn't have that much time to, but trying to find someone like Kristi in your areas is

really what I think, especially the younger families need that are just starting off. But even when you're well into it, it won't ever hurt to get more of a professional opinion on where you're going if you're having those troubles.

When we moved from Kansas to Iowa, we were armed with the latest IEP. They had us get doctor's recommendations galore. They had us get therapist recommendations. We had a notebook full of everything from Kansas to prove that Hannah needed an interpreter and needed other services. So when we moved to Iowa, the heavens literally were opened up. Because we walked in to the administrative building, we had one IEP meeting. It was about 8 minutes long and it was all done. We had everything we wanted. It was one of those high five moments that we just couldn't believe what happened. We didn't need any of those supporting documents. We walked in, does Hannah qualify for these services? The person from the ADA [sounds like] which they provide the interpreters here in Iowa, she said yes. She qualifies. So then the administrative, the special education person said okay, she gets it. That was the meeting. We had everything else. We lined up the therapies that she needed. It was unbelievable.

Not everything is perfect, and the work continues as we go on. Unfortunately, if there was a rule or a gauge, I think we probably do have one of the better deaf or hard of hearing programs here in the state of Iowa. Hopefully that's not my bias. But it is pretty amazing and they really try to balance class time with extra support and they do a lot of field trips. They go to McDonald's -- probably not right now -- they go out to the grocery store. They do a lot of activities out in the community, as Kristi was saying, try to make it so it's for your future. What was going to happen after you graduate? Try to get those experiences in.

The one thing that we are working on right now is establishing the Intervener language in her IEP. We have mentioned it a few times, but it keeps getting brushed away, because, I don't know why. They are providing intervener type support to the level that Hannah needs. Things are going well. But we're looking two or three years down the

road to try to keep our minds open on what kind of roadblocks we run into when she goes into middle school and then high school.

The big thing is getting that intervener language in there, because even though she's progressing extremely well, the people, the administrative people, and sometimes the teachers, they don't understand what Hannah's interpreter is providing her, put her subject matter in front of her face and pull the subject matter that they're done away. Rearranging her desk so that she can have the things in her line of vision. Little things like that the interpreters do an amazing job with.

We've tried to get that in the IEP right now. Unfortunately, the intervener is not really, it's not really identified in the state level of verbiage. That's one thing we're trying to work on. It's not a huge mountain that we're trying to overcome, but it's something that we're trying to work on. Everything else, we're extremely happy about.

Hopefully the experiences that I have shared help some of you, at least one of you, to keep moving forward and try to find that solution. It's the one thing that I think has helped my wife and I, is we are positive people. I can see two different types of people. A lot of times there are the belligerent ones that try to yell and get their way by raising their voices and yelling louder than other people. Or, you can try to be positive and stay calm and do your research beforehand and go prepared. And, if you are prepared, you won't have to be doing a lot of yelling, because hopefully the support Kristi shared will be able to support the goals of your kids at home and the goals you expect your kids to achieve.

That is what I have to share today. I did have a video here, but I won't share it here because of the problems. It had to do with *Field of Dreams* and about how Iowa is heaven. I don't know how many of you are familiar with *Field of Dreams*, but that was one that came to my mind when I was preparing this. [<https://youtu.be/izF0LoBkhZY>]

Thank you for your time.



>> MEGAN COTE: Ricky, this is Megan. Before you jump off, we have a question in the chatbox, it says can he also elaborate why you are considering intervener services?

>> RICKY TEED: Yes. She has a full-time interpreter that does exact sign [sounds like]. That interpreter went through the, I think it is called the Open Hands, Open Access, the free tool that is provided. The interpreter does act as an intervener, to a certain level. We don't want just an interpreter, because in my mind, an interpreter is only required to interpret. Our interpreter is going beyond that and does more than just interpret for Hannah. That's why we want to get the language of intervener in her IEP.

I think the big caveat is when you say "intervener" there are many different levels of intervener. There is one that has a lot of interaction and a lot more support. But my daughter doesn't need a bunch more support. But she needs an extra support, because when she has a substitute intervener -- sorry, I keep mixing that up -- which he has a substitute interpreter, Hannah will come home tired. So we know that she is not getting the support with a regular interpreter. So that is one way we've identified it. She was coming home tired for an entire week, and we found out they were giving her a substitute interpreter. That little extra that our regular interpreter provides is what Hannah needs to not be tired by the end of the day so she can still focus on the school work.

>> MEGAN COTE: Ricky, thank you. This is Megan again. I put in the chat a link to the Open Hands, Open Access modules that Ricky mentioned, so if parents are not aware of what they are, you can check those out. They are a free, online self-paced modules to help anybody who wants to learn about good intervener strategies and intervention strategies for individuals with deaf-blindness. Those are a product that were created by the National Center on Deaf-Blindness in collaboration with the state deaf-blind projects.

One more question, Ricky. The question said, "Can you elaborate on how the IEP meetings got worse?"

>> RICKY TEED: I probably can't elaborate too much. One thing I suffer from is not being able to remember. That can be a blessing sometimes. Our very first IEP meeting, we identified that she would need an interpreter. It wasn't written in her actual IEP, so they decided that she wasn't going to need it. After two hours of trying to decide and set goals, we decided to leave and re-intervene at a later date. We got there, things kept getting worse in terms of the interpreter requirements. They kept telling us that they could not provide an interpreter with some kind of intervener training. Then, that was probably the main focus. There was a lot of heated discussion. But it just deteriorated each time about the interpreter, because it was clear that she needed one to learn. She has moderate hearing in one ear. So, because she could hear, they felt she did not need an interpreter. But that is the way she learns, is through that interpreter. It got worse and worse. I don't have tremendous detail on that. They kept withdrawing and changing words and getting further and further away from where we were trying to get to.

>> MEGAN COTE: Perfect, thank you so much, Ricky, for your insights. If anybody has any additional questions for Ricky you can put them in the chatbox and we will get them answered at the end of the webinar. But now, we're going to pass it off to Donia Shirley to share family story around the IEP process.

>> DONIA SHIRLEY: Hi everyone, I am Donia. I live in Miami, Florida. I have two little boys. I have Niles, who is my typically developing six-year-old, then, my superstar, Jackson, who has CHARGE syndrome. Jackson is three years old, and Jackson is currently in a reverse mainstream pre-k program in the same public elementary school as his older brother.

Our IEP journey actually started in August of last year. Jackson is very new to school, which has been very exciting. Recently, he signed "I love you" for the first time, so that's been really exciting for us, too. June of last year was on we started talking about the IEP with our provider. So we were in an early intervention program here in Florida

called Early Steps. So they started the process of phasing us out the program because it is a birth to three program, to phase us into the public-school world.

So that is when we first discussed it. At that point, we had a few other early intervention programs we were involved in with the Florida School for the Deaf and Blind, the Lighthouse, Miami Lighthouse for the Blind here in Miami. All those providers started to talk to us about our role in the IEP. Everyone made it very clear to us that we were vital to the IEP process. That was really helpful from the beginning, because it empowered me to know we are important here. Our input is really important. So then I started the process of figuring out where we wanted to go with school for Jackson.

So we did a lot of research on schools in the area. Unfortunately, our county here in Florida doesn't have to greatest reputation for having great services for children who are deaf blind. So we struggled to find a program that would be, I can't say perfect. We looked into a few deaf and hard of hearing programs.

We kind of went into the IEP process with a few programs in mind. One of my first contacts with the IEP team was an individual who was speaking to me about the assessments we would have to be. And in speaking to me about that, she asked me what programs I was interested in placing Jackson in. I mentioned the programs to her and her response to me was, based on what we see on paper, we actually feel like the best program for Jackson is another program which is for children who are severely physically impaired.

I turned red a little bit, I was a little upset. Because on paper, I think Jackson does appear to be very impaired because of his medical issues. But until you assess a child and obviously get to know them, it's unfair to decide what program the child is going into.

Once I had that conversation, I decided to speak to some of our providers. And it was recommended that we actually speak to an educational advocate. We spoke to an advocate in the area and they joined our personal IEP team.

I would say, I had a similar experience as Ricky did with our first IEP meeting. It was not right. We were in our IEP meeting for five hours. For us, they agreed with us on so many points that some of the things that Jackson would need in the classroom, obviously, he would need visual services. He would need a deaf interpreter. He would need PT, OT, speech. But the two sticking points for them were a one-to-one nurse. The other sticking point for them was a paraprofessional for intervener, which is initially what I wanted. But our county does not have an intervener program. So a para was the next best choice for us. They didn't feel like a one-to-one for either of those was appropriate for Jackson. But Jackson is trach dependent, so certainly one-to-one nurse is certainly needed for him.

During that five hour meeting, these are the big issues that kept coming up and we just couldn't agree. After the five hours, I decided not to sign the IEP and we actually ended up putting through a due process complaint, because for us, certainly, having the nurse was, it's a safety issue, because Jackson is trach dependent. Because of his visual issues and obviously his being deaf, having a one-to-one educational assistant, whether it be a para or intervener, was also important for Jackson to be able to have access to his educational materials

So we ended up going into a due process hearing, at which point we brought, we had lots of stuff from his doctor and various other providers explaining why these services were necessary. They ended up agreeing with the one-to-one nurse, but did not agree for the para because of the size of the classroom we were going to place him was a mainstream classroom. So, that classroom has a main teacher. It has a classroom para. And then, the classroom had a one-to-one para for another student. And then, Jackson's one-to-one nurse. They felt like there were enough adults in the classroom to give Jackson what he needed without an additional one-to-one para. So we actually, in

that meeting, decided that we would withdraw our due process complaint without prejudice, which means that we would be able to refile the due process if we felt Jackson's needs are not being met once he was in the classroom.

He's been in the classroom and so far, it's been good. His teacher is so great, and she has really embraced Jackson and actually comes to us for a lot of information. Whatever I give her, she tries to implement it. His one-to-one nurse also happens to be our home nurse. The agency we use is the district agency, as well. So our home nurse knows sign language, so she has acted a little bit like an intervener. So she presents materials to him, even though that's not her job. We've been very lucky that way. Obviously, we know this might not be the case for the future, so we are working toward potentially moving to a county where intervener services are available so we can [indiscernible] get Jackson an intervener.

From our IEP meeting, one of the things I took away from it was how vital our role in that meeting was. I always say to people there's this thing, kill them with kindness. But I believe in killing them with research. So that's what I did. I brought in so much research to our IEP meeting that backed up every service and every, everything that we needed or wanted for Jackson to have a better classroom environment. One of the greatest resources we had was the education packet that is on the CHARGE syndrome website. It had so much great research. It had an educational, like the IEP quality indicator. A lot of things where I actually printed out that entire packet and brought it so the people within the IEP team could look over all those materials and see what's recommended by the experts on CHARGE, especially on deaf-blindness, too.

I also brought in a lot of people, so we had our advocate with us. Then we also brought in statements from Jackson's private therapy providers. Those were really helpful, because, in the assessment with the district's provider, Jackson just did not perform the way he does with the people he knows. So it was really good to have those statements from his providers showing what he actually was able to do and talking about his progress over the time they had known him. We also brought in lots of videos -- and not

just videos of Jackson doing things that were really positive, but also videos that showed where Jackson struggled. Jackson is a new walker. One of the things that Jackson struggled with is bumping into things. So I had videos showing where he would be walking along and there was something very large and clear in front of him and he accidentally bumps into it – so, to show them that the classroom would need to be set up in a way to show that Jackson was as safe as possible. And certainly, to have nursing there, and, some sort of one-to-one would also be necessary for his safety.

Outside of that, I also would say to everybody going to an IEP that you're going to hear things that don't feel great, sometimes. It's a struggle and something I struggled with about was kind of hearing about the financial aspect of the school district. So it was something that was said to me in our IEP meeting was, we are here to make sure that you only get the services that you need and that we're not just spending money on unnecessary things. It was kind of this upsetting moment to me, because it was very obvious that Jackson needed services. Again, research and kind of bringing in as much information as you can is so, so important, to show the team, listen, this is what my child needs. This is what he's able to do. This is what he can and can't do and this is where I want to see him go.

It was also really important for me to have Jackson in the least restrictive environment. I mentioned they wanted to put him into a program that was for children who were so physically and cognitively impaired and I did not feel that was a place for Jackson. That was something that my advocate said to me, by law, they actually have to put him in the least restrictive environment. That is something I think is really important for parents going into the IEP process to remember. You don't have to agree with their placement. If you feel that placement is not the right space for you, express that and really research what options there are. We looked into the deaf and hard of hearing programs that were available, there was an audio verbal program that was available because Jackson does have cochlear implants. None of those really felt like the best fit based on his level at the time. But this reverse mainstream just felt so perfect. It had a couple model students

[sounds like]. And also his brother was in the same school, so I thought it would be really great for the support to be there.

Then, I would say don't sign that IEP unless you feel like you've gotten the items on the IEP that are really necessary. I think that, or I hope that in the future, our IEP meetings are a little bit less, less hours, and definitely more like Ricky's IEP experience in Iowa. But I think, again, it's really, really important to do your research and go in there and know you were in a position of power. We as parents know the most about our kids in all areas. I think we have all probably done so much research over the years. So it's really important that you remember that you really are the most important part of that team and be really confident.

The other advice I would give is I actually brought Jackson with me to the IEP meeting. If you can do that, I think it's a great way to show them, too, what's going on. It was really helpful for us to have Jackson with us there, too, in terms of us getting our one-to-one nursing. They were able to see how often Jackson required suctioning for his trach and also, his medical needs, as well. And again, the education professional packet on the CHARGE foundation website was really, really helpful and has been helpful not just to the IEP team, but we also give that to Jackson's teacher and she has said that has been really helpful resource.

So that's it, thank you. Megan?

>> MEGAN COTE: Perfect. Thank you, Donia. This is Megan Cote speaking, and I want to thank you and Ricky as well as Kristi for all of your important insights, your stories and your perspective -- because I have to say in my many, many years in the field of special education, I wish I could say I knew of a family who had a non-hiccup filled educational experience for their kid. But I don't know it's feasible when you have really strong opinions about your child and you're the most knowledgeable, you're always going to have to be an informant and keeping in the forefront what you know

needs to happen with your child into the minds of the educational team. And, that's a big part of advocacy and it's so critically important.

So we have a little bit of time left, about 20 minutes. At this point in time, I would like to encourage people who are in the webinar to ask questions. You can either hit \*6 to unmute your phone to ask a question, or you can type it into the chat pod if you have any additional questions as our presenters to make.

It's \*6 to unmute. If folks want to hit star six to unmute, or you can type in the chat pod.

>> TAKRIMA SADIKOT: This is Takrima Sadikot. I had a question, when we attended the CHARGE conference last year I was very impressed meeting some of the interveners who were traveling from Maryland. At the time I thought okay, this is what my child needs. She is five years old, she is fairly independent. She is hard of hearing. She has a cochlear implant on one side and [indiscernible] on the other. She has glasses, she has fairly large [indiscernible] that do not affect her [indiscernible] so she is safe [sounds like] in that sense. She does not pay attention to what's going on around her, she is always in her own head. There are certain things that are locked, still. I would love for her to be able to get intervener services. I have noticed when I work with her one-on-one at home she does much more, she is much more responsive. But I'm getting a lot of pushback from school. And we are in Kansas, and we do have intervener service here at the school district we are at in Olathe. But despite that they are saying she is going to become dependent on that person and never learn on her own.

>> MEGAN COTE: That's a very good question. This is Megan, again. I will have Kristi unmute, but I want to make sure you know of a resource that I will put on the chat pod that is available on the Intervener.org website where it lays out, distinguishes the difference between a traditional para-educator and the role that an intervener can provide in terms of access for a kiddo with deaf-blindness. I will put that resource in the chat pod. Kristi can add more to the conversation.



>> KRISTI PROBST: This is Kristi. The first thing I would tell you is I think a lot of people are not really sure what an intervener is. That's still something that a lot of people have a question about and school districts often will say oh, well, we have paraprofessionals and that's good enough.

So I think part of your job as the parent, and, with any other people who know about interveners that you can get with you, is to educate the educational team, as well as your district, about what an intervener is. I did put the intervener services and interveners and educational services definition, the link to that, I put that in the chat pod. That's one thing I always tell parents that you can share with people, is because it helps them to see in writing what an intervener is. It's about a two page document. The other thing I'm putting the link for right now is the IEP discussion guide. It's really about intervener services. I think it's called *Are Intervener Services Right For My Child? An IEP Services Discussion Guide*. That helps the team about your child and make the decision if an intervener is necessary or would be helpful.

>> TAKRIMA SADIKOT: Kristi, I am not trying to interrupt you here, but right after I came back from the CHARGE conference, I did go and look at these documents and I provided them to the school team before our IEP meeting last October. Despite that, I was told that she does not need or they don't think she needs intervener services at this time. The thing that I don't know, and because there are no clear guidelines as to when an intervener should be used as service, it's kind of hard for me to say that for watch out for, for these, these, these reasons, I absolutely would like to have an intervener. Is there anything that can solidly point to, "Let's do this. This is why we need an intervener. Let's try it and [indiscernible] the idea."

>> KRISTI PROBST: I'm going to have to tell you no, there is nothing that says these are the things you absolutely have to have that show that an intervener is necessary. We don't have specific documentation that says yes, you should provide an intervener. It's not in law, intervener is not in the IDEA law. But the office of special education

programs did write a letter that said interveners are considered, by them, as a related service.

However, because it's not in the law, it's not something that school districts absolutely have to provide. So that's something that we've had parents, multiple times, have contacted us and said, I'm fighting for this. Do you have a guiding document that says that they have to provide it? And my answer, always, unfortunately, is no. We don't have a guiding document that says you have to provide an intervener. Unfortunately --

>> MEGAN COTE: Kristi, this is Megan speaking and I will piggyback on what you're saying. Because I understand your frustration, Takrima, I also reside in Kansas and I'm very aware of the district where your kiddo goes to school. We have had good luck advocating in that school when we have asked the school district to prove to us they're providing equal access to information -- auditory information, visual information, environmental information, other human beings that are around them interaction. Ask them to visibly show you through documentation whether the video or written format, how it is they believe they're making the appropriate accommodations to provide that equal access to information for your child, as well as what environmental modifications they're putting into place for your child.

In other words, I'm hearing you say things like your child can focus better at home. The question would be, why is that? Is there less auditory distraction? Is there less visual distraction? Is there less... you get my point. How is it that they're providing equal access? Because if they can't document that, those are the grounds with which you can advocate and say we really, really need to be considering an intervener, because my kid is missing information that provides them that equal access.

So I would ask for documentation. Maybe you have already done that, but until they can actually prove it, then you have little bit more ground to stand on to say, but I'm not seeing it. You're not demonstrating how you're providing those accommodations to provide the equal access. Because really, that's the significance of the role of the

intervener is that they're filling in the gaps for individuals who are deaf-blind with all of that contextual information.

>> TAKRIMA SADIKOT: So in your experience, do you guys ever notice that a child gets extremely dependent on an intervener, and even if they're capable of being independent, they are not independent?

>> KRISTI PROBST: The question is, do we see children becoming overly dependent upon the intervener. I think that what a lot of people struggle with is that, when it comes to paraprofessionals, they have been seen to be more of a barrier -- not across the board, but, they have been seen to be a barrier for children. However, with interveners, what we have seen is that because they provide the information that the child is missing, yes, the child depends on the interveners. But the intervener's role is to provide that information and then allow the child to be independent. So as long as the intervener is being supervised by someone who knows that the goal is always independence, and that is something that they're always going to be working on, when the intervener provides the information, provides only the necessary support and then removes themselves for the child's independence. Does that make sense?

>> TAKRIMA SADIKOT: Absolutely.

>> KRISTI PROBST: Thank you for asking such a good question. Does anybody else have a question? I can see that Katrina asks if we can caption the response that I gave and I know that because of the [indiscernible] coronavirus, we've been having some technology issues. So it may be that it got lost. But we will be happy to do what we can to make things right on this end from the technology standpoint.

Are there any other questions that folks have? I think the concept here is to always remember the whole principle behind intervention services is that concept of do *with*, not *for*. So really, intervener services in an ideal situation provide equal access so that

kids can function more independently and have that support and not be done *to*, if that makes sense.

Robbin says in the captioning pod for the folks who are just listening as well as Kristi, she says she was watching the captioning, it looks like the captioning got my comments so it will be the captioning in the transcript, Katrina. Sure.

Any other questions from anybody? I'm practicing pausing. I see Jane is typing a question, so we will hang on for a sec. She says thank you, and Katrina says thank you.

Okay, well, I know on the east coast it's even a little bit later than it is here in the Midwest. As a closing, on behalf of the CHARGE Syndrome Foundation, I'd like to thank Kristi, Ricky, and Donia for speaking with us tonight. Their perspectives are extremely beneficial in navigating the IEP process. I would also like to thank Robbin Bull from the National Center on Deaf-Blindness for ensuring that our technology worked well for our webinar tonight.

I have a quick favor for you all. Your input is extremely important to the foundation. So if you would take two minutes to click on the survey link that we're going to put in the chat pod here, to give us your feedback about tonight's webinar, and future webinars that we may have planned for the future, we'd really love to hear from you. It's extremely short. It will take about two minutes of your time. But we definitely look at those and use these to inform future trainings and resources that we put together to give back to our members. Please, provide honest and critical input to us and we will watch, listen and learn.

We hope you will join us for our next webinar Wednesday, April 22, Lessons Learned: the Sibling Panel. It will be at the same time from 8 o'clock to 9:30 PM Eastern standard Time. And we will have some dynamic siblings on to talk about how they feel their role has been in supporting an individual with CHARGE syndrome.

One last thank you to our presenters and to you, the attendees. I know this is a crazy time in our world right now with the coronavirus, so I'm extremely honored that you chose to spend some of your precious spare time with us. We hope that you have wonderful remainder of your evening and one last thank you for supporting the CHARGE Foundation and our presenters tonight. Thank you very much, and have a great rest of your evening.

[END TRANSCRIPT]