Event ID: 2330933
Event Started: 5/18/2014 6:49:06 PM ET
Please stand by for realtime captions.

Survey --

Please stand by for realtime captions.

When you have completed asking questions, press star six again which helps keep background noise down. The chat pod is in the right camcorder in the bottom and you can ask questions at any time and we will be keeping track of those questions as they come into the chat pod so please feel free to use that. And you'll notice on the left-hand side, in the files pod, and has a PowerPoint presentation to download, you can click on that and quick download. And with that, I'll turn it over.

All right, hello. I'm having a little bit of Internet difficulty so hopefully everyone can hear me okay. Can you indicate that you can hear me?

Yes, Lisa, this is Randy. I forgot an important function which is the start the recording for the meeting so I apologize. One moment probably get that going. Okay, now we can go.

My name is Lisa and for those of you who do not know me, I'm the vice president of the CHARGE Center foundation and it's a great honor to introduce you to our very special guest speaker this evening, Pamela Ryan. And for those of you who do not know Pam, although I cannot imagine she is famous, she is a school psychologist in the deaf, blind program at Perkins in Watertown Massachusetts and has been working with individuals with deaf blindness for 42 years and 32 of which have been after school psychologist. Current work Burka says on work conducting educational and cognitive assessments for students in the Perkins program and for many children who come to Perkins for evaluations from across the country. She has a great interest in syndromes, particularly CHARGE, lucky for us. And their impact on education and life. Her interest has led to the acquisition of a certificate of advanced graduate studies in clinical genetics. And, Pam meets and counsels families with children who have CHARGE syndrome around the world and gets very generously of her personal time to support families along with serving on the Board of Directors for the CHARGE syndrome foundation. So we are extremely fortunate to have him with us this evening to share knowledge and experience on the topic of intellectual assessment. So without further ado, going to welcome you and him the floor over to you, Pam and hit star six, right? Okay.

Okay, well thinks. I was just about to say that I could not see the PowerPoint so I was getting nervous, but there it is. So thank you to everybody for giving up your Sunday night for this and Kathy for pushing me a little beyond my comfort zone. So I think this should be an interesting conversation and in some ways, I was thinking that it really is a conversation based on the world according to Pam. So that we see how that goes. So this is who I am and the title of our presentation is a conversation about intellectual assessment with parents need to know. And I think more often than not the statement in parentheses might be the most important thing. What we are really here for. So that's what we're going to talk about and hopefully we can shed some light on this particular topic. Which can be very tender for many people. And can cause lots of upset and grief so as we go along hopefully you can make clarifications about that related to our schooling, kids particularly, but also the kids beyond school age, testing is really difficult and often the idea of an intellectual assessment has a very negative connotation so our kids are very complicated and have the cute consolation on complex issues related to their vision, hearing, cognitive and developmental things, balance, fatigue, sensory issues that make a consultative bundle of kids and getting to the right classroom starts to be that, you know, one of the first struggles that we might have and then somebody suggested that we need to have intellectual impairment. Of course, that we might have to have intellectual testing to further your looking at for kids and be able to plan well for them. The subject of assessment in IQ is really big and we don't nearly have the time to cover all of the interval items related to evaluation. Especially one that is leading to an IQ. Within the context of our time together tonight, we will focus on the IQ part, what it is, how we get it, but we need to know as it relates to our kids, your kids, we are not going to talk about the history of IQ testing, we're not going to talk about the in depth of our details investment materials used. What we will do is have a review of the process of the three-year evaluation and talk about some of the materials that may be used and what the results mean mean and/or certainly how they should be used. Even though you might be coming into this discussion with innovative discussion of why assessment is that in general and IQ specifically, I hope I can give a reason or two of why that would be helpful, not that I always agree with that but we need to be using the IQ score. So, all of that said, let's review why that is that we are here. And without going to click on this PowerPoint. Very go, why we are gathered here. These are the reasons they came forward about why we do understand our time can come about IQ and sharing conversations. So over the past month you have had the opportunity to read many things about assessment on the charge website related to the awareness theme of the month which is assessment, all of the information is so important and how you put so much of her child possibilities in the spotlight, not to mention the things he or she cannot do. But the amazing things that happened once they get past their early scary life-threatening times. The little beginning steps lead to bigger things. Perhaps more slowly than we are dust and other kids in the family. But, they get there on their own time. Something that we always must keep in mind. I can get our kids have a longer growing season but with the right nurturing and understanding and planning, they grow and bloom into their own wonderful selves within their own timeframe. Something we have always kept repeating, their own timeframe. That way, this talk will be centered around these formal testings, the kind that we all may fear, and the kind that we focus on what this child can't do and the comparisons where he just doesn't fit in. The awareness subject has been around things like environmental assessments, persons, futures planning. Those things are important but we'll talk about the formal part of it leading to the IQ. Let me try and push this button. So, let me try to give you background. I am a school psychologist. And what that means is, that I am specifically trained to formal intellectual assessment of children. My degrees are from the University of Massachusetts and Gallaudet University. My entire work as Lisa had said had been deaf blindness and I have been a school psychologist since 1982, my work before then was different. But it's with children with deaf blindness. I continue to have a significant passion and thrill an inordinate respect for the kids with CHARGE and not to mention the parents and educational profession in doing the best they can to help others understand the youth neatness of these young -- the uniqueness of these young people. My job is to evaluate children following the educational and regulatory mandates and federal governments, what does that mean? It means that the evaluations I am expected to do must include testing that leads to the reporting of overall cognitive functioning and eligibility for services. Educational services and adult services. That said, let's talk about, and this is supposed to be -- the triennial evaluation. These words can really strike fear into the hearts of the heartiest appearance. The idea of triennial is to determine if the child has a disability. There are three reasons to find, by IDEA, about the needs for triennial evaluation. To see if the child is a child with a disability, to gather information that will help determine the child's educational needs and guide decision-making about appropriate educational programming for the child. The testing, as you know, happens every three years and his children moved to their lives, the testing changes. Some of it stays the same, some of the changes as they go along, as they get older and think different criteria is for the use of doing tests. For our children with the charts, disabilities might be for children with the rest of their lives. So their initial diagnosis of the disability might be true and their screening or hearing screenings stayed with them. Their disabilities, sensory impairments, all of the things that need extra intention and not to mention specialized learning needs will be with them and it's up to us to determine how to make those needs for successful life for these children. But that they are in school or at home. Their very first evaluation is their vision and hearing tests. Those are done in an informal way and authentic evaluation and ecological evaluations, where the baby, the young one is in the room, parents are there, observations and interactions are in play, lead the way and do not lead to an IQ score. They are essential to looking at the whole child and it is my contention that this kind of informal information, informal only because it does not lead to an IQ should always be a part of individual evaluation along with a formal measure as we move into their school years. Their ongoing evaluations based on federal regulations should continue to document their disabilities, vision, hearing, sensory, medical, developmental and physical. But, kind of like the progress and strings which will provide backup for continued appropriate educational needs and placement. So, how does the . Well, there's lots of steps and I'm going to focus only on my part -- to do the testing, this is facilitated by her specialty contact person. If you have agreed to the testing and your questions have been answered, and the school psychologist is building a story ever told by listening to others on the educational team, regarding their views as a student, the reviews of records to get back of information, and from all of this gathering determines what materials might be best use. The conversations to get their ideas of how this should go, and, that time is when the psychologist should be sharing what she would like to do. And also, observations of the student in as many of their natural habitats as possible.

Home, school, vocational, sports, things that might be of interest. To the student and how they interact with those activities and people. And of course, organizing the direct, formal testing sessions. All of that is in the beginning of steps. Conversations with parents, review of records, getting their permission and making a plan for what needs to be done. For most of you, these steps will be filled with if there is somebody qualified to evaluate my child. What if my child doesn't do well? What if the tests are right for my child. I've read the testing isn't good for my child. But, the psychologist is using the materials. My child's report is [Indiscernible] negative information. A psychologist for the Mike and more. I have heard them all, you have felt the mall and have asked the questions. You should feel confident, it even with all these questions, but the psychologist really does have the child's best interest at heart. And, that should be clear as he or she begins to explain what the process will be for evaluating. And what she is looking for, leading to the proper recommendations for planning. If you don't feel comfortable, that is a different conversation that must be had between you and the school psychologist. And perhaps a school person. Now, after three years of federal mandate, if the school psychologist is expected to carry out, we don't make these roles as a federal mandate and when the permission to test is signed, the school psychologist then begins to think about the plan. And I hope that certainly this process, that you parents would be getting a call fairly immediately from the school psychologist to engage you with this process in the beginning. If you don't get that call, and it is being just left to chance that the school is looking at the evaluation, I don't see a reason why you cannot contact the psychologist yourself and begin a dialogue. I'm lucky because I am in one school. And I see my kids all the time and it makes evaluations easy and it also gives me access to parents at a different level. The school psychologist that many of you, perhaps most of you will be doing with have several schools that they have to deal with which can be a real hindrance and how they get to know your child. It's not impossible, and there are several school psychologist around the country who don't have the background in deaf blindness, and or with the kids with significant needs like ours. But, they take the time to reach out and -- before we move on to talk about materials and more specifically about the IQ, I think it is important to talk permanent about the designation of developmental delays and intellectual disabilities. These are terms that are under IDEA and determined by a specific set of criteria. Under IDEA, it means a developmental delay in one or more of the following areas. Physical, cognitive, communication, social or emotional development, and adaptive behavioral development. This is a designation as an angel rage -- English -- age range of 0 to 9 and intellectual disability or impairment means sub average, their words not mine, General, intellectual functioning, existing with deficits in adaptive behavior, and manifested during the developmental period that adversely affect the child's educational performance. I have this because as children progressed to school, it can be a surprise for parents and other changes with the children getting older, they will need to know, we all need to know as professionals that there is meaning behind these words and they are according to regulations and not just the school psychologist making it so. It can be confusing, and really in the long run, does not matter. Perhaps not. But perhaps if we're looking to services as a child moves through his school years, and eventually gets closer to 18 years old, it is important. It is something to become very aware of. As a school psychologist, I feel that this is an important message. Sometimes. Don't get this message. Anthony to share it. It doesn't change anything about the child, but the words and meanings you or others attached to it can be upsetting. So, how do we get this information, this classification? Well, we get this information by theory out what we are going to do, how we are going to use the materials we have at hand. These particular test that are on the site are very typical tests. They are good tests used widely and I personally have found good success with them and I personally have found Pacific information that we can gather leading to pictures of overall skills, strengths, need areas and ways to compare school performance of daily life. And he trained psychologists will know how to use these tests and how to interpret them in general. However, we have these tests there are many barriers to using them. We have these tests but they don't quit your children. These tests, the ones pretty much used by everyone everywhere to not include children with more than one disability at a time. We may test for kids with visual impairment or hearing impairment or motor interference, but not for hearing, vision, balance, communication, fatigue, low muscle tone, all at one time. Not to mention, other interfering issues, such as OCD, anxiety, and physical limitations. His limbs, missing digits, scoliosis, which might hinder some access to materials and of course, cognitive delays. This is putting out the worst-case scenario and I don't mean to, but there are children who have all of these issues and it leads to a very complicated testing situation. Many think about Tessa get used, when I think about the test they get used and all get pulled out time after time after time, and they are not meant for these kids, what is it we're really trying to figure out? It is the test limitations, not our kids limitations. And then, there may be the very related to the psychologist. She or he may have limited experience with specific disabilities, not to mention the cluster of disabilities our children present with, and how they can make the appropriate accommodations for a full and fair evaluation. I sit here with a footstool under my chair with my feet up, which keeps the more focused and more comfortable. As an inexperienced psychologist, which you know the grounding of students? Not to mention myself, grounding the students with low muscle tone can help with low muscle tone, communication and fatigue, not to mention other commendations it may need to be made for vision, hearing, lighting, temperature and communication. All of these can affect how our young people perform. And, when none of these I met with a good way for kids to access materials, to access even just the room for testing, what is it that the results provide to us? Does it mean anything? The test are designed for our students and the psychologist may not be experienced. And as children get older, closest to the big transitions, the middle schools, high schools and graduation times, IQ becomes a factor. We cannot change that the testing has not changed and still is not appropriate for these young people. And, more and more, IQ is being recorded, I should actually say demanded, and S school psychologist, we don't have much say around this. The tests are good, they're well researched, and they are widely used to provide an IQ. But, they may not be a true reflection of our people's overall abilities. But, as time goes on, we might be able to make it work for us. It's up to the school psychologist, then, to have conversations with parents, to discuss the limitations of the tests, perhaps for that school psychologist to be discussing her own limitations as she goes into this evaluation. And also, to share the why of the demand for the testing and then the IQ results. Part of that conversation should be around the time you start thinking about when and if we need to report IQ and why we have to report it, which we will talk about. Why? Because having an IQ reported below a certain range indicates intellectual impairment, and it must be identified before the age of 18. And we will talk a little bit more about that. If planning ahead for adult services for your son or daughter, in order to qualify for adult services in most states as well as for guardianship needs for your young adult, you're going to need an IQ documented somewhere. It may not be right, but, it is the way it must be. That said, just using an IQ -- oh, hang on. I've lost something, here. Did something just happened? Something just happened.

Pam, it's copy. Are you all there? I think Randy is fixing it.

Okay, thank you. Anyway, if planning ahead for adult services for your son or daughter, in order to qualify for those services and for guardianship, you're going to need IQ documented. Somewhere. At some time. Of course, just using an IQ is not enough. And, that is the message we also have to get through. But also, IDEA also says that, that you can't just use an IQ to determine a child's or certainly young adult placement and needs areas. There is a requirement that if you are determining intellectual disability for the purposes of forward thinking and planning, then there has to be results for measures of adaptive behavior. All of this must be done before the child is 18 years old. So, for all of us, those of you who are experiencing testing with our kind of kids, as well as those who don't or haven't experienced it yet, as we begin to think and prepare for materials, we need to -- we need and want and what kind of outcomes they will give us and we, along with thinking about the outcomes, have to think about accommodations in order to get those outcomes. Large print, CCTV, and magnification, real, sign language, picture communications. So, for helping the child understand what is happening, seating, lighting, and noise interference, visual business, and their own tolerance for something new, with someone new, which may require one lengthy session, or ideally several overtime. But, also still, often within an unfamiliar place. To state the obvious, all of this affect the child's access to the evaluation process. And thus, the results. When we are looking for results that may require an IQ, and really that is what we are talking about, this can be tricky, the child clearly has skills and strengths that he or she demonstrates every day, but the test results in materials may not reflect any of this, leading a parent to question why this is being done in the first race and parents can also succumb to the feelings of confusion and upset around the results that may have been reported without further explanation around the limitations of the tests, around the limitations of the psychologist, and, just the limitations of the situations in general. I feel it is my job and I feel it is every school psychologist job to make sure that these bases are covered before we begin any testing. And the idea that what may appear as a poor result is explained in the context of why we are using it in the first place and why the results are being used, especially if it is an IQ. So, let's talk about the IQ. I can't move the PowerPoint. Thank you. So, what is the IQ? How do we find it? Where does this go? You all know that an IQ is an abbreviation for the term intelligent quotient. And over the years this meaning has changed some to reflect the work of how is regarded from Harvard University who introduced the theory of multiple intelligence. And that broader lines include spatial, linguistic, knowledge gold, bodily, kinesthetic, musical, interpersonal, and naturalistic. But, the IQ itself is just a number. It's number that we have as part of our child assessment, but, it surely will talk about it isn't the most important thing. And, in its simplest form, it IQ is a number. It is a number from 0 to 200 that rates a person's cognitive ability in comparison to the general population. So, I'm having trouble with this. Moving the PowerPoint.

You might try your right arrow key on the computer.

All right.

There you go.

Sorry, so what happens is we start to make decisions on testing and reuse test that we know and psychologist, please test that we know and a classification systems have become important because as kids get to be close to 18, these kinds of things need to be determined. So, how do we decide these kinds of things? We use the materials we know, and we start to think about us. What they may mean in the long run.

Classification systems that begin to define the terms that we often hear, some of which we don't like, but the classification systems differ from test to test. This is what the Wechsler skills look like. It's an IQ range, and then an IQ classification. A number, a range of numbers, equal to the classification. You know the Wechsler scales are very widely used, and probably many other children have been given subtest from any of a number of the Wechsler scales. And, there classification is broken down into seven categories from 69 and hello, of 2/130 with descriptors for each one. And then, we have the IQ range to the Stanford Binet, and you'll notice that there are nine classification areas here, with a whole set of different numbers from 40 to 54 indicating moderately impaired or delayed, up to 145 to 60 indicating very gifted or highly advanced. And, I pulled these two arbitrarily because they are the most widely used tests when kids are in schools and starting to be evaluating, but there are several more that are all very good and they all have their own way of looking at these things. The classification systems and upping very similar, the numbers would be different, and the goal of all of it is to provide ranges of performance. So, what is important to keep in mind is that each IQ test may have a different way to categorize scores, resulting in different IQ scores. Your child could have several different measures being used in her evaluation, and then have different IQ scores being reported for each test. And some tests have different aims rages for tests, which breaks down things even more. For example on the Wechsler scale, there are IQ ranges for three different age groups. The preschool and performance section from two years, six months after seven years, seven months, the [Indiscernible] which is the Wechsler intelligence scale for children, which starts at six years up to 16 years 11 months, and the [Indiscernible] which is the Wechsler adult intelligence scale that starts at 16 years and goes through 90 years 11 months. The Stanford Binet, there is one test that includes all of the age groups from age 2 to 85+. So what does that tell us? The IQ number is four So what does that tell us? The IQ number is 40 to 200, rate the person's cognitive ability in comparison to the general population, and we know that it can vary from test to test. A simple concept for something that causes us all such angst. I wonder how many of you probably have had IQ testing during our lifetimes. You may have, or there may have been concerned about your learning as a young person. He did it predict your life? Probably not. There are some very intelligent people, some that we know well, some that might even be with us tonight you have had IQ testing during their life and were told they were not college material or their educational needs should be very focused. Some of these people have their PhD's. Go figure. So this leads to the next slide which I want to review. You know, these things, those things are numbers. They're not really, and as a parent, it's probably not the thing you want to hear about a child's triennial assessment, you want others to know the things that make your child stand out. And at the very least, you want to know that you valuator knows her child. You want to make sure that the evaluator knows how to be with your child, to get the very best results. You want to know that their results will form a good picture of your child and that the recommendations will be helpful for continued educational planning, not just for categorizing your child. You want to know that the things that the psychologist learns about your child and included in the report are his and hers strengths, personality, interest, sense of humor, fears, joy, all of which are part of the complete package. You want to know -- you want someone to know that your child, love reading and math might not place them on the honor roll, but his work ethic, his independence and his vocational training activities, his ability to make friends, his ability to be a friend, his overall zest for life are shown and honored. Those are the essence of your child that you want to know, just not a number. When the child is young, the needs of the information is for educational planning and for making and fulfilling goals and objectives on the IEP and moving to the curriculum. As your child gets older and becomes vastly become young adults approaching 18, this nation becomes more crucial and it needs to be included when you are starting to think about planning for adult service agency involvement in your person's life, and also give out guardianship options. If that is the goal for your family, for your child. 18 is the magic number, and if your son or daughter will need adult services for living, working, leisure and recreation and being an active -- an active and productive number of his or her community and as continuing and has been showing and is continuing to show below a slower performance, then all of a sudden, that IQ number becomes our friend. Why? Because if you have an IQ number below a certain point, on a [Indiscernible] and [Indiscernible], is below 69, on the Stanford Binet, it's below 70, for example. Along with below average adaptive behavior scores, scores that are measured like violent, which we will talk more about. In the adult service door should be open to you. Now is the time you begin to say, maybe having a high number should not be the priority. Maybe having a high parity IQ number is not so important. Maybe having a high number is not our friend. And what does it all mean anyway? Outside of getting adult services? Alan Kaufman is a psychologist and researcher at Yale and wrote a book called assessing adolescent and adult intelligence. And his quotation is very interesting. In talking about the idea of IQ testing and what does it really mean? And, does it really lead to very important information about a child? Does it classify them in the same way as it does everybody else? No, it doesn't. These scores and numbers are different from everybody. And, they can be used for descriptive labels, for communication purposes, which is what we hope we can do for good, but in reality, it is a member and it's a number that becomes way more important than it needs to, I think. So, that said, our job is to use this number well. For the right reasons. For positive outcomes. For the best possible future planning opportunities for those who will need it. Over the past few years, I have put into the uncomfortable situation of having to report IQs and, if uncomfortable because I've never had to do that before. My entire career as a school psychologist, I have fought it tooth and nail, because the tests don't meet our kids needs and it does not give the essence of who they are. And now I'm having to explain to parents I need to use it. Why? Because of it being demanded, because the physical changes in the need for more stricter control over who is eligible for services. The test alone do not and will not give a comprehensive picture of it child's performance in what he does and does not know. As we have said, but it bears repeating over and over again, the evaluations should always include many areas of observations of the child and when we're thinking about eligibility, we need the IQ but we also need the adaptive behavior scales which will complete the picture along with her parents are thinking and what observational information gives to us. The information we get, we want to make sure that we put into a good package that reflects daily life for people, and one of the ways we can really do that is by using something like the violent adaptive behavior scale. If listed on the typical use materials slide, not an IQ test, but it gives us a broad look at a person's daily life skills. How independent is this person? How does one care for himself? How does he or she relate to others? What about communication skills, including reading or writing beyond that? Pictures, sign language, how does one communicate? It is filled out by those who know the individuals at the very best. The parents, obviously. And there is also a format for teacher or care provider to fill out. Somebody who knows the child. The young adult. Information from that is been melded with the other testing and the observations to make it more complete package. What this person needs so far and how we can make it away to go into a fulfilling adulthood, to make this plan so that this person can have a life full of interesting things and can be a productive member of his or her community in ways that he or she would like to be involved. The results from something like that [Indiscernible] correspond to daily life with her talking to people and adults in agencies away to look beyond a number that is any part of it because frankly they are going to notice the IQ score, that is what they are going to go for because they will look for what the person is eligible for by way of the IQ number and then they will read the rest of it. I hate to say it, but it's absolutely true. And I have come to realize that sometimes, we have to do things, agencies ways, in order to get our own way. And by that, I mean if they are demanding an IQ, I guess we have to think about how we are going to present that information because we need it. And as a school psychologist, I'm being told I must report it. And I can tell you a story about a young man that I was just evaluating, getting ready to leave school, he is very interesting. He's had a very confiscated life. Aside from his CHARGE syndrome. And his family has faced many problematic situations, not collegiate list has been chronic homelessness. And this young man's mom has a really good idea of who her child is, and since he was a young teenager, she has a goal for him living in group living. Partners for that is because her chronic, Smith may continue to be a factor in her family's life. And, if he can qualify for adult services, which means group living, which can include things for him, she pulled no punches about that. So as I was putting together his reports, I was thinking about that and writing about that, the necessities for this for him. I had never reported an IQ on this young man. There had never been in indication I was going to need it. I submitted all of his work and he came back immediately saying he does not have an IQ, we are not even going to consider him for service. Nothing had changed about him. Nothing had changed about any of the needs that his agency were going forward with. But they wanted the number, date needed the number, they did name and cash they demanded the number. My experience has been I would talk about how this was not important but I had to go to this young man's mom and say, I know I told her I was never going to use numbers, the numbers don't mean anything, the tests are inappropriate, but now, that has to change. And she totally understood, because she knew it would be for his best interest, and certainly for her peace of mind. So, she said do it. Just report the number. It will work for him, and it is what we need to do. So, by spending my own rules, it's working in his best interest, but, I really came to realize that the agencies are going to demand them, and so now, -- excuse me, I needed to think with parents about how this was going to help, rather than hurt their children.

So, I'm wondering now if this is the time that we want to think about having our parents talk to us. We have three moms with us of different aged children. Kathy, is this this time they should be introducing you?

Yes, a great time.

Great.

So, we have Karen [Indiscernible last name] who is with us who has two children. Karen was living in the South and moved back to Massachusetts in thinking about her daughter's grades. Her educational needs. So in thinking about and asking for an introduction material, Kerry would like you to know that she is a full-time number -- mother of two sweet children, Grace is 8 and has CHARGE and Grace has a five-year-old brother named Jack. Grace is in her third year at sure -- at Perkins after her family relocated back to Massachusetts from South Carolina. And we also have with us, so, Karen is actually representing the youngest group. And, we have Emily Murray who is with us, Emily wants us to know that she has been married for 21 years to her best friend and the most amazing father, Jay. Emily is the proud mother of Â¬17 identical twin brothers, both which have CHARGE syndrome. We have a very big fluffy golden retriever named Neptune and they live in New Jersey. Emily is an elementary schoolteacher for over 18 years specializing in math for struggling readers. Emily's boys are 17 and were tied notes with CHARGE when they were 1. And, they have been on quite a journey from the day they were born. Given that there were two of them. But, despite all of the hurdles, speed bumps and forks in the road, we have discovered that with almost everything possible, -- and our other month has joined us is Debbie who has joined us who is the mom of Michael who is 17 and has CHARGE. She also has two other daughters, 14 and 19. She has many years of experience learning, advocating and enforcing bylaws within the educational system. Debbie has now become a transition plan her to move her son in the educational system into adulthood, and I have to say, these three moms step right up and they were asked when they joined to this. All have been very fierce advocate for the needs of their children. And, I think that we will have lots of things to share with them tonight. So, the panelists were presented with four different questions or points to talk about in terms of IQ. What it means to them, do they know their children's IQ numbers, when and why was testing required, and when was it that they first heard about the IQ for their children. So, Kathy, I will let you go.

Okay, Pam, which is going to ask the parents if they would like to,, camera, Randy can help make that happen. But, we can also just continue to keep looking at you, Pam, too.

[Laughter]

I will have that at the moment.

Okay.

Too late. I realize I should have had pictures of these young people.

Oh, we see you.

You see me.

Okay, panelists, if you click on the little icon at the top of the screen, the little phone with a man with his hand raised, you can start your cameras.

Okay.

Or click, start my WebCam.

So we are waiting for Debbie, Emily and Karen.

I see Debbie.

I see Karen.

Karen?

You won't see Emily because Emily does not have a WebCam. I'm sorry.

Okay, no problem, Emily. And, Pam, did we lose you?

No, I seem to be in the middle of my little screen here.

Oh, there you are.

There I am.

There you are.

I will be the big blob in the middle.

It's not there, Emily.

[Laughter]

Sorry, dad -- Deb.Okay, so Pam, should start with the questions again? I think so, yes.

Do you want me to read them?

Yes, take the first one.

The first question we pose to the panelists was, what does the term IQ mean to you? What do you think of when you hear the word IQ? Do you want me to read all four of them? Because I know that people were prepared.

Yeah, I think just starting this first one is good.

Okay. Karen? Debbie?

Well, for me, IQ has always been cognitive ability.

Yeah.

I agree with Debbie. This is Emily, and the same ring.

Yeah. I think that is what most people think about.

Right.

I am unmuting my phone and actually missed what she said, I'm sorry.

Both Debbie and Emily said that when they hear the term IQ, it means to them, cognitive disability.

Right, I agree.

Or, it seems like it is automatically setting limitations, when you hear that. It's just like, where am I going to be limited? How are you going to look at my child's number?

Because we don't typically go around testing people who are doing fine in the world. Usually we are testing people who are having trouble, so it does lead to that, I think.

Rate.

The second question was, have you been told that your child's IQ, when did you first hear your child's IQ number?

I can go.

I'm sorry, go ahead.

I am new to all of this auto number who is talking and who is not. The first time that I heard my son's IQ score, was when he was 3. And, that was when he was being determined if he was being accepted to the preschool program where he was. And, they brought in the specialized study teams for my state, and so, the testers did not know him at all, they never met him before, it was the first time before he was introduced to them. And I was a little weary because I forget the details, but he was tested in three different categories and one of the testers said to me, afterwards, she said, you know, I was very pleasantly surprised by your son, because the minute I heard he had CHARGE syndrome, I was dreading him coming here. And, that just really bad taste in my mouth. I'm like, I don't know where we were going with this. I got his score when he was 3 and at that time, he tested at the high end of average. So, now he is put up on this pedestal because one, he was with CHARGE sender by now he has CHARGE syndrome with a great IQ, but I think that really sets the stage for that particular school and the teachers that work with him and every therapist and everybody that came into contact with him who got his IQ score says, without even before meeting him, oh, this kid can, you know, do a lot.

So for us, I don't think I was given a chance to say do you want him tested or not, I think that we should assume that this was going to be down, because this is the protocol in our state, and it really worked in his favor for quite a few years.

Emily or Karin Is Emily. I had the opposite situation. Ping the mother of twins, the boys had IQ testing several times throughout their lives. You know, doing the triannual, as Pam explained it, and a few other times. And, I think for us, it was a number that really did not speak volumes for what the boys were capable of doing. And, I think her parents, with children of charge, and that art deaf, blind, or even multiply disabled, I think that you need to take that number and try to push it to the back of your mind and kind of look at who your child is and what your child is capable of doing. Pam had said something very good the other day and might have even touched on today, that you almost hate the IQ numbers until you need them, and I think for my state -- for my sake, actions speak louder than words. That my children can prove to the world that although on paper, because there are nonverbal and his IQ tests cannot be valid, especially if you are nonverbal, might be a 40 or 50, maybe even on the high side. For me, I was lucky enough to get a 70% somewhere. That does not mean anything. I think what you need to know is now that my children are 17 and starting to be in a transition period, the IQ will come in handy, I guess you could say, and as a start to look into adulthood and meet their needs for hopefully a group home and state funding, this is where those numbers are going to come in handy. And, I think that parents just have to realize, again, that you know, actions because in words and trust what you're noticing, what you're seeing, and if you have a good team behind you, and a good educational team behind you that understands your child for that child is, it's much more relevant than a number on a piece of paper.

Very true.

That's really true, Emily. True. Your child is not a number.

Pam, and Karin, if you wanted to make a comment or jump in, but I also wanted to direct Pam that Paul and Trish have posted a question. So, maybe if Karin wanted to say something and then we will hop over to the question in the chat box, okay?

Sure.

Okay. We have not actually had IQ testing done, yet. Only because it hasn't really come up. Someone asked me why we had not done it yet and it did not really have a good answer because it just hasn't actually, up as an issue for us and I don't know if that is because we were moving and maybe we should have had it done or maybe it hasn't been required, yet. For where we are. But, for whatever reason, we haven't actually done it and this conversation is really getting me wondering if it is something I need to be doing now or do I wait until she is 18. So, we will talk about that later. So, yes, we don't actually have a number for grace, yet.

And I can tell you, Karin, that it will come up, I think that your move happened in the midst of what would've been her three-year timeframe, so, it gets determined, certainly at the IEP, what is the date.

Thank you.

And you don't have to wait. The testing will happen, it's near 18 that we start thinking about the IQ part. Unfortunately, certainly for Debbie, getting an IQ score at 3 is amazing. I can't even imagine somebody would do that. First of all. It did work for Debbie, which was really great, and Emily has the other experience, and she has the foresight, she and J to say, it's a number. My kids can do more than this.

[Captioners transitioning]

THERE ARE NO ADJUSTMENTS TO AGE-RELATED NORMS ON BRAIN OR IQ TESTING. AND YOU ARE RIGHT, THE KIDS START OUT delayed. So at such an early age for so long. But there aren't adjustments to that and certainly when children are little in my opinion we wouldn't expect to be doing IQ testing. Especially when kids are so little and still recovering from their hospital stay and illnesses.

The next question.

The next question is was the testing required when your kid -- when you were doing IQ. How where is the information presented to you. What was your reaction when you first heard the number. We heard a little of that but I think people might have more to say about that.

Anybody first? Emily or Debbie?

We're looking at number 3.

For us it was required especially because we were trying to keep them in this particular program. They wanted to make sure he was a match to the program and when I say that, I don't know how to say this without -- within the school for the deaf, and he was really a minority in terms of having other issues besides deafness. So they were weary going from EIP to keeping him in the preschool program. They wanted everything that you could possibly have for that transition done to make sure that it was going to be a match and stay in that program. In that sense, yes, it was required. The information was presented in a report. My -- honestly my reaction was very [Indiscernible]. Out because I didn't think my son was capable of course. I could see what he was doing that just as all the things that Pam presented in regards to testing, you were not testing a typical kid and they were using a typical means with their tasks. I was surprised at how he was able to compensate and do that. That was at age 3. I wanted to add one thing about talking about this because it did eventually become a problem for us having this IQ score. When he was in seventh -- they made him sit and take the standardized test.

It was middle school I think. Sixth or seventh grade. Because of that, my state -- he's not considered -- he's not in a certain category so he is required to take any standardized take -- state test. They brought him in for a week with accommodations with the sign language tutor and behaviorist trying to think who else was there. He would show up every day for a week. He would put his name on the paper. He would answer one or two questions. And then he would just shut down. It was really torturous for everybody involved and it was a waste of everybody's time and money. It was valuable waste of his time being at school for that week. I wanted to add that. It did come back to bite us a bit.

It goes back to something that we talked about in terms of testing in general even though he might have been up for it. There's a lot to consider when we have kids that have to then go somewhere else to be tested. And they may have some anxiety or they may have some different reactions to how this all happens for them. It and said being a bust again. And it looks like he might have been the problem when in fact it wasn't him at all.

In our case he wasn't -- he was clearly not the problem. But what it also did was it brought his self-esteem down during that week because he felt like why am I here and why are they making me do this. I can do this. And now I'm being asked to do this and I can do it. What is wrong here.

Emily, do you want to hop in?

If family. I can piggyback off of Debbie. Testing was required similar to Debbie. It was considered for placement in different programs. My children were in public school until they were eight in a very specific self-contained classroom. And then we had tried to other placements. I pushed for testing on one and not because I wanted to put my children through the testing and to see what was going to come out but to get them into the best program that they possibly could find. So it was a combination that testing was required both the school district and then it was -- I pushed it to get them to where they are today. And at Perkins. They've been there for three years and I think it justifies when you look at testing and you look at some of the placements how important these things all fall into place. Again, I think you all here it on paper first. I think you are handed a pretty in depth report so it's not pallets given to you and then you meet with your team which I'm sure most of the panel knows it is reviewed at your annual IUP meeting. I don't know if I have a reaction to talk more than what I said before. The only thing I keep repeating to myself is I know my children are much more capable than what I see on paper. And nobody can tell me otherwise.

I think it goes into and not to change but Pam, there is someone asking a question about the IQ shout -- I'm not sure if I'm saying it correctly. That kind of goes into this also. We might want to address this.

You are asking about IQ testing every three years and you are noticing the difference in your son that he keeps developing over time and that's what we would expect for most children. Overtime every three years we would notice the progress and the milestones that are being met. Your idea of thinking that change will be from when he's eight 8 to 16 that you will see these changes. Hopefully that is the case and that speaks to school understanding him and following a good learning path for him. When is the best time to get an IQ test? I think that should always follow and I think it will always follow the try and I'll -- triennial will, every three years. As you are seeing it now every three years you will go. It doesn't in my mind make sense to test more often than that unless there is a problem or it kids are losing skills or something dramatically different has happened to them. Related to their learning. But for keeping on that three your schedule seems like a good thing for your guy and you probably will continue to see some nice gains each time he has a test. I hope -- I don't know if that answers your question. Karen, did you want to add anything to that? There's another question from Wendy about something different.

I don't have much to add to that only because we haven't been through any of it yet.

You will.

Kathy, do we want to take Wendy's question first?

That would be good. Wendy, hello. You are asking if there are research can focus on ways numbers to delineate address children who are nonverbal. There are tests that have been designed for using the kids who are nonverbal. They typically use a picture's and or different kinds of concrete matching tasks to try to get some of those things. Will there be ways that I do -- that other factors can be evaluated, I think it's hard to know. I'm not sure that anything like this would be a priority for many researchers. Who now was [Indiscernible] would continue on that path. You have a daughter who could read but not sign which looks at a whole different level of skills. And how that translates into her own communication needs. Will there be ways that other factors can be evaluated? One can always hope. As Emily has said, the numbers don't to find who our children are. By having somebody who reads but not signs and test that is expecting expressive communication in some form might work against your daughter that we know that she has far more skills and she will show by using a mode that is not comfortable for her. Does that add to the question? I think the question -- the answer is I don't know but one can always hope that people would be paying attention.

I thought there was another question.

Katie. I think what you are saying, Katie, is important, the you haven't allowed IQ testing. Parents need to know that that is their prerogative. They don't need to say yes every time somebody says or when the triennial comes up you can say no. I will just say however as kids get older and we may be looking at what you may need for any adult options for going through extra school or community living or whatever it is, then it becomes a little more important because we want to qualify for any services that you want for her. In many ways you are smart to say no. Because for everything that Emily and Debbie have said about limiting who your child is. As you near transition planning should you allow the IQ testing? I would say yes but I hope that you could have the opportunity to move into that situation slowly with somebody who knows your daughter and who can appreciate why you haven't allowed it to happen yet and take the time with you as well is the time with her. I don't -- you don't need to make that information widely known. And you can put some limits on where the testing goes. I see here you say you don't feel like you have a good educational team. And that you are up against a wall at each meeting. I'm just reading your question. I wonder if there is any -- another team that could be available to you that you would have more confidence in. Package the evaluation. Or you could just wait a little bit more to CF the team around you and your daughter changes at all and you feel more confident.

I don't know if I made it more complicated.

This is Emily and to the entire team what Pam is saying and I am also -- I'm a teacher and part of the small part of our child study team in my home district. I think some of the people keep saying and looking for educational teams -- I think for our children specifically if you have a child with deaf blindness regardless charger no charge I think that is extremely important to make sure that whoever is on the team has an understanding of both the deaf and the blind peace. For years. We had our state -- most states have a specialized child study team in each state and that is what some people can look up were look at. The problem with that is there people that focus on deafness and their people that focus on division part and there's not a lot of people that focus on the combination. And that is extremely important for you when you are looking for specific things in testing. I think there are fabulous teams in each district and people that are compassionate and willing to do almost anything for our children. But you also need to make sure they truly have a good understanding of the sensory issues that our children have.

I want to add with what Emily said because oh my gosh, that was a huge problem for us. Here I have a son who he has vision. He has a lot of problems with physician. He has hearing. Not good but he has usable hearing. Via telecommunication program we didn't start seeing the gaps that were always present until about age 7. What Emily said is so right because everybody up until that point actually it -- up until that point he was always tested as a hard of hearing child or deaf child. Vision and all his other sensory issues were not once taken into consideration. So what started happening in our programming and when you talk about testing -- we got great test. When he was age 3 but as he grew and developed and we started seeing major deaf he -- the information that was coming to him -- the other sensory problems that he was having besides just hearing were not being addressed at all and so the gaps got bigger and bigger. Very quickly. And the more they tested him the more different people would be brought in to give a language test or a math test or now I'm finding out that map disability -- map disability. What we ended up meeting was people who specialized in deaf blindness. To address the entire thing as a whole and not as pieces. That I think is the key to all this.

I wanted to ask Pam, there was that assessment you had done on Michael. What was that called? It wasn't IQ.

You did the [Indiscernible] adaptive behavior scale to.

I found that went to be the most useful.

This is Emily. The same with me. We compared two different studies and that seem to be more beneficial.

I don't know why we couldn't use that as an IQ test.

It doesn't give an IQ. But it's important to have something like that along with the IQ so you can get the picture of what the child can do. And not just what he can't do.

Katie, hang on. Somebody had a question.

Pam, there was one and I apologize if I miss pronouncing the name but Shelley. I wanted your opinion school psychologists this is independent entity and [Indiscernible] wanted to know what constitutes a good team. And some of the comments have been testing upon that that Pam, I also have to bring your attention -- we're at the 8:20 PM Mark. We are to end at 8:30 PM and I know you have wrap up comments you wanted to do.

A time check.

I want to comment back to Wendy who had a very important thing to say about the communication issues. The Shealy in terms of getting an independent evaluation for your child, you probably also -- you always have to have a group psychologist there were a neuropsychologist. There -- their training is different. In order to have the IQ portion done it would have to be a school psychologist or a neuropsychologist. If you went with an independent team somebody like that would be on it to provide you with the testing for your son. As far as experience with charge syndrome that would be great that you probably are not necessarily going to find that. You may find somebody who has had seen a child with charge or maybe has evaluated somebody or has read about charge. That would be a great thing. It's a good beginning. Becomes your job as a parent unfortunately to have to teach that part typically. Heidi, tying into your question about what would be a part of a good team. You would want your school psychologist to start with to be somebody who was open to working with you to learn about your child. Yes, they will be trained on the test material. That is one thing. That as they learn about your child then they can think about how they will use those materials best for the best results for your child. Thinking about the accommodations needed and the reporting of the results. What you needed for and what do you want for and the rest of the people on the team depending on what you are looking for -- is it a PT or OT or speech -- all the things that make up the needs of your child. This people need to be working with you to provide the best report to get the best results. Not just focusing on a number. Or their camps -- campus. What can she do. -- What can't she do. It needs to be a positive way of looking at what can happen and how you will then move forward to make this things possible for her to learn.

Katie made a comment how she would love to come to Perkins. We would love to see you. I think you are right responding to Wendy about the research question. That's a great idea. Katie, your comment to Debbie that exactly that we have vision services and you have hearing services. Nobody is putting it together to think about what -- what deaf blindness means. Especially if the kids have vision they use wealth or hearing they use well [Indiscernible] and we don't have to worry about it. That is not the case. They need to understand about those [Indiscernible] and how they do interfere whether the child is maneuvering wealth of the world there are things that need to be looked at with that vision and to accommodate for those [Indiscernible]. She can hear things that she can say yes and she can respond. It doesn't make her a hearing person or understanding those things. Randy, thank you. For posting the name on adaptive scales. They were included on the list and there and there's lots of information about each of those tasks. The breadth of knowledge it can provide.

We had another question but I think we might have are ready answered them -- already answered them especially about time. Share your experience which they have done eloquently. In your opinion has knowing your child's IQ helped or not. It helped in the beginning and then maybe how it could have worked against your child. I don't know if you want to add more about that. Also who do you think benefits from an IQ test? How important has it been to know your child's IQ?

I could care less. All I need to know is what I can see he can do. That's it. I could care less about the test scores and the IQ scores. As Pam was saying now we are starting to think about transition planning to adulthood. If that is what they are requiring to say yes, you are eligible, then I would want in his favor. However that needs to be. I could care less what it is but what do we need to accomplish to get him to where he needs to be.

That's right.

I feel the same way.

I could care less about the never but if it means getting her the services she needs than that is what we have to do.

Pam, Randy just alerted me that Holly and heady both have their hands raised.

We will go with Holly first. And then heady. Holly, you will have to do star six.

Heady, if you would want to do star six that would give you the floor so to speak.

Thank you. I was agreeing with all that that was said. Great.

Pam, this has been a terrific discussion. And I feel like I'm a Debbie downer but it's almost 830 so it is back into your hands. Next steps on how you would like to wrap it up.

So as I said in the beginning of this there is always so much to say. And there's never enough time to say it. So we talked about the IQ number. We talked about whether they are important and how we get them and what we do with them. Of course we discussed how we need them when we need them. We hate them until we need them. I can't get back to my PowerPoint. I had some closing thoughts that were related to that. One of the thoughts was that testing is going to be inevitable in your child's life is what happens every three years. Is the purpose of the triennial. Your team should always be working together. It behooves all of us who are on the team to be working the best way they can with parents. So we can get the best we can do. As inevitable as testing is IQ scores will also be inevitable as any of our special-needs children head towards 18 years old. Most especially if adult service agencies are to be involved. What even perceive that is the idea of guardianship. If it's part of your plan to be thinking about guardianship and maybe assuming guardianship because the child is yours doesn't mean that after -- that you don't have to -- if they're 18 you will all have to figure out if you will be guardians of for your child. It's part of the law and what happens. The IQ score will play a factor in there as well. The third thing is the IQ scores can be our friend. If we understand why it's being used and if we understand that and we use that number well it will provide good outcomes for your children.

Pam, we are at a point now. One last slide.

We have to slide the resources. These are easily found everywhere. I added on these final -- there is one more slide. I added some -- they are not there. I added a couple of more. We can add them before I posted. Three more web addresses for information about guardianship. Related to children as they hit 18 and above. I will -- they will get added to this before it gets posted and then of them are the special-needs alliance.org and autism speaks.org and E parent.com. They all have good articles even easy to read and think about. What it means to apply for guardianship and how you apply for guardianship and what it all means. Also any of you -- your state governments websites also have links for guardianship and also a way to download forms if you will start the process yourself. Some people will go to a lawyer and some people will go to special-needs advocates. All of the information is available online. You'll need a lawyer somewhere that you begin the process and start to think about it.

I always think I'm not going to have enough to say and of course now we have to stop.

I'm so impressed with everybody that came tonight. Certainly the questions and a special thanks for me to Debbie and Emily and Karen and He and Randy for helping work this through for this techno-photo but -- phobe.

You did brilliantly well. I want to repeat again to thank everybody who joined us tonight and this was a great discussion. I know I learned a lot and I want to thank Karen and Debbie and Emily it again as well as Pam. Wonderful. There will be more webinars to come. Be looking for those notices and be sure to check the website. This will be recorded. If you want to revisit or share that information with friends who you think would also find it of interest. Having said that, I think we will say good night everyone and all the best. Thanks again.

[Event Concluded]