**wintac – ID200302 Engaging and Communicating with Individuals with Autism - Transcript**

>> Welcome, everyone. I'm thrilled to be presenting this second seminar in our new series of webinars specific to understanding and working with individuals with autism spectrum conditions.

I'm Dr. Mary Baker-Ericzen, an autism specialist and trainer at the WINTAC. I'm also a research scientist at the Interwork Institute at San Diego State University and a practicing clinical psychologist at the Intricate Mind Institute in San Diego. I have worked with individuals with autism for about 30 years now and counting. I'm so glad that I can share with you today information from research, clinical work, and in the field experiences.If you have not viewed the first webinar titled "Understanding Individuals with Autism Spectrum Conditions within Vocational Rehabilitation Services", that may be of interest to you as well, and I recommend viewing it. It's available on our webpage. This webinar is particularly focused on the entire process of enrollment of individuals with ASD in vocational rehabilitation services, including improving community outreach and access, all the way through to engaging with individuals within the intake process for eligibility. I will provide some background and overview of data specific to those with autism, including the continuous increases in prevalence, increases in number served by VR over time, and some information on the most up to date data of who is actually being served, what does that autism population look like. I wanted to state that there is appreciation for both person first and identity first language in this population.

So, I will be interchanging the use of terms as autism spectrum condition, autism spectrum disorder, autism diagnoses, and even autistic. Autism spectrum, in this talk today, will include those who identify with autism, as well as those who identify with some of our previously used terminology such as Asperger's and pervasive developmental disorder and those who also prefer languages that are often viewed as [inaudible] such as [inaudible] and autistic.

To be respectful of all, you will hear me use these multiple terms interchangeably. I will also spend ample time today on how to make adjustments to engage and connect more successfully for those with autism. I will discuss using specific communication styles, creating sensory supportive environments being aware and acknowledging social and other anxieties and addressing executive functioning challenges. These adjustments will be of value with working with other populations as well, so keep that in mind. I will also focus on identifying and promoting an individual strength's and special interest. This is particularly important for those on the spectrum. Next, I'll provide you with an example from San Diego to increase community outreach and access, using a brochure approach and what we did and how we targeted VR counselors to understand the autism population more through this process. And then finally, I'll end with a few additional innovative ways to increase outreach and access for autistic transition age youth, as well as adults, to address this underserved issue and get all our minds thinking.

To start off on some background of the employment for those on the autism spectrum, as many of you have probably learned by now, the employment rate for people with autism is between 50 to 75% lower than that for others with disabilities, including those with intellectual disabilities. So, it's estimated that overall only about 15% of adults with autism spectrum conditions are working, and of those who are working, the majority of them are underemployed, meaning they're working in a setting that is not capitalizing on their skills and abilities. And or they're working for less than optimal hours per their interests and their abilities. So, if we remember back in 2014 that the WIOA updated the laws for the VR programs in the US, right? And it was specifically designed to increase the opportunities for individuals with disabilities, including transition age youth, for the sole purpose really help them all find and maintain employment. As a result, there are definitely increased numbers of these transition age youth or as I might refer to them as TAY being served, but unfortunately the autism population continues to be underserved and as a result underemployed. So, a group of researchers at Drexel University led by Paul Shattuck and [inaudible] and colleagues were particularly interested in understanding further how the autism population is served in the VR system. And they reviewed 51 state plans following all these WIOA changes, in particular, pulling out these plans in the year of 2016. Forty-four of those plans contained references to autism and 19 explicitly identified autism as an underserved group in their state's VR system. They also found that 53% of the plans identified a need for autism specific training and or to be -- or they themselves had begun to develop an autism training of some type based on that need.

However, no plans indicated any particular actions that would focus on outreach and access, such as communications to the autistic community specific about VR services or other methods to increase enrollment in VR for this population, and that was really surprising to them. I'll show you in a few more slides why this is such a problem, because our enrollment numbers are far too low for this population. So, in some, the autism specific VR strategies, goals, and services appear to be the exception, not the norm, at least in terms of what is documented within these WIOA state plans. So, it's our hope that these targeted webinars on the autism population will help impact that.

So, now looking at the data over the past two decades from the US Department of Education's Rehabilitation Service Administrative Case Service Report or otherwise known as the RSA91 Database, we look at the data across all the states. We see a very similar trend that occurred in the years 2009 to 2014, just as they had occurred earlier in the 2003 to 2008 years. This relatively steep exponential curve. This is often being referred to now as the great wave or the autism tsunami, as the prevalence for this condition continues to rise over time, and the children continue to age and hit the adult service system. When I speak to various community groups or at conferences, I usually like to state that we have finally found one symptom that all children who have autism actually have. And I'll pull a little survey seeing, you know, what the symptom may be, what the crowd thinks this symptom might be, and then I reveal the answer. It's aging. So, you can see the trend lines for both of these six year increments is the same, and in 2015, about 18,000 VR cases of youth and adults with ASD were closed, which is double that of what were closed in just five years prior, in 2010, when only 9,000 cases were closed.

So, our VR services are still at actually an early stage of serving the autism population. We will continue to see yearly increases in numbers over the next five to 10 years as well, and we know that from data that's coming out in young children. There's absolutely no signs of flattening this curve or any kind of plateau effect. In fact, the newest data from the CDC that was just released a few weeks ago here in 2020, that one in 54 children have autism now. So, that rate is increasing, basically indicating that 5% of all male children have a diagnosis of autism spectrum condition. And those prevalences range by state where some states like New Jersey have even higher numbers, 7%, even up to 9% for males. And this was data that examined four-year-olds and eight-year-olds, and both of these age populations had the similar findings. So, they clearly haven't get our adult system yet. In fact, we do know that about 50,000 autistic youth turn 18 each year, and with the new results from the impact of the WIOA's changes in 2014, a majority of those seeking VR services and becoming new enrollees who have autism are between 16 and 26 years old.

Interestingly, an important piece of information from these studies show that it is taking a significantly longer amount of time for these transition age youth to move from the application to eligibility determination within the VR service systems. Unfortunately, though, we don't have much information on the why to this occurrence, because all of this data, it was just coming from databases and quantitative studies. It's definitely an area for taking note and further study. We've also learned that 30% of states indicate that autism is currently an underserved population from their individual data studies. So, when we look at the autism population within VR services, and the group from Drexel University, again, did a very thorough study in this area. They found that overall only 3% of VR applicants who were found to be eligible had autism. Now, this varied, again, across states, so this 3% is collapsing kind of all the states together, and it's varied across states, where some states had up to 9% of their VR users having autism or others had as low as 1%. And this is far less than any other disability. Then, when we look at the information of those who are found eligible, only 32% used the VR services. And again, this ranged from, you know, across different states, with some states having higher usage, but they're generally quite low. And then, if we look at of those who used services, 46% were secondary students, basically, they were still in high school. And again, this ranged across states with the range being even broader with the low end of 0% to the high end of 73%. We've also learned that most of the services that were provided were provided by community rehabilitation programs under contract with the VR system, and that assessment was the most common service used by those with autism. In fact, again, a number of those who used services only used the assessment component.

So, trying to understand further, how do those with autism get into the VR services, a study was done by Chen, Sung, and Pi, again, using the RSA911 data set. And what they examined was that since the population was so large for this transition age youth, they decided to break that down into kind of two separate groups. So, they looked at those that were under 18, basically, still within the high school setting and those who are more likely to be out of school between the ages of 18 to 25, although some, of course, could still be in school as well. And this data shows how valuable that direct referral source is to enrollment. You can see the huge rates of enrollment for those who are still in school that were enrolled directly from the educational institution. But you can also then see if you're looking at the adults, so 26 years and above, there isn't a dominant referral source. In fact, the highest referral is self-referral.

To explore a little bit more of what the adult, well, transition age and adult population with autism, what do they look like, who are those who are involved in VR services and have completed the intake in eligibility procedures? You can see that they're a rather homogenous group. They tend to be white, young, again, highly likely to be in a high school setting, less likely to have any post-secondary education at the time of VR service use compared to other VR service users without autism, looking at all the different disabilities kind of grouped together. And it's giving us an indication that there's some clear challenges with enrolling diverse populations, including those that are more of adult age. Our own local data here in San Diego, California, gave us similar information, although it was much more -- we studied it in a qualitative level. But our community revealed that the autism population were either one, unaware of VR and available services, or two, feeling that VR was not supportive of their needs. Therefore, many autistic individuals and family members shared with us stories about the problems with the current VR eligibility process, starting with the need to self-initiate and attend, and then they also told us about these horrible experiences they had in this requirement to attend a large group orientation that was often overstimulating for them, that was like held with -- it ranges from 50 to 100 people across all types of disabilities. And that was kind of their first experience with the eligibility process, and they were honest to say that they ended up just walking out and stopping the whole process all together.

So, let's talk more about what the autism population needs, and then we'll move into discussing what to do about it. So, I wanted to first start off with a couple quotes taken from an article in the Autism Spectrum News. This article was entitled "Improving Vocational Rehabilitation Services for Adults with ASD", and it was written by Yvona Fast, an autistic self-advocate, in just this past November of 2019. So, she first writes, VR professionals need to know that a person can go to college, achieve a degree or two, and still have difficulty with specific tasks required for work. They need to understand that all people with ASD are different. Many are visual learners who, like Sheldan, can benefit from shadowing programs. Others don't learn by observation and need specific detailed instructions to carry out a task. Further down the article, she also writes, the most important thing to realize is that these individual process -- that these individuals process information differently. They can be easily overwhelmed by too much information and find many things about job hunting and the workplace confusing. These are concrete, literal thinkers, who focus on details and require explicit instruction and examples. You cannot presume that they understand what a job really entails just from reviewing a post, or that they can apply information they read to their particular situation. If tasks aren't completed, it may be that the steps are too big or that the individual doesn't know how to begin. The person might be too anxious to make telephone calls or visit a company to fill out a job application.

I think this article was very consistent with what we've experienced and what our community population has communicated to us over and over again, which is that the VR process is not yet welcoming to the autism community. I want to clearly emphasize the word yet, as this is a very general statement, and, of course, there are many individual examples across states or within states, within agencies, within people that have already started to make adjustments to fit autism needs.

But globally speaking, we can do more, and now for those who can benefit learning more and moving forward on the process of making adjustments, let's get started. I know I'm one of those. First, you'll note that recommendations for adjustments will be presented at what might be considered multiple ways or levels. So, you'll start to see how I'll be talking about changes that could be done at a system level, provider level, and even at the setting or environmental level. And we'll be starting to discuss moving forward in this seminar is really meant to increase our knowledge and information of autism, but also, more importantly, I would say to fuel you all for further thought. Let yourself figure out how to make your own localized changes and your own personal changes. Much of these recommendations come from our experience, much more than research, as the research is very limited in this area. And we don't really have the processes or procedures that can be termed best practices based off of study.

So, doing a quick kind of review, as it was explained much more in depth in our first webinar presenting on what are the special needs of the autism population, I wanted to quickly review and state that they are highly related within social, cognitive, behavioral, and communication differences, right? A few of these are illustrated here. They typically use a much more concrete literal communication style. They often have unique sensory sensitivities to any or many of the five senses. Anxiety is rather prevalent, that may be a social anxiety or even a specific or general type, and there's also often quite a struggle with taking initiative, including making calls or showing up to an event based on a flyer. These are related to those executive functioning skills. They can have other challenges with time management and organization, not using calendar systems or not having a good understanding of how and when to attend to a meeting, again, under executive functioning challenges.

Often, we describe autistic individuals as having splintered skills. This means that there can be issues, as we've just kind of named above, that are substantially impacting their ability to work and function independently, who at the same time have very high abilities in other areas. These high abilities often might be related to their specific interests. We kind of shorthand that and call it special interests. They also may be more general, like being very detail oriented or having strong memories. These memories can be strong and visual or auditory. I have one individual who came into my office at one point and said something like hey, where did it go, and I wasn't quite following where did what go. Well, and it turned out, they were asking me where a thumbtack went that was on my wall that was no longer there, having that level of visual detail and that memory.

Somebody else I just met a couple weeks ago let me know that they could listen to a song one or two times and have all the words of that song memorized and be able to resing the whole thing. It's an amazing skill, right? So, their brains may be more typically -- they typically process information in more logical ways, and they like to link information together, but we don't always follow that link. Their links may be a little more creative associations from what we notice right away.

They may also so-called see things differently or think outside the box, also, resulting in this high level of creativity, and these things can manifest in so many different ways, through the arts, music, but also through computer programming and analytics or through writing or design or even just these amazing organizational skills. So, it really can be so different, right, for each individual, but we can still do some more generalized adaptations, or as I call them adjustments, when we're interacting with the autistic individuals. And these can have a very large positive impact on them and particularly in this enrollment process in welcoming them to be involved in VR services.

So, if we first start with the communication style, there's a number of adjustments that you can make to more fully engage and communicate successfully with those on the autism spectrum. First one, be mindful of language, say what you mean and mean what you say. Watch out for that figurative language, like idioms or metaphors or even words that have multiple meanings, right? Saying a phrase like, it was so cool, well, right, their brains don't know right away are you talking about like, cool, like, it's like, you know, rad, like interesting, like nice or cool like the temperature.

We have -- there's a very kind of common assessment measure, the autism quotient. But we get so much feedback on one particular item the item asked for them to kind of rate whether they agree or don't agree on the statement of I am fascinated by dates. And that's really confusing to their brains, are we talking about dates the food, are we talking about dates like going out on a date, are we talking about dates like, you know, on the calendar, and they get really hung up by that question, because it can have multiple meanings.

Second item, be explicit about what type of information you're asking for. Don't just say, you know, bring in the records, state exactly what records are you talking about. Are you talking about an IP record? Are you talking about a medical record from their primary care doctor? Wait, are you talking about a past evaluation from an employee or from an employer, sorry? You want to ask many direct questions. Open-ended questions are much more difficult for this population and can be confusing.

So, ask, you know, direct questions and then ask them to tell you more. Wait up to 10 seconds for a response. This one is really important. They need some time to think. You also need to let them know that it's understandable that they don't have an answer yet, okay? I'll often use the phrase, take time to think, because you didn't know I would ask that. Some of them have fairly significant processing delays, and so those 10 seconds is really required as well for that -- for their brains to come up with that answer. But 10 seconds can feel like a really long time.

Let me give you a quick example. I'm going to ask myself a question and then give myself the answer. Dr. Baker What color is your room? Blue. So, that was only five seconds, but it felt like a quite a long time, and so by allowing for 10 seconds, it really can feel sometimes painfully long. So, a good trick is just to count to yourself, count to 10, so that you're allowing that time and you're giving your brain something to do to, because that waiting can be challenging.

Next, provide feedback, especially reinforcement during the conversation. They need to know that they're kind of on track or that they answered in a way of that you were looking for to keep that flow going and to keep them interested in continuing the conversation. So, you can say things like great answer or I like the way you thought about that question and gave a response. Also, prompt for additional information to understand their perspective. If they give you a response, and you're not quite sure what they mean, or they might have linked it to something else, ask for that clarification. Say, tell me what you mean by that, or tell me more about that. Use the think aloud method. That means communicate what you're thinking and or what you're feeling. So, if they do something or say something, let them know I'm feeling confused, because I'm -- my brain isn't understanding. I am not able to think about what you meant by that.

Demonstrate things, model roleplay, even use video modeling. So, if you want them to maybe communicate with somebody else within the enrollment process or with maybe an eligibility assessment, role play it out. What would they say to that other person and do kind of the each role, model at first and then let them try it and you be, you know, pretend to be the other person and give them a, you know, a chance to play it out before they have to go, you know, do that. And lastly, my motto, assume nothing and explain everything. They often need very specific detailed, clearly spelled out expectations. Don't think they -- assume that they, you know, know how to make that phone call, they know where to find that phone number. Don't assume that they can make it to the office nearby. Explain how to get there, walk them there, show them what it looks like, write things down et cetera.

So, now considering environmental support, these also are rather key in maximizing the functioning of those with autism. You might need to ask them direct questions to kind of really get a sense of that particular person, because it can [inaudible] vary quite a bit. You could also carefully observe and see what they might be reacting to, and then sometimes, you just have to make some smart guesses based off some generalities as a starting point, until you get to know your consumer even more thoroughly during this intake process.

So, here are some common changes you can make though. Prepare for each meeting with an agenda and or written questions and or visuals. It means if you can give those to the person ahead of time before the meeting, that's even better, but at the very least have it there at the time of the meeting, give him a copy of it, or write it on the board what this agenda is, what you're going to do during that meeting and what some of the purposes is.

Secondly, avoid meetings with them in areas that are potentially high odor environments, maybe near a break room or a cafeteria where foods can be -- smells of foods can be, you know, lingering or coming into your office area. Be mindful of yourself in smells, in colognes, or perfumes. Be mindful of the space and how it smells. Are there air fresheners or anybody using essential oil infusers or something like that that's bringing out additional smells. Even if they're lovely smells, even if the person doesn't necessarily find the smell of a disinterest, just the fact that there's these extra smells can throw them off and can make them feel more much more distracted.

Thirdly, offer hand -- only handshakes and understand that they may not be received but watch out for other physical touch. So, I know sometimes that we will, you know, shake somebody's hand and also sort of touch their arm as kind of just more of a form of respect or showing that we care or well, you know, put our hand on somebody's shoulder, and our intentions are good, but those can be really unexpected for them and difficult. They often, you know, understand that to give a handshake at a greeting and have learned that process and will tolerate the feeling of that. But all of these other kinds of forms of touch, especially with somebody who's new to them, less familiar to them, can be really off-putting and just get them into an uncomfortable state of mind that doesn't bode well for the other more difficult conversations you might be having within the eligibility process.

Look to provide fidget items and or moving chairs, maybe a chair that's a swivel type or that rocks a little bit. Sometimes, too, you can even just manipulate a chair by taking one of the little feet off and just so it wobbles a little bit, because that, having some new mints like that, could be very helpful for them.

Again, this is a new place, a new environment, and that can be comforting to be able to have some movement and to fiddle. I recommend using increased social distancing, much more of a kind of a two arm distance rule, rather than the one arm distance rule that can just, again, feel more supportive for them to have some more of that distance, as they get to know you and get to become familiar with the environment.

Also, be aware of external noises and sounds. You might think the fresh air from the window being open is lovely, but those noises outside can be overly distracting. So, often you need to close those, close windows, close doors, and restrict that kind of outside noise.

And then last, you know, be on the lookout for discomfort with fluorescent lighting or even high natural light areas. If somebody is wearing their sunglasses inside, that might be telling you that light is difficult for them, and they have a sensitivity to the extra light. So, be mindful of that as well.

So, moving on to anxieties, anxiety is a very common co-occurring issue for those with ASD, and the research shows rates between 60 to 85% of individuals with ASD demonstrate significant levels of anxiety in one or more areas. So, certainly social anxiety is a highly common type, but there's also a lot of more generalized anxiety conditions or anxiety over specific environments or specific items even. And generally speaking, just as newness and new place, new people can cause anxious reactions, so you want to be providing as much preparation, priming, and advanced notices as possible as kind of a staple meaningful adjustment for them. So, those are things like providing, again, information in advance, written and visual forms are preferred, even things like if you're going to change your office, you're going to meet a different place. Even if you move your furniture around, those are things they'd like to know in advance. Be explicit about what will take place during each interaction, again, and as much advance notice for that as possible.

If you can't get it to them before the meeting time, that's the first kind of thing you say, you know, welcome or thanks for coming and then you say what is going to take place. Prime them for all that is new, people, places, activities, if you want them to then be talking to somebody else, let them kind of see who that person is first or a real brief introduction first before they need to actually then go and meet with that other person. If you want them to go to a new location, walk by and let them see it first, before they actually have to go there and have that as a kind of a meaningful activity. Allow for those comfort items, sometimes they'll be carrying things with them. I had somebody who wore their backpack, and it was a rather large backpack, and they wore it sitting down, standing up, or walking through a narrow kind of passageway when we're observing a job location. And sometimes that's just needed, right? They need to kind of have that comfort item with them until they truly feel comfortable, and then they'll maybe be able to start putting it down.

Slow down the pacing and provide increased processing time. That's a really important one to support this anxiety. I'm going -- talking kind of quickly in this webinar, but we would want to slow down our verbal pacing with this population. Again, keep providing encouragement and praise, as they take one step in the kind of clinical world, you know, we'd call that a graded exposure, and we would want to praise them for each step towards, as they expose themselves or towards facing their fears.

And so, we want to be mindful of that in this VR process, enrollment process as well and reinforce each step along the way. Keep establishing familiarity and really look to minimize change as much as possible, be thinking about that even ahead. We had a situation where we knew one of the vocational counselors was going to be going out on maternity leave in two to three weeks. Well, we don't want to give her any new autism cases, if that's the situation, because that makes it very difficult for them to have to change again so soon and so quickly.

So, you know, thinking ahead, even with things like that, and then be aware that anxiety can often look like an attitude problem or uncooperative or, you know, behavior issue. So, be mindful of that. If you see those kinds of things, it most likely is maybe, you know, anxiety that's going on.

So, moving on to supporting social uniqueness, autistic individuals may not want to shake your hand, as we said, they may not want to look you in the eye, or they may even posture themselves during a conversation away from you rather than towards you. And these unique social forms are not to be interpreted as any direct relation to their abilities or to their intellect. And you want to be careful not to be viewing them kind of personally as well, right? It is part of the autism spectrum, it is part of the diagnoses, and we have to be very careful in interpreting them incorrectly.

We also want to watch out and don't interpret it as a motivation issue. Basically, social awkwardness or these social mishaps or misuses are part of the condition, part of what to expect, and hopefully, they'll maybe get better over time, even just improve with less anxiety, as they are more comfortable and familiar with you. But, you know, be really aware that this is part of it. You know, obviously, in general, in order to qualify for services, the OVR must determine that you have a physical or mental disability, your disability causes a barrier to employment, you have the ability to benefit from services to prepare for, obtain, or retain employment and that you want to work.

So, certainly these social challenges are definitely related to their disability and definite causes to barriers to employment. But you want to be very careful to not interpret their lack of social graces as this poor motivation or this disinterest in wanting to work. So again, like ask those types of questions directly and remember, assume nothing. So, in particular, be open minded about these social expectations, right? Be mindful about your own interpretations and don't take these communication for pause or blunders personally.

I had somebody tell me one time that I sounded rude. So, instead of taking it personally, I just asked for clarification, can you tell me more about that? What makes me sound rude? And it was just my voice. I was coming off of a cold, and it was a little scratchy, and that tone in their ears was interpreted as rudeness. But it wasn't anything in terms of the statements that I made, or I even asked about my facial expressions, and it was really just the actual tone. So, watch out for those kinds of things, and, again, ask for clarification.

Also, understand that the sufficient social abilities in these eligibility meetings is not a predictor of employment and service needs. Acknowledge, again, the value of supportive people or even animals or objects for the individual that can help them feel more able to socialize. You're going to see that these social conventions are likely not demonstrated, but watch out for those interpretations, and certainly, please, don't interpret them as not being motivated.

So, executive functioning challenge is another big area, right? And there are certain accommodations we can do to really acknowledge that this is a challenging area for them. These executive challenges can make it hard for them to even complete and turn in the application or complete the first task in the intake towards eligibility, like showing up on the right day and coming at the right time or attending an orientation. So, you want to be thinking more creatively and taking on more of the initiative of setting these kinds of things up for them. It's very difficult for an autism population or an autistic individual, I should say, to call the VR offices to schedule an intake meeting. That is something we have heard over and over and over again, that that is an extremely difficult thing to do and really limits the enrollment process. So, they might require these proactive contacts for the VR related activities, and that's actually part of what's happening with the transition age youth and happening within the school systems is it's a lot of proactive enrollment that's happening, and that's working a lot better. They'll need support with the prospect of memory, like emails and text reminders, calendar invites. They need to be guided to use their calendar app, and those things need to be -- somebody [inaudible] for them first and put in there [inaudible] to create routines for meetings, so that the meetings are happening on the same day, the same time, the same place. That goes a really long way for this population. It's very hard for them to change meeting times quickly and or just have it on different days. So, look for ways to have those routines.

Tell them in the meeting to take notes, give them paper, give them a pen, have them take out a notebook, have them take out their calendar or they'll pull up their cell phone and enter something in their calendar right there with you. Ask them to write something down as a to do list right there with you. State out loud what should be written down and provide information in steps, step one, do this, step two, do this, step three, do this. They really need that kind of that organizational support, even from the very beginning. Request them to state back what they're going to do, so that you have a sense that they did encode it all or they did write it all down or they did understand it. So, have them tell you what is step one, what is step two, and also, again, be aware that these executive functioning problems can look like motivational issues or behavior problems. But it's really, the core is the is the executive functioning and or in combination with anxiety or social challenges.

So, last but not least, you want to adjust your practices, so that you are purposefully taking time to gather information about their special interests and talents. You really want to look for ways to match their interest, their skills, their strengths within this, you know, job pursuit activities, and this will definitely improve outcomes, and we do have data on that. But it's not always easy to learn and understand what their strengths and their special interests are. They are sometimes not so good at knowing it themselves. It's just something that they do, but they don't always understand that it truly is a strength or that it truly is this unique ability that they have. So, they don't always just -- they can't quite explain it. So, you have to kind of get at it in some other ways.

Maybe, you know, asking more questions, what do they do in their free time, what do they do when they're alone and certainly through observation as well. Look for things that they have, their personal items for themes, right? Do they do they have a shirt with an airplane on it and an airplane backpack? Is that something that they're particularly interested in is airplanes, and do they know a lot about it? And have they ever, you know, learned anything mechanical about it and then dive into all that they know. Inquire about how much time is spent on some of these activities each day to get a sense on how, again, their skillset, how much they know about it, how good are they at it by spending a lot of time on it, are they kind of really enhancing their skillset? Allow for these, what I call, one-way discussions to gather more detail.

So, let them kind of just talk at you and tell you a lot, because you can kind of learn a lot about their interest, as they go on and on, potentially, you know, talking about what they like to do. And then really start to activate your brain, right? Think creatively of how these special interests relate to employment options, how they might even relate to meetings with them, and how you can bring those topics back into future meetings and help them feel comfortable and, again, engaged. Maybe you can have an item that you bring up the next time or a picture you -- that you show them related to their interest to get that engagement going and that conversation going as part of that eligibility assessment process. And then identify those skillsets related to the special interest activities. One of the [inaudible] one more excerpt from the Autism Spectrum News article, and it's written like this. Steve describes his experience with the state VR office. They would help me look in the classifieds and send resumes to different places. It was kind of bizarre that for three years they kept asking me what type of job I was looking for. He had a few interviews, but with meager results.

Finally, they said his time was up. So, from his perspective, he thought it was bizarre that, you know, why are they asking me what kind of job I'm looking for? And they never, right, he didn't have that experience of anybody linking, asking him what he likes to do or what he already does and helping him that get linked to potential jobs and job markets. And so, that became frustrating, obviously, for both parties and something that did not lead to a successful outcome.

So, let me share with you some of what San Diego has done, and we are very lucky to have what we call a research community partnership. And we have called ourselves the ACHIEVE Group. ACHIEVE stands for active community hub for individuals with autism to enhance vocation and education, and what this is, is a dedicated group of community stakeholders, including a research team led by myself and doctors Caren Sax and Lauren Brookman-Frazee, along with our VR administrators, our vocational agency leaders, disability services administrators, other educators and professors within secondary and post-secondary settings, disability counselors, family members, and autistic self advocacy and transition age youth with autism. And we meet on a regular basis, and they help really guide us in a lot of different areas, certainly within research and pursuit of different grant opportunities, but they also really guide us on what truly the community needs, and what they made it very clear to us was that our community was not welcoming yet to enrolling the autism community in VR services. And many reported that it was -- there was all kinds of barriers basically coming out of this process, this eligibility process. They felt overwhelmed at that orientation. As we had kind of mentioned before, they were -- did not feel able to initiate phone calls to the VR counselor to start this -- any of these processes or these conversations. They did not understand how to communicate their needs, and so they weren't always qualifying for services or certainly not at the level that was truly necessary for them to be successful.

And so, they weren't kind of leveled correctly in this assessment process. They also felt like they didn't even really know what VR services did, and they didn't know how to activate it. So, what our community did is we first created a brochure. We called it an enrollment guide. So, we -- you can see there the front page of the brochure, it says quick guide to enroll in the Department of Rehabilitation. We go by the acronym DoR for adults with an autism spectrum disorder and some, you know, kind of encouraging graphics there. Let's get working, the dream job next exit on that street sign, and just a real kind of priming, again, kind of letting them know what DoR can help with, finding a job, keeping a job, learning job skills, preparing to work, things that would hopefully make sense to them. And then you see the very last page of the brochure just to demonstrate that it was clearly a full community effort. We had lots of partners who gave input and feedback in creating this brochure, and once you open the brochure up, the first pages on the inside was designed with steps. So, we used that step approach and we clearly walked them through all that was going to be happening. So, we provided -- we provide scripts what to say in there. So, when they're making a call, exactly what to say. We're priming them for the process, what's going to take place. We are trying to balance this, and it was always such a careful balance, and we got lots of feedback from our community of how to provide this balance of giving them details of like scripts what to say and knowing what is going to happen, but not too many details where it appears overwhelming.

So, we're really always working on trying to strike that balance. We got a lot of feedback of feeling overloaded by too much information. We also tried to use the colors. You could see there are different colors and different font changes as visuals to help break up the information, and they can help provide some emphasis and get that -- the kind of the strengths in their visuals. But we also learned how important it was to prepare them for the type of information they would need to share, as many autistics felt it was invasive, when the intake counselor asked questions about them. And they often didn't answer or said I didn't know to -- as responses, because they weren't prepared for those kinds of conversations or prepared for those kinds of questions. We also try to give specific directives in step two and step three of what to bring, again, kind of get -- make it a little bit more explicit. And you can see that we try to communicate-- That they need to kind of tell us their challenges in obtaining or maintaining work. We've learned that too many of them were not, again, found eligible for services. These, especially the high functioning folks, weren't at the correct level, because they didn't really share the problems. They didn't really share the concerns that was going on, and so to kind of further enhance that sharing, we then went to this kind of the next pages of this brochure here is we created -- we generated responses for them that they could then use more of as a checklist of different challenges and weaknesses, because we've learned that that was really hard for them to just kind of generate on their own in conversation. And when they did try to, the -- it wasn't really organized very well, and so then the VR counselors had a hard time tracking where they were going. It was a bit all over the map. So, we put some kind of organization around these challenge areas and gave them some examples for them to be able to just check off, and that seemed to really help as a guide in what to communicate about. It also gave them an opportunity for people to give them feedback into check off some things for them, and they could bring that in as well. So, it was a way of bringing, you know, a fair amount of information together in one location.

We then said, you know, hey, bring this actual, you know, brochure back in with you for the eligibility assessment discussions, and it, you know, and just hand it to your VR counselor and show them to get conversations going. Then, we were -- added a few more things into this brochure. These, the final pages was a section on helpful tips, providing specific information explaining, again, what the Department of Rehab is and what services particularly they offer. We learned, again, from our community that very few individuals and families understood what VR was, and they really wanted some more information about that. And we know that this is, you know, they have better understanding each year and especially now with the focus of enrolling in a younger age and through the high schools that that's already in our community has grown dramatically. We also just wanted to, again, kind of give as much expectations, be explicit about those expectations as possible. So, we explicitly state that parents or other support persons are welcome during the intake appointment. We found that it was very helpful to have the support person, but that they thought it was an adult services and that they were an adult now and that they needed to come, and they took that a little bit too literally of coming alone. In fact, we learned often that parents were sitting in the car waiting, instead of joining the meetings. So, we added that explicitness to our brochure.

We also learned that they were concerned about disclosing personal information, and so we wanted to be explicit to say it's all confidential and highlighted that through a different color. We learned that the counselors weren't always asking specifically if the person had autism or so -- and it wasn't coming out early enough in the process. So, we then added that, you know, hey, tell them you have it and say it directly as early as possible, because that then allows for everybody to make those adjustments, right, and for that process to go more smoothly.

Again, due to perspective taking challenges, this population doesn't know how to anticipate or predict what information is needed or helpful. So, we, you know, told them to take time to think and not just respond I don't know. What we learned was happening way too frequently. We learned that individuals being asked novel types of questions, and so that's part of why they would say I don't know. So, we wanted to guide them through that a bit. We also wanted to specifically address this sensory overload issue that we've heard so much about regarding the orientation. So, we wanted to let them know that they don't have to go to the orientation. They can skip that and still pursue. Many of them felt like they -- if they didn't go to the orientation, then they had to stop the process of enrollment. And we -- it was amazing how many had stopped because of that, and then we just wanted to give them some motivation there at the end, right, kind of end on a positive empowering note. They're remembering this is a team effort, and we're here to work together, and without that visual image there, this [inaudible] the advice and help and support and guidance, so that they know that this isn't something to be so fearful about, or it shouldn't be punishing for them.

And then, you know, we, again, just did a short bullets there of some variety of the DoR services that are available and then just let them know about a particular program that we have going on in San Diego called Success, so that they're eligible for participating, which is a soft skills development program that was specifically designed and tested for the autism population.

So, we have just a little note about that, and in future seminars, I'll be presenting some more information about that program for the rest of you. So again, kind of going back for a bit on addressing this community access issue, so remember that this autism population within the VR services across the nation is not representative. It's just too homogeneous, and we need to impact that. So, the brochure is kind of one idea that we did in San Diego, you know, some of you may want to adapt a similar process or I'm happy to share more information with you, or if you want to even use our brochure as a template, please do so.

But unfortunately, we don't have a lot of research on how to, you know, improve this access and how to improve this awareness. So, we're all in the kind of trial and error part here, but we also learned a few other things, right, from this data, remembering that, you know, VR counselors assign two codes for the type of disability a person has or either an impairment. The reason that the employment is difficult code as well as the cause of the underlying condition that causes the impairments. So, here's data, right? We know the cause is all autism, but now we get a sense of what were they coding, and it's because it's consistent with the adjustments we just talked about, right? They're coding them as having cognitive impairment and psychosocial impairments, as is predominant. So, we have to keep that in our mindset, right? And we have to keep remembering that that is consistent with the autism diagnosis, but that does require us to make changes in our service system for them.

A large percent, right, also are not continuing with services once found eligible, and we've learned that 46% are refusing further services. So, you know, we don't have a good understanding of why, exactly why are they refusing them. We don't have any qualitative study on a large scale that's letting us know that, but, right, clearly something with the engagement process, something with the kind of our way of communicating with them and really helping them understand is not going well. And they're, you know, often reporting things like being just assigned to apply to jobs or assigned to attend workshops or assigned to send emails, updating the counselor, and those they're not seeing as helpful. In fact, those are things that are extremely difficult for them to do. So, this data just kind of, again, reaffirms what we need to be doing, and that we all need to take action, right?

This is like a call of action to not only understand these dropouts, but to truly make some system changes and provider level changes and environmental changes to match this ASD population. And it requires us to be creative and borrowing from any other successful models that we can.

So, in speaking of that, I've pulled together some potential creative ideas that is borrowing from these other environments and particularly the military. So, here in San Diego, we've got a large military presence. We've got Navy, Air Force, Marines, and so they're always recruiting, and I learned more recently and attended one of these out of curiosity, but what they're doing is marketing these services is they started with enrollment guides, kind of like what we did. But they've moved on from there, and they are now hosting what they're calling video game expos, and they are allowing folks to come in and try these new releases of video games. And they are partnering with the video game developers to create these places where they can kind of come and game for a while, and then they've got recruiters and tables kind of around in that population in that area, making it easy for them to come and ask questions about the military. And so, they kind of entice them to come with the game exposures, and then they're present, providing them with more information.

And I thought, wow, what a great creative idea, right, for an autism population. We know hey, they're high gamers as well, wouldn't that be, you know, a neat, innovative way to go? Other ideas, right, creating more welcoming environments, this idea of mobile meetings, Child Welfare Services has done this for quite some time. They're very mobile. They go to the people. They don't expect the people to come to them. So, I thought that was also a very interesting creative idea of how can we be more mobile and we can go to them and we can meet them in comfortable places, their home or a community, a setting that they're already used to and take away some of those barriers?

In fact, that's really what is being done with the take group. They're being recruited and enrolled within the school setting, where they're already there and comfortable and familiar, and it's working. So, let's be a little more creative about that.

And then lastly, I thought, you know, engaging with our community groups more. Can we be creative in that way? Can we be pairing up with religious groups in the community or healthcare clinics or ABA providers? We know a lot of our adults in San Diego are participating in recreation programs. So, it's about finding them. That's what we learned is like how do we find them, and by linking with some of these groups is where we can find them. And then we can maybe combine some of these models together, but the task really is for us to be creative and innovative, and let's start to really establish some new models and some new systems. And to end, I wanted to use this as another form of motivation to make changes, because now is the time. But you -- what you'll see on this slide is really some disappointing data about our autism population, and this is particularly describing what are they currently doing and what are they currently accessing. So, here you can see that only a few are employed, 11%. Most live at home, 96%. A quarter of them are uninsured, only about a third of them receive Social Security income. So, they really don't have any money coming in, and taken together, right, we see that this population is basically in poverty with little public services, staying at home, stuck at home without work and without, you know, involvement in the community. So again, you know, use this to activate yourself to make some changes, and we'll be there to assist you along the way.

So, we do have two more seminars or webinars. We are under development right now. That will be coming out over the next months, and the two additional topics include tailoring assessments and individualized plans for employment, those IPE plans for consumers with autism, and then our last one in the series, we'll be talking about intervention services supports and accommodations for individuals with autism to specifically enhance their competitive integrated employment outcomes. So, we hope that you stick with us and attend each of our webinars in this series. Thank you very much and feel free to reach me at any time.