 Please stand by for realtime captions.
>> This is Robbin Bull and I hear the bells tolling. It's the top of the hour. I will get started. I want to begin by welcoming everyone. I will go through some housekeeping items before I hand it over to Linda McDowell who will kick off today's webinar. All lines have been muted to alleviate background noise. The question—and—answer session will happen throughout the presentation and the presenters will talk to you about that. It will happen mostly in the chat pod and will be monitored throughout the webinar. We want to let you know this webinar is being recorded and will be archived for viewing at a future date. I will start the recording now and then Linda, when you hear the voice indicating its recording, that is your cue to begin.
>> It's good to see everybody in the room, at least in the chat pod, folks participating and it's my pleasure to introduce the speakers for today's webinar. This webinar is part of a series of webinars to discuss recent research findings from the field of deaf—blindness addressing what we know, what we need to know, and what we might do about this as a field. Last month the focus was on professional development, personal separation and this month and last month the focus is on recent research—based information to help us in our knowledge of how to best help children who are deaf—blind communicate and learn. A link to a forum post about last month's webinar is in the chat pod or will be, I am asking Robbin to help with that. That forum post includes a link to December webinar recordings, there were two in December, and I am posting for post—webinar discussion. If you will follow that link you can see the past webinars and some of the discussions on those topics. For today's presentation our presenters are Dr. Susan Bashinski and Dr. Sarah Ivy. Susan is an associate Professor of special education and the director of graduate programs in education at Missouri Western State University. She has 40 years experience working with partners who experienced multiple disabilities including deaf—blindness. Susan has directed numerous federal and state grants and low—incidence disabilities in deaf—blindness including personal preparation, research, model in—service training and assistive technology. She has extensive experience in providing professional development and technical assistance nationally and internationally with numerous publications and presentations related to topics such as augmentative and symbolic communication for learners who have low—incidence disabilities including deaf—blindness. So welcome, Susan. We also have with us Dr. Sarah Ivy who is an Assistant Professor in the school of teacher education with visual disabilities program at Florida State University. She serves as a Principle Investigator on our research investigation establishing homeschool partnerships to develop and implement preteens. She received her PhD in August 2014 from Vanderbilt University while she was a fellow of the National Leadership Consortium and LCA C. Previous to her doctoral work, Sarah completed a Masters in special education

for students with severe multiple disabilities including deaf-blindness @Hunter College. She was also a classroom teacher at the Helen Keller School for the Blind. Her bachelor's in psychology and was completed at the University of Kansas. Her research focus right now is on teaching interventions for communication and skill development with children with multiple disabilities and visual impairment. As Robbin mentioned in the introductory remarks part , you are encouraged to make comments in the chat pod and if you are interested in continuing the conversation on this topic or issues raised by these presenters or if you have only been able to listen to the recording and want to join the conversation, please consider an impartation to partner in national efforts to develop qualified personnel in deaf-blindness I coming to the NCDB website where there will be a place for ongoing discussion . I have asked Robbin to put in the chat pod a link to join in the intervener and qualified personnel initiatives where there are already forums to use your voice as we seek solutions to the need for qualified personnel for children who are deaf-blind. Susan and Sarah, we appreciate you putting this presentation together today and look forward to this time with you. I believe Sarah will start things off.
>> Thank you Linda for the very kind introduction. Actually this is Susan and I will start us off today. You are very generous in your remarks and captured very well so Linda, thank you and what I say and 12 words or less is I'm old and been doing this a long time and Sarah is new in training and brings a lot of energy and enthusiasm and a new perspective to the topic. That's what we have tried to do today is to combine some relatively new research investigation in regard to preference assessment and try to brainstorm together ideas that might help you think how you might utilize that information to expand and extend what you are doing with the letters you serve in communication programs. All of us agree that communication is the central core of what we need me to do, we want to do, we strive to do with learners who experienced deaf-blindness. Here we go.
>> We have four primary purposes, topics, components of this webinar. You have them on your screen. We will first talk a little bit about the focus of what we are all about and I will cover that with you to try to introduce some of the basic terminology and the way we interpret them for the purpose of today's discussion. Sarah will cover the middle two points. There is some very interesting research on formal preference recent -- formal preference assessment. She will present a case study how she and her research team conducted a variety of preference assessments and then I will try to wind it up with a formal discussion to try to suggest some ways in which we might use information from preference assessment to try and promote communication development. Here we go.
>> The overarching goal is to demonstrate how to use data from a learners preference assessment that can be effectively combined with the results of a learners communication skills assessment to talk about one particular assessment but we're not married to that one instrument. It is basically any result of any rigorous well-founded,

evidence-based communications skills assessment. We will try to combine those two things to build a foundation for an appropriate, powerful communication program.

>> If we had to reduce what a lot of our conversations have been about as we prepare for today, Sarah and I think we would reduce the conversation to the words intentionality. What is intentional and how do you define a? We talk about intentional behavior. Are we talking about intentionally commutative behavior? Are they the same? Here is a preview. No, they are not. How are they different and what is important? Sarah and I believe that is a pivotal point where we need to do some in depth investigation if we're going to move children along the continuum of communication development. We have to take a critical look at that point. Many learners with deaf-blindness can move very slowly through that developmental phase and they use behavior very intentionally. They might sit and bang their head on a wall or window because it feels good. They are doing it intentionally. They might sit and gaze at the sunshine through a bright window because it feels warm and I like the stimulation. Those are examples of intentional behaviors but that doesn't mean that learner is using those episodes in an intentionally commutative way. If I bang my head on the wall not because it feels good but because I know if I do it you will come over and stop me because you want me to stop, it shifts. That behavior becomes intentionally communicative. That is a hugely significant development -- developmental step. Young children that Arden euro typically developing move through that phase from intentional behavior to intentionally communicative behavior very quickly and they use -- they usually do it without any direct instruction. In my opinion that's what makes it hard is we don't have a lot of practice with thousands or hundreds of thousands of children figuring out how to make that happen when they do it on their own. That's why the development of communication intentionality is so challenging to all of us.

>> We have two key concepts about this. One is that behavior is communication. I think every single person who signed up and is with us today would say Susan, we know that. You don't need to tell us that. We believe that you all know that but we think its foundational to the points we want to make so we want to bring that to the forefront of our minds. Behaviors communication.

>> As we observe, and Sarah will talk to you and has some forms and strategies she will talk to you about how to structure systematic [Indiscernible] observations of the learner to try to correct data that can inform communication assessment. We think you can look through a filter that interprets what a child does as behavior or you can choose to look through a filter and view what a child does as communication or at least as potential communication. We challenge you to say which filter do you use? Sarah and I suggest to you that if you throw up the behavioral filter and you see what kids do strictly as over behavior, lots of times they are challenging behaviors like grabbing things were grabbing people or self stimulatory behavior. That ends ups taking us down a path toward acting out and challenging

behavior and in structural programs often eliminate it, reduce it or replace it. We suggest looking through the filter of communication when you see a child kicking, throwing something, grabbing someone's hand, it's not it's challenging but what does that mean? What is he saying to me? What could he be saying to me? When you use the communication filter we think you are well on the path to develop really strong communication programs. Secondly it will come back around and you will hear us say this word intentionality quite a lot. We think it would be a good idea to define intentionality as we have used it and incorporated it in the talk we are having with you today. Intentionality development is deliberate pursuit of a goal, as well as the means to obtain the goal. That is communicative intentionality.
>> As I alluded to before but we're coming around again and try to look at it more deeply, we have to characterize a learners overt, misspelling and my bad, overt behaviors in terms of is the behavior intentional or is it intentionally communicative? I do know how to count from one to 2. If the behavior is intentionally communicative the learner gives something to have some impact on another human being and to have some interaction from another person. Not just object interaction or object play.
>> We're going to talk with you about a sequence of intentionality development from the point where a learner is reflective or apparently random non-intentional behaviors to the second stage where the behavior becomes very intentional. I bang my head because it feels good. To intentional unconventional communication. That might be a common phrase for you because that's one of the levels in the communication matrix that Rowland contributed to our field and provided as a significant source of data for all of us. Intentional but idiosyncratic type of communication and behaviors happen in the third level. We get to a point where there is a transition to more conventionality so the idiosyncratic forms and idiosyncratic modes of communication start to morph and become more conventional. Maybe instead of talking on someone's shirt or tugging on Verlag, maybe the child or young adult will reach for a hand to lead someone to something he or she wants. Taking someone by a hand to a place is a morphing form and it can morph into gesturing. And finally you get to the point we hope with many of our learners, not all but many, we reach a point of intentional conventional communication. We celebrate and that's where we want you to be and that's when they really take off with symbolic language which is where we are all trying to go.
>> Non-intentional could be random, it could be reflective, it could be things the learner does that are driven by behavior state. I am an old Jayhawk myself and all the work we did on behavior states never totally escapes my mind that with many learners sometimes young learners or not so young learners some learners who are challenge neurologically, there is somewhat of a limit of the kinds of things you can do when you are in dazed behavior states to try to move them to more alert states. We found we can do some things environmentally, socially, but there is somewhat of a limit by behavior states. Those considerations need to be made when you are building communication

programs for a learner. The best Sarah and I can do today for you in that regard is to say we are sorry that we just don't have time to incorporate in-depth investigations or consideration of behavior states in regard to communication programs but know it's potentially important as a variable. If you want to talk to us more about that we would be happy to do that. It needs to hit your radar screen but we won't explore that today. In the non-intentional stage, the behaviors are very idiosyncratic and therefore the partner for potential communication have to begin to interpret the behavior as if it was intentional. You might say how do I know? You use context cues and social cues. You give your best professional gas to what you think it might mean. If you consistently see a young adult pic -- kick out his right like when someone walks fast you feel that they do that consistently, it might mean stop! I am here, stop and talk to me! Or I want you to do something for me. We have a better chance at being on the right track for an appropriate test with that been saying I would like a drink of water please, or that's not a good idea, or I would like to go to target. You have to use your context, social cues, to inform the point in of all partners of the learner decide we think we're going to hypothesize that when this learner kicks out his leg when someone walks past, it will be interpreted as a communication signal for I want some attention, come talk to me! If all partners consistently interpret that way, over time that can shape the intentionality of the behavior. Its long and can be a very tedious process but it can be a very successful process.
>> We reach the intentional behavior stage. It is under the learner's control. It eliminates state-controlled mannerisms and reflexive behavior. Intentional behavior includes the things the learner voluntarily chooses to do. At this stage, behavior is not used to communicate intentionally, but partners have a better clue of what's going on because the behaviors meaningful within certain contexts. Sarah and I believe the most pivotal point here is the point in red at the bottom of the screen. The learner does not realize that this stage that she can use these behaviors to control another person.
>> When you reach the next stage, intentional unconventional communication, the behavior becomes intentionally communicative. With an intention or meaning to impact another person. To get another person to do something, to get another person to stop doing something, to get some kind of response from another living human being. Not just interacting with objects and mouthing objects and getting sensory stimulation from objects of a tactile nature or reflective nature. At this stage, the communication is still not symbolic. They are unconventional forms because the forms are not acceptable by the general society for common use and common interpretation as those learners age up and moving to the community.
>> When you have the transition to conventional behavior, behavior is used for the purpose of communication. It starts looking like the gestures that other people within the given region or culture or society will use. Shaking your head, holding out your hand with the palm up to extend your hand, pointing at things, shrugging her

shoulders, those conventional gestures we all use. Those are the kinds of things we can use that are very conventional that will help people within that same social group and culture. Those are more socially acceptable forms. I think it's important to say these unconventional forms are not be acceptable forms by society but as all of you may be thinking, if this is how far we get and we don't get any farther with a particular learner we will take it. We want it because at least it is Intentional Communication. We want to continue to have high expectations and continue to stretch and try to help these learners who have depth line this grow. -- To have deaf-blindness grow.
>> By the time you get to intentional conventionality, the partners responsibility for successful communication interaction is diminished. The communication interactions benefit from context just like all of our communications do. I was involved in it conversation yesterday and someone said let me tell you what she said, and I said wait a minute because I don't know who she is, and the context helps us all. It's much less important when we reach this stage and at this point kids begin to benefit from the introduction of concrete symbols, 3-D objects and get ready to move on to more abstract symbols and true language.
>> As we move to Sarah and a critical examination of the preference assessment, their two caveats we would like you to hold in the forefront of your mind. We believe communication is both a skill and a sensorimotor experience. The earlier a learner has communication or intentionality that is functioning in those stages that we just blew through quickly, more and more of the sensorimotor scheme and that's what we're looking at is switch senses, which types of input, which features of sensory input and we think if we can maximized the learner sensory access to features to ones they prefer, those experiences in and of themselves will enrich the communication interaction and facilitate communication growth. Before I turned over to Sarah , I have two questions in the chat pod so does anyone have any questions now?
>> Okay Sarah, on to you.
>> Thank you so much, Susan. Thank you for framing and defining our very critical term of intentionality and different intentional behavior and Intentional Communication which probably people who are familiar with than most of us in the communication Atrix is hopefully not a new concept. I think you have to think about that critically any time meeting a new kid to wrap my head around the difference between these two stages of development. It has been really helpful to look at this particular case with you, Susan, to discuss if we are seeing the same thing in terms of business Intentional Communication, intentional behavior, what tells us which? So thank you to Linda for providing the opportunity to work with Susan on this and think about these questions.
>> One of -- I am at Florida State training future teachers of visual impairment and one of the things I'm interested in doing is defining an effective, meaningful approach to viewing the comprehensive assessments that TDI is responsible for when they have a kid with

deaf-blindness on their caseload. They do a functional vision and learning media assessment which a lot of the time is focused on is this kid going to be a braille reader or a [Indiscernible] reader. I am thinking a lot about how can it be more meaningful for kids who were earlier in the stage of communication, before we got into any symbolic forms of communication. And even before what might be readily recognized as communication which I would say is that intentionality, that Intentional Communication stage. But even before that when they are in reflective behaviors or intentional behaviors that are not yet intentionally communicative. How do we structure assessments to guide TDI's to perform a meaningful learning assessment and what should that include? Preferences are really important to this discussion. An assessment of a child's preferences is going to be a key element of this assessment. I thought about how to get meaningful information about preferences for kids who don't have a lot of conventional behaviors, they are not readily exploring their environment a lot without of a lot of facilitation from an adult. I just wanted to frame this part of the discussion in that context. Now briefly I don't think I would be preaching to the choir about the importance of preferences and don't think I need to go in depth about it. I would make the point that incorporating preferences is a good idea because it can be motivating for students as well as reinforcing and makes a distinction between the two things. By motivating I mean increasing interest or engagement in the child's surroundings outside of their own internal experience would be a good reason or rationale for incorporating preferences. Also looking at the science of behavior and knowing that skills increase as a result of coming in contact with a pleasurable stimulus after the skill which increases the rate of response in the future which is by definition a reinforcement. The motivating piece is setting the conditions for interest and encourage a child to be interested in their surroundings. The reinforcer is something that happens after a behavior and there is a lot of research that shows that the natural principle of the way the world works is that increases the frequency of behavior in children. We can use preferences in a way to increase skill levels. There is a lot of research that shows that for problematic behaviors, incorporating lots of preferences into instruction can have an overall mitigating effect of problem behaviors in general. Good reasons to be able to identify preferences. We know students with deaf-blindness, at least the ones I have worked with, and I give a copy it that I mostly work with very young children with multiple disabilities and visual impairment, some of those include kids with deaf-blindness and a lot of what I will say today and I think Susan would agree because we have talked about it, if you tailor instruction tool your kid with deaf-blindness, you are probably going to be serving other kids with multiple disabilities that include visual impairment as well. Students with deaf-blindness and kids with multiple disabilities have a limited repertoire of preferences. It's another good reason to have some good tools to really uncover preferences of the kids I work with.
>> Preference assessment methods, we could divide these into indirect

types of assessments versus direct types of assessments. Indirect assessments are those that you are gathering information not through direct observation that through reports. I have observations as an indirect assessment method so I have to back up about what I just said. I typically think of it -- I typically think of indirect assessments when you conduct interviews and in the slide I put observations under indirect assessments because when I think of direct assessments I am thinking of a systematic presentation of stimuli or items in succession of one another and noting the child's response to that presentation. That is how I am categorizing direct assessment. Did you have something you wanted to add?
>> I want to ask a question if I may. Where you said you wanted to back up with what you said, is it fair to say that maybe a way we could differentiate between these types of [Indiscernible] that indirect assessment would be more unstructured observations as opposed to structured observations that might be more in the direct category? Is that a fair description?
>> Yes and I don't think the nomenclature is particularly important but I think indirect and direct is a little misleading. I Inc. unstructured and structured is how I have them divided here. The direct assessment procedure, I have a list here and I think it would take an hour and a half to go in depth to talk about how to administer each one of these types of assessment so I won't do that. I will give a general description of each one. A single stimulus would be presenting one item at a time and noting the response of the child. Multiple stimulus would be making available an array of items and noting a child's response. If a child starts to engage with one item, multiple stimulus with replacement, when the child is done with engaging with the items they need to have the same array with the same item included. That would be multiple stimulus with replacement. If you took away each item as they engaged in them than the array would get smaller over time and that would be multiple stimulus without replacement. Pairwise or forced choice assessment is providing a choice and the student is selecting one over the other. Of preoperative assessment would be providing -- a free operant assessment would be offering an option of items and not changing the array over time but noting the duration that the child engages with each of the different items. And have reinforcer an assessment -- and a reinforcer assessment is to systematically present an item you think might be of preference to the student or is known to be a preference but thought to be a preference after a behavior of the student that is already in their repertoire that does not occur frequently but the child naturally engages with it without prompting. It provides the access to this item immediately after [Indiscernible] behavior. Also noting to CF that behavior increases in frequency when you provide to preference right after it. Under conditions which you don't provide access to the preference right after the behavior, the behavior will decrease. Providing an item directly after it and then looking to see if the item actually serves the function of a reinforcer which would increase the rate of that behavior. Then we have a preference here and

a reinforcer. You can imagine the reinforcer assessment is pretty time intensive, labor-intensive type of procedure. I have not encountered many settings without support from a behavioral staff where reinforcer assessments are done because of how much time it takes to do it and the technology is so significant. I just wanted to make a note about these methods, there is research that show that direct assessments and structured assessments are more accurate than indirect assessments and parents can inaccurately predict preference for unfamiliar items. And I don't think Kenzer & Bishop me to say at all the parents don't know what their kids like. That is not the case. Suppose a scenario where you want to identify going back to kids with very limited repertoire of preferences, and you want to identify some preferences you don't already know about. You generate basic list of potential preferences and you ask parents to predict which of these will be preferences for the child and parents tend to inaccurately predict those. There is a case here for the value of direct or structured assessments. There is a recent review of Virues-Ortega in 2014 who reviewed the literature on profit -- on preference assessment in response to a teacher concerned about how they adapt preference assessments methods for learners with profound disabilities and particularly those kids that have a visual impairment, motor disability, or difficult behaviors. These researchers reviewed the research literature that was published on these kind of assessments to come up with a decision-making model to help address these [Indiscernible]. Of the research, out of a total of 49 studies that met inclusion criteria so the kids have intellectual disabilities, visual impairment, other sensually disabilities, motor disability or difficult behaviors and of the 49 studies only seven have participants with visual impairments and only one study had a learner with deaf-blindness and none with deaf-blindness. So this is an area that needs more work. A couple other findings they noted was that eye gaze and emotional behaviors and other indirect responses were used more frequently for learners with visual impairment and/or motor disabilities. That is in relation to those without disabilities so rather than a collect selection response in reaching out to select an item, more often than not they would use indices of happiness to determine if something was a preference. Pairwise assessments were most often used for kids with visual impairment and/or motor disabilities.
>> Here is the decision-making model that they came up with. I want to point out a brief orientation and you can play with this for a while and I encourage you to track down the resource. I think it has some value. There is a series of selections and you start with number one and depending on your answer to number one, yes or no, you are directed to another question of the 12. It's like a choose your own adventure game. It will direct you to a particular type of assessment. The question that they pose can be looked at incorporating information that the person who is trying to make decision on what preference assessment to use, they want to know from the person who will use the model what type of results do you want from this preference assessment? Meaning are you interested in tangible stimuli or tangible

and social stimuli? You need a hierarchy or do you just need a list of preferences? By hierarchy I mean do you need to know the relative strength of these preferences or do you just need a list of preferences? That is one factor that is included in these questions. The other is student characteristics. In order to decide what preference assessment method you should use, take into consideration what behaviors does your student have in their repertoire? The questions they present really only probe on student characteristics in a purely behavioral manner. There are no questions about does your students have for instance intentionality? Number two says could the student display engagement and selection responses? I will pose next what does it mean to have a selection response and is that intentionality or does it require a [Indiscernible]? If you have time in terms of how long you have to do the preference assessment and all that factors into the questions. It's a great resource to make a model.

>> I want to introduce to you John who we will now focus on the discussion on for the rest of the presentation. We will look back at this model with John in my. John is seven years old. He is diagnosed with deaf-blindness as a result of a chromosomal anomaly present at birth. The eye report doesn't provide very much useful information about what he has but I had quite a bit of interaction with John and he wears glasses that he really dislikes. He scratches them up quite a bit and really doesn't want to wear them so I question whether they do much for him although they have been prescribed in the eye doctor has given a prescription saying he has 20/200 or worse visual acuity. He has a binaural hearing loss of at least 70 decibels. Both parents and teachers and anyone who works with John has reported that he has more useful residual vision Dan [Indiscernible] and is able to actively reach and grasp and manipulate items in his environment. He uses a wheelchair. The SIB-R which is an instrument that will give you an age equivalent for adaptive functioning and adaptive levels of behavior resulted in about 5 to 7 months. The majority of John's behaviors through observation seem to be intentional, although a very small percentage may be intentional on conventional communication. He is one of these learners that Susan talked about that are right on the cusp in the transition from intentional behavior to intentionally communicative. You don't have to hang around John very long to know he responds well to music, lights, scratching, textures, rolling, so that is John.

>> So going back to the Virues-Ortega decision-making model, I want to look at this through three lenses briefly. The first scenario is that let's say we want to use this model to say let's do a direct assessment with John and keep it simple where we don't necessarily need to get a hierarchy and we just won a list of tangible items that would be preferences that we could incorporate to build a communication program. The first is do you need to assess preference toward social stimuli and we say no. That says go to question two and that's is can the student display engagement or selection? In this scenario I will assume that engagement or selection response requires

not just intentional behavior but some kind of Intentional Communication. Intentionally saying yes I want that. Our student John does not have this. In that case we would answer no to this question. It says to go to question eight which says can the student engage in indirect responses? We will answer no because we assume the indirect response is intentionally communicative by definition. In that case the decision-making model tells us to do reinforcer assessment. If I am a teacher like it was a few years back, I really didn't have the means or support to do a reinforcer assessment. That is one scenario. The second scenario we are looking at his let's assume the engagement or selection that is active out -- that is acted out does not require intentionality but requires the student can reach and grasp with the environment which the student can do. To the first question we say no, to the second question we say yes and it says go to question three it says do you need to avoid tangible maintain problem behavior? The answer is no. Go to the next question and do you need to establish a preference hierarchy? We will say no. Go to question five and do you need to identify long-duration high preference items? No. Do you need to assess the preference toward a single stimulus? Yes. That leads us that we need to do a single stimulus preference assessment. That is the second scenario.

>> The last scenario is let's say deaf-blindness and this may not be the case for John particularly but for a lot of kids with sensory disabilities, especially kids with deaf-blindness, let's say we have a deaf-blind student who has ability to select without real exploration of the choices of the items. Some real experience. Therefore we feel we would have to rely on engagement or selection response measured by emotional response. In other words indices of happiness as opposed to I am showing you two things or one thing and I want you to reach out because you want this. We will assume we can measure an in direct response which is more reasonable for kids with sensory disability. In that case we would say go to one -- no 21, no to 2 and that brings us to a and it's is can the student engage in indirect responses and that is yes. So that is indirect or idiosyncratic response. An idiosyncratic or indirect response assessment is not very well described in the paper or literature but essentially I present items or facilitate engagement that I know has indirect responses.

>> We did a battery of preference assessments with John. What we did was adapt the preference assessment features from a man you lies communication [Indiscernible] called a picture exchange communication system. Partly because there is increasing work or evidence that the model may have some merit to teach kids who would benefit from tangible [Indiscernible] to teach requested behaviors. We conducted interviews with parents and teachers. We get replay observations at home and school and then we did single stimulus preference assessment which in these particular procedures allow us to present one item at a time and note not just a selection response, but also note indices of happiness or protest when we take the item back or rejecting the item. There is a point system to total the response that the child has to a particular item. We can use that number to say

whether there is a relative preference to the item. Just a preview, the interviews and free play observation, we were interested in coming up with a tangible set of items that were fairly age-appropriate. And our free play didn't give us anything to go off in that way so we generated a standardized list of items and we asked parents to predict what they thought the standard list, which ones would be preferences for the child.
>> We asked whether these preference assessment procedures could be used to identify tangible preferences for this unique learner with deaf-blindness and we also asked whether the procedures might be adapted to obtain other types of useful information regarding learner preferences.
>> I will try to be quick because I'm running out of time to go over these procedures. It's a lot of detail so I won't go into all the detail but I know the slides are available and the webinars recorded and available to field questions. This doesn't have to be the end of the conversation. The interviews a fairly comprehensive and asking parents to think category by category about eating, drinking, social games, what they like to do. If you think categorically and list anything that the child prefers including people that the child likes to be around or things that they don't like. We asked them by category and we asked them to rank order the items and then to look across categories to rank order the top 10 things that the child likes.
>> We asked parents to do that and we asked the teachers separately to do that. In the end the top 10 ranked items for the parents were really quickly loves grandpa and follow-up specifically was what do they like to do with grandpa and he tickles, snuggles, bounces, he likes music and he has a deep voice. He loves playing on the floor like the carpet and tile. He likes to be tickled and play peekaboo games. The last five items are all food items. That also includes grandma's potato salad. We asked the teachers she said number one tickles, the floor time on the mat or floor time on the tile, scratching textures, swinging, close contact and deep pressure, drums, water stuff and he loves to play with the parachute. We finished up the interview we looked at it and I could summarize by saying if I count how many times I see anything mentioned it looks like the number one preferred type of input. That's followed by tactual and vestibular and then auditory. What we don't see besides food and drums is we don't get much information about tangible items. At least that we could test in a direct assessment.
>> We kept going and said -- we set up a free play situation and asked the parent or teacher to look around and find anything that the child enjoys engaging with the make that available. We video recorded for replay for 20 minutes. John was out of his chair and that was his preferred position. He was very active on the floor and we made the items available around him. We wanted to make it as natural as possible and wanted to see what he would do on his own. We instructed the teacher and parents that if you felt he needed help or it was natural to give help then by all means provide whatever necessary assistance he needs but we just want this to be natural. When we watch

free play activity for tangible stimulus, he loves the ball he can easily grab and can shake it and it has an interesting weight. He hung onto a shiny mylar pom-pom for a while. He had a rattle which is not very age-appropriate and then he had a toy which he could pull on a lever.

>> We can come up with that much tangibles items that were age-appropriate. So we went on to single stimulus assessment. I have the next four slides to give you details on the procedures of the way we conducted the single stimulus assessment. I won't go in depth but they are available. I want to tell you overall do it in the as quickly a manner as possible which isn't enough time to experience a new item and I would agree that the time adds up really quickly. We're trying to come up with something that would be something that teachers could do in the time they have, a reasonable about -- a reasonable amount of time. The procedure is engage, provide as much support for the briefest amount of time with an item and then pulled the item away and wait for a little bit to provide the opportunity that the student would try to reach it when it was out of the reach. This could be an indication that they particularly like this item. Maybe we could get some differentiation between low preference and higher preference items by setting up the scenario. So we stop operation and pull it away a little bit and then provide within arms reach to present the item and don't engage the child with the item but just make it accessible. The emphasis was put on that if you have to present it with movement, okay. If you have to even touch it with the back of your hand to let them know it's available but without engaging them, then whatever you have to do to let them know that the item is accessible, been presented in that manner and wait for 22nd so the student can make the selection on their own. And then play with the item if that's what they want. In the time when they could play with it we wanted to go ahead and provide whatever support they needed to experience the item after they made the initial choice.

>> That was the last portion of any trial was allowing them to engage in play with the items that they had selected. We would record a number of things, whether they showed any sign of pleasure through the entire trial, whether they protested when the item was taken away from them, and whether they overcame minor obstacles like if they dropped it in their lap that they look for it and try to pick it back up. Also if they tried to reach when it was out of their reach, whether they took the item a second time after engaging with it the first time, or whether they rejected the item at any point during the trial. Each of those behaviors were given a point system. A total score was generated for each item. We were hoping that would distinguish high preference from low preference and no preference items. The slide we are looking at now is the agreement among the different assessments for highly preferred and nonpreferred items. I had asked the teacher and parents to predict what they thought would be a preference based on the direct preference assessments that we did. When we asked teachers and parents to predict which items are preferred out of 37 items that we presented to John, and the top six are listed. So the top six for the teacher

and the parent and three of which they were in agreement. They were
50% agreement for the top six items they thought the child would
prefer. The direct preference assessment yielded little agreement
between administration. We administered the test twice in a different
person administered it each time. We get very different results. As a
matter of fact we got some conflicting results where in the first
assessment the tambourine was identified as nonpreferred where in the
second assessment it was a preferred item. So little agreement here.
>> When we totaled the scores from both administrations of the single
stimulus, we got the top items being the sound effect machine, a toy
tiger, a fan, a light up ball, and a kazoo. Of those five items, only
one of which was predicted by parents or teachers. Just to summarize
the assessment results, the conclusion I would draw is the singles
stimulus assessment did not differentiate relative preference. In
terms of total scores there was only three different scores that items
ended up getting. There was little differentiation. Assessments appear
to be highly dependent on either the time they were administered or
the partner who administered them. The question of whether parents
inaccurately predicted preferences, we have to know what is the true
answer or preference. Is it what the teacher said probably the kid
would like or was it the result of the [Indiscernible]? There needs
to be more work on that before we can draw conclusions. I would
certainly not want to draw the conclusion that teachers and parents
were inaccurate in their assessments of what their kids like because
it didn't agree with the direct assessment method.
>> We will switch now to Susan I know we are running out of time, to
bring this back to communication, thinking about these assessments, I
want to make a couple of points. First children and young adults who
experienced deaf-blindness, particularly young children, typically
initiate little exploration. I made that point early on, you would
logically need know they need experience with items before you can
determine [Indiscernible]. We know many of these children with deaf-
blindness need to be slowly invited out of their own bodies to join us
in the world and understand because the world seems like a chaotic
place. In the case of a learner who also experiences significant motor
challenges, the lack of exploration is further exacerbated.
>> Going back to the Virues-Ortega recommendations, we think in light
of the non-convincing results, the preference assessments we did, the
Virues-Ortega decision-making model does take more into consideration
about student characteristics and not just in behavioral terms but in
terms of does this child have intentional communication? Although it
can be a great tool, it needs to be supplemented, the direct
assessment. We went back to the drawing board with the data we had
collected and interactions we had to see what useful data or
information could we get about preferences from this and we came up a
way to [Indiscernible] observations that we had conducted. Before I
introduce that really briefly and I don't know what we will do, Susan,
I'm so sorry about the time but I will open up for questions right now
and I'd like to hear from Susan.
>> I'm sitting here trying to think about which parts I want to

highlight with what time we have. The chat pod has not been really active with questions so I say charge on an introduce the forms quickly. I think we need to have at least a little time at the end to talk about some of the communication slides we've got ready to make participants aware of what is there.

>> That's great. So systematizing observations to get preference and permission -- to get preference information, I would encourage you to take video of the [Indiscernible] I described earlier. With team members, I will comment on who should be on the team, but with more than just yourself, up with what discrete various behaviors do we see over intentional behaviors the child is making in 15 minutes. What you are looking at are these discrete activities and behaviors from a single observation of John. We saw moving, kicking, holding up his legs, actively rolling around, engaging in visually guided reach and so forth. For each of these behaviors consider the type of input that the child is giving, is a giving auditory input, visual input, tactile input? And list them. And we encourage you to do some systematic data collection. We have something called momentary time sampling and that is simple. For east of those behaviors you can write in behaviors in the first row and each would get its own activity. As you watch the behavior, you watch it from a video and stop it every 10 seconds an note with a X or leave it blank whether the child is engaging in behavior at that time. You do this every 10 seconds for the entire 15 minutes. At the end you can count up the total number of 10 second intervals that the child was engaging in that particular behavior. The total for each activity and behavior and go back to the first sheet where you had already brainstormed the types of input that the child is getting from the behavior and put it there to remind of the import that the behavior is giving the child. You can rank order the behaviors in terms of which behavior did the child engage in most, second-most, third most. Been below you can total the number of intervals by the type of input and rank order the type of input. If you have five different behaviors that are all giving tactile input, you would add up the intervals for each of those behaviors and put it under the tactile category. In the end you see if the child from the behaviors in their behaviors they are gauging in if they are engaging in which type of input. The results for John R that we did a school observation and a home observation and we'd had two independent observers watching the video and they identify the behaviors they saw. We independently did a time sampling. So the first observer and we saw the most frequent behavior being holding glasses and scratching a mat service and so on. The agreement between observer one and two for how often they engage in this behavior was very high. That's a positive thing. When we looked across behaviors at what is the most frequently thought-out type of input from this child, we got tactile being number one, number two being auditory and number three was visual. At the home observation we saw different behaviors. We had really good agreement and the number one thought-out type of input that the child is getting his tactile. That is followed by propriocept event vestibular and visual.

>> I know I went over that pretty quickly but if anyone wants to use those with your kids to get this type of information about sensory channels I'd be happy to discuss it on the phone or email or follow up.
>> I will turn it over to you.
>> Okay. Put on your racing shoes. We have 10 minutes and I have 20 slides. We are not going to be able to cover everything that we had planned. If you will bear with me I will tell you there are 20 slides with a variety of different ideas. I will try to pick out some I believe our of most salient use and can connect interesting information that Sarah shared about the preference assessment. I think it's important on the slide to say we will make some comments connected to the communication matrix for parents and professionals and we chose that because we believe it's something with which I would bet every one of you is familiar and has used and if not all of you, nearly all of you. The bottom line takeaway is we believe a preference assessment, sensory preference assessment, and a communication assessment can inform one another and should inform one another. Together those can be utilized for programmatic decision-making.
>> You know these general overarching function categories from the matrix and don't need me to go over them. In terms of the level of the matrix it's worth a couple of comments. The information Sarah and I have been happy to share with you today connects primarily to levels two and three of the matrix that we show in red on the slide. Intentional behavior, intentional and unconventional communication are the actual name of the levels in the matrix. Dr. Rowland uses those levels. We ask you to connect what we presented to you to the matrix and we're calling it lever four -- we're calling it level IV and I want to say we realize that is not the name of the level IV in the matrix. It just is called conventional communication. We will try to connect those two things for you to what we have been talking about today. And levels five, six and seven are abstract. We are concentrating on the ones in red.
>> This is what a profile looks like. I'm sure all of you have seen this. I need to clarify explosively this is not John's profile. I don't know John personally. I have gotten to know him because Sarah shared videos with me that I watch. This is a profile I pulled on a child I know who seems to be similar in a lot of ways to John and a lot going on in levels two and three and starting to reach into conventional communication. You see the growth from the top to the bottom and in the middle levels especially two, three and four where we think the magic happens. The problem is the miracle doesn't happen by itself. We have to structure and plan for it.
>> Before we look at strategy which is critical it's important to say there is an attitudinal piece we cannot skip. When you work with kids trying to incorporate their preferences to develop communication, you need to listen with our ears and eyes and hands and hearts. We need to talk with more than our mouth's or hands for kids who are manual. We need to keep the learners preferences in mind. Also features of sensory input. If you don't do these things, no matter how systematic

or evidence-based or data-driven you are we question the degree which you will be successful.
>> Another general caveat that is worth using precious little time to say and probably preaching to the choir but a good reminder is for learners who experienced deaf-blindness or complex multiple disabilities the ways in which she receives information may be entirely separate from the way in which she expresses information. You may have two entirely different modes that are primary and I met last week with a high schooler with deaf-blindness who is 18 and have been following him since he was 3. Has total receptive communication is almost entirely through manual signs. He signs maybe three words in a week. His expression is through a speech generating device and it's a fascinating study in communication so remember receptive skills and expressive skills may not look the same at all in terms of mode of primary communication.
>> We believe you can use preferences of the learner to promote mitigation development. Sometimes you have to directly teach these things by reading and interpreting and making your best professional guess. Observe a learner as Sarah said and follow the learners lead . If John is kicking and he's a really good kicker, he isn't kicking in an aggressive way but he's a very good kicker and has strong legs. Find things that allow him to kick. He can make sounds. We can get feedback so let him kick and make something burst and/or let him take and make a light change color. Make it a goal in some way and then he may be he will kick more. Offer him items that incorporate features he prefers. Embellished whatever potential signals he gives you. He was reaching for his father's hand in one of the videos and I don't think that was purposely communicated. I think he was trying to get at the tambourine his father had. But you can shape and embellish the potential very can junctional -- very conventional gesture. You can take it and run with it. Touch input to him when he had the tambourine, he was using it tactually more than auditorily. It had metal symbols around the edges. What do we as partners need to do? We know this. Sometimes reminders are helpful. It's our attitude. It's our expectation. That young child or young adult with deaf-blindness or the young adult with multiple disabilities and congenital deaf-blindness is not intentional. Expect she is communicating with you and she can learn to communicate better. Expectation is important in the process. It takes responsive partners to respond to subtle cues and to embellished use. At one point it came out in the preference assessment that I drill home is the variability of data, in my humble opinion are due to some extent by sensitivity and responsiveness of the partner. By how well they can read the child's behavior. That is a key part of what you do in our work with children with deaf-blindness is more of an art than a science. I love the stuff that comes out of Europe about being attuned to the learner. Maybe this is a point to say our last slide is a reference slide. So the Virues-Ortega article and the article about Kenzer & Bishop are listed both citations for you. Watch for kids to shift their attention. To persist and recast or do something with great intensity. They can use different body parts or

additional body part. Watch with a quick scratching. Watch when John quick kidding effect kicking. Did he quit because he achieved what he wanted? I don't think he quit kicking because he got tired because he never gets tired of taking.

>> We have some information about how you can build a dictionary. We have steps are you can do that. We are out of time but I would love to talk with you about how you can build a dictionary and videos. You can build video portfolios to show what it looks like when John says I don't like it and want to move or I am scared, I'm happy, I want some more, do it again, if we can capture that in words or on cards that team members can have in parents can share, it looks like this. When it looks like this, this is what he wants. I'd love to talk about those things. We're out of time. I really have numbers

[Indiscernible] use personal identifiers. This is Emily and now you will work with her. Use identifiers and if kids are not tactually, they are tactually defensive. One of the most brilliant things and this is my last remark what a great story, for greetings, a lot of tactile defensiveness doesn't like a lot of touch and pretty severe visual impairment. They were going to greet his young child with kissing so it would body the identification of the person and mom always kissed her on the top of her head. Grandma always kissed her on the four head, dad always kissed on her cheek. It's not rocket science. Keep it simple and we make our work hard sometimes but it doesn't have to be. Identify who you are and let them know I'm watch and build on what they do and expectant to communicate with you when they will do more. Here is our contact information and our email and phone numbers. Linda and the NCDB people will send up a form and thanks for taking time in a Wednesday afternoon and hanging with us. We would love to talk to you further but we want to let you go. Sarah , Linda, Robbin thank you. I could hang up for a few minutes Alyssa Wrubel shutdown if someone wants to ask something. We appreciate your interest in intuitiveness with us.

>> Thank you Sarah and Susan. I can leave the room open for a few minutes if people want to hang if anyone has questions so we can say officially the webinar is over. Thank you so much for the great information.

>> [Event concluded]