

Association of University Centers on Disabilities
Transition in Autism Spectrum Disorders
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>> Hello and welcome to Transition in Autism Spectrum Disorders, a Webinar from AUCD's Autism Special Interest Group. My name is Sarah DeMaio, and I'm a program manager here at AUCD. I would like to thank you all for joining us today. Before we begin, I would like to address a few logistical details. We will provide a brief introduction of our three speakers first, and then after all three speakers have been introduced, there will be time for questions.

For participants, audio lines will be muted throughout the call. I would also encourage you to mute your lines on your end. However, we will unmute phones one at a time during the Q&A period at the end of the webinar. To indicate that you want to be unmuted, press star and then pound on your phone, and you'll be unmuted to ask your questions.

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You can also submit questions at any point during the presentation via the chat box on your webinar console. You may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please note that we may not be able to address every question and may need to combine questions in the interest of time.

This webinar is being recorded and will be (audio echoing) -- AUCD's webinar library. There will be a short five question evaluation survey on the end of the webinar. We invite you to provide feedback on the webinar and for future topics.

Please welcome me in joining Eric Moody, moderator who will introduce today's presenters.

>> Hi, everyone. It's a pleasure to have you here to talk about what I think is a very important topic related to autism. This is, as Sara said, all about transitions for people with ASD to postsecondary education and employment. We have got three great speakers lined up for today, and I'm going to introduce each one and then give each of them an opportunity to speak. And then, as Sara said, we'll have time for questions at the end.

Our first speaker is Liz Getzel, and she is the director of the Center on Transition Innovations at Virginia Commonwealth University's rehabilitation and research training center. She has experience in transition of youth with disabilities to career or employment, planning for careers of those with autism, and for veterans with disabilities. She has published widely on transition, career development, postsecondary career development and employment, and is the coeditor of the book *Going to College: Expanding Opportunities for People with Disabilities*.

Our second speaker is Michelle Thompson, and she is an occupational therapist who has been practicing in early intervention school based and adult home health for 30 years. She holds a BA in Spanish from Indiana University, a master's of science in occupational therapy from Virginia Commonwealth University, and certificates of Leadership, Education, and Neurodevelopmental Disabilities from the Virginia LEND and autism spectrum disorders from VCU. She volunteers on the Board of Directors for Mosaic, which is a private nonprofit organization that provides housing for adults with developmental disabilities. She is currently a doctoral student in special education disability policy at VCU, where she is researching the implementation of the WIOA Act on increasing employment for individuals with disabilities, including ASD.

Her career is specifically exploring the pre-employment transition services, or Pre-ETS, as they are often called, intended to support the school to work transition as well as exploring multiple stakeholders' perceptions of supports and resources needed for interagency collaboration.

And our third speaker is Julie Taylor. She is an associate professor of pediatrics and psychiatry and behavioral sciences at Vanderbilt University Medical Center. Her research focuses on the factors that support and promote transition for adults with autism and their families. Her work has been funded by Autism Speaks and National Institutes for Mental Health. In 2015, she was appointed to the United States Department of Health and Human Services' Interagency Autism Coordinating Committee.

Thank you all for agreeing to present with us today. And with that, I'll turn it over to, first, Liz. >> Excuse me. Thank you, Eric. I think my sound is good. Can I get a little feedback?

(Audio difficulties) -- to talk with everyone today, and I appreciate this time to talk about some of the work that we are doing in the center for transition innovations at VCU.

So, what do we know about youth with ASD? And you'll see on some of the slides -- there is the -- at the end of the presentation. As you can see, youth with ASD are really not entering the workforce in a way that we would like to see. A high percentage have never worked, and if they are working, it's in part-time low-wage jobs, and with the national longitudinal study of 2012, youth with ASD is one of three groups that were identified in the survey work, follow-up survey work that were the least likely to prepare for college and employment, and they are left very much -- very much less likely not to work in high school, which is a really important part of what this whole transition is from secondary ed to out in the community.

What we do know, in terms of what some of the predictors for successful transition, are career awareness. As you are probably aware, there is college and career readiness now being talked about quite a bit in the field and in the literature, which is -- which is a strong predictor for postsecondary ed and employment transition.

Community experiences, being out in real work and in the community participating is a strong predictor for employment.

One of the most, strongest predictors across the board is paid work experience, paid employment prior to exiting high school, which is very much a strong predictor for postsecondary ed employment and independent living. Self-care and independent living across the board is very important, and inclusion in general education classes. So we know that there are -- there's really evidence-based and strong documentation of what are successful predictors, and our work here at the Center really revolves around what these predictors are, and then we can move into the schools with demonstration and technical assistance and training to assist youth with disabilities, and students with ASD are certainly

part of what we serve.

So the Center on Transition Innovations is the Virginia portal for all things related to transition, and as you can see, really our mission and our goal really revolves around employment to the fullest extent possible, and that means there are different ways that we look at employment. That could be secondary education, higher education, or going directly into employment. I do want to say that within the RRTC, where I'm located, we also have the office of the center for academic excellence, which we collaborate very closely with them in our work, and also at VCU, the partnership for people with disabilities, which is our youth set. So there are uniform organizations that really we collaborate with and work very closely together in terms of the services and supports that we provide.

Today, I'm really focusing on some of the work that we have done through state and federal funds on youth with ASD, some very specific to youth with ASD, but also some that are transition-related, where youth with ASD would be involved. So we are looking at family members and the transition process, career awareness, employment, higher ed, and then how some of these activities, demonstrations, research that we have done has moved into some of the online resources that we are providing, as well as direct training.

A few years ago, we held focus groups across the state of Virginia really interacting with family members representing ethnic or cultural minorities who have a son or daughter with ASD, and we wanted to find out from them what some of their experiences have been in the transition process. Some of the themes that really came out of this, as you can see, is that the family members, especially the parents or guardians of the individual with ASD really felt caught between the cultural expectations and norms of their particular culture in relation to really wanting their youth, their young adult to successfully live in American society. So they felt very much -- there was one participant who said, you know, that her mother, the grandmother of the son or daughter, didn't know why they weren't teaching the native language to the individual and why they weren't teaching all of the aspects of the culture, and they felt caught because they wanted to pass some of that, of course, on to their son or daughter but really are striving to have the individual become really part of the mainstream, if you will. They really are concerned and really want their son or daughter to work. They are concerned about the lack of life skills, and for the transition process itself, they still do believe that the planning does need to be paired with the cultural norms of the student and family, as well as school personnel and others to really understand the unique makeup of the family and sort of things that interpret decision-making that take place within the family and other aspects of family life that could shed light in terms of really helping in this transition process. They really expressed a need for a sort of more cohesive and cooperative communication. They wanted to find ways to communicate with the schools and some of the teachers, perhaps in a less informal setting so that there could be that type of understanding gained.

We also did structured interviews with two and four-year college students on preparation for college, and this sort of moves us into the career awareness area in accessing transition. When we talked with these students, they indicated their family members really are a frequent source of information and feedback about sort of career steps or awareness or potential careers, although they did say that other sources were their own personal research, maybe on the internet, classes that they had taken in high school and college. Work experiences were also brought up.

Career centers were the least likely source of information and support, and we really have been trying to tighten that relationship with career centers. One student said I don't know why I

need to go to a career center, because I know what I want to do. So we really are trying to work with college students to educate them about what career centers can offer and the various services that can help them further into their career. They really felt they needed more information opportunities, job shadowing, mentoring opportunities, internships, and work experience. One thing that was really expressed is they really felt they needed to develop a disclosure plan to really understand how they can negotiate those accommodations in the workplace and have a better understanding of what those accommodations would be.

There was a recent study that was conducted by Susan White. She was at Virginia Tech. She's now at University of Alabama, looking at the transition process, the UA-ACTS program, and she has been doing some research on this. And during that time, she also did some work with focus groups, and I am sure many of you are aware of the challenges that students do face in terms of reduction of social support, the academic stress, and sort of those difficulties in balancing daily living responsibilities and social demands. Our work here at VCU, we have done work with the number of students matriculating, really being able to live in a dorm and handle all of the responsibilities and sort of social engagement, on top of wanting to do well in school, and really sort of outside of -- for many who are maybe not in their home communities, reduction of those supports becomes very critical.

So, that's sort of some of the -- just a very small example of some of the work that feeds into some of the things that we develop in terms of demonstrating and putting together online resources. So we know that looking again at career awareness, that the earlier career awareness activities are infused in a student's life, a student with ASD, the better that they are as they transfer all the way up or transition, if you will, all the way up through from elementary to middle school to high school and beyond.

We are currently looking at a process that does build on the discovery process as part of customized employment, and we call it Discovering ME, and we have really infused those principles of discovery that have designed it so that it fits within a school environment. So it is something that we have been testing in middle school. We hope to push to elementary school. It really does focus on the interests and skills of students. It's very much a team approach, so family members are an integral part of this. School personnel, community agencies, really anyone that plays a role in the student's life are invited around the table, and the focus is what are those experiences that could be happening now in the home, school, and community to really build those career awareness sets of skills and looking at the 21st Century skills and areas, occupational areas that are really infused as part of this process, so focusing on home, school, and community, and really looking at building those experiences and knowledge.

We also look at students who are getting a regular diploma, and as you'll recall, one of the things that especially -- it's sort of across the board, but in particular, the statistics that we looked at for paid work experience prior to exiting high school. So we have -- we are modeling a program called Start on Success, and we are looking at individuals right now prior to graduating high school. They are on track again for a regular diploma, and oftentimes some students fall through the crack. So it's a first coupling kind of process. It's a two-semester program right now. The first-semester individuals take sort of a work readiness class that they receive credit toward their diploma. That can be through CTE or another class that is looked at that they would give credit for sort of the employment or work readiness.

And then the second semester, they spend a big part of their day, for up to 16 weeks, in a paid work experience setting, so their employer involvement, rehabilitation agency involvement, and right now this particular program is funded as a Pre-ETS activity, because it

meets many of those services that need to -- that are part of the Pre-ETS. So this is -- we see a number of students going into college, perhaps two-year and working part-time. We had an individual that, in one of the larger city locations, that we are working with the high schools, the high school -- the division determined that the students would have to get to their internship site on their own. There's a lot of transportation training and that kind of thing, and a young man with autism who had been pretty isolated in his community, because he was unaware of the transportation and how to use it, and at the end of the internship he could use any of the transfer systems and had been going out and doing many more activities in the community, so that was really a wonderful benefit for him.

Another initiative that we are working on is preparing for college and/or employment, supported employment initiative, and this is looking at, in many respects, students who may end up needing a more customized approach. We are providing technical assistance. Really, the whole groundwork of this is work based learning and those components of work based learning and getting those students out into the community, and the idea is that we would like to get more students out into the community, into employment, like any youth who goes through high school, and we are hoping two very large school divisions that we are working with now, assisting them in the process of implementing work-related supports.

And also, then at VCU, within our center, we do have a college for students who receive a special diploma. It's called ACE-IT in College. Students are on campus, taking regular courses for audit. They have an education coach for support. It's very employment-driven. They work part-time in student worker jobs all across campus to earn money. We have great collaboration with our Department of Education here and our vocational rehabilitation. It's very, very student-centered, person-centered planning. We do a lot of career awareness. The last semester they are with us, they go into an internship. Currently with students, we have been implementing this since 2010, and we have 95%-98% employment outcome in their career choice and interest. What we are trying to do is help them build a career, not going just, if you will, into a job. We have one student who is very interested in working with children, for example. She went through the program. They earned a School of Education certificate, and she started out as a nanny and then decided to work in a child care center but really wasn't happy with that, and then into a position with Head Start where she is earning her certificate through this program. So this is a way for students to really look at career building, and we find their academics, their reading levels, because of exposure to technology and other supports, that their comprehension or their word recognition sometimes goes up two to three grade levels during the time they are here.

And I know I need to be mindful of my time. I wanted to just touch on some of the online courses. We do provide what we call a Transition Changing the Outcomes course. And you can see that we have many of the topics that we have included in this are online, at no cost, that we provide as professional development for school personnel. Family members can take it, agency personnel as well.

We have something, Get Ready for College. This is a free course also available to anyone, and it is designed for students to learn about postsecondary education and their preparation for it. So, it could be a facilitated opportunity in a class, or students can do it on their own. We have had students, family members, service people take it. College students have taken it. So it's really based on a lot of knowledge and information that we have gathered over the years on being successful in making transition into college.

We also have done a series, and I would encourage you to go to our website. We have

done several series of webcasts, webinars, videos, and fact sheets on students with autism in the community, and in particular, this particular series is on college, looking at college students' experiences, their families, about the transition to school, school counselors' and teachers' and college professors' experience. We call them Fast Facts, which you can see, and this is available on our website as well.

We also, for students who will be in need of more intense employment service supports, we go through a whole series of what we call clinic assessment, and you can see it goes step by step in an overview and then step by step on the process. So we are helping school personnel really look closely at performance and tasks or consists on employment work site, so there is even more gathering information that can then lead to career choices.

The last is I have been involved with NTACTION, and there was a technical work group. We looked at research-based resources, and this is still in the process. I know that manuscripts and conference presentations will be coming. It's a very, very comprehensive annotated document on resources for teachers, families. And anyone who wants to really look at what's happening can program ideas, so we think this will be an invaluable resource for researchers, families, personnel, and others. And I appreciate your time so much. I hope I haven't gone over too much. Thank you very much.

(Quiet speech away from microphone.)

>> Eric, do you want to try introducing her?

>> Yep. Can you hear me now?

>> Yes, we can hear you now. Thanks.

>> Okay, great. Thanks, Liz. And just so everybody knows, I see that people are putting things in the chat, which is great. I'm going to put those in the parking lot and be sure to bring those up during our question/answer. Thanks, Liz, and now we are going to turn it over to Michelle and just talk about Pre-ETS more generally. Thanks.

And it looks like Michelle needs to be unmuted too. You should be ready to go, Michelle.

>> Can you hear me now?

>> Yep.

>> Okay. Well, thank you, everybody, and I really appreciate being able to share with you some of the new information I have learned in this world of transition and autism. As my introduction said, I worked, you know, 30 years in the field with babies and early intervention through K-12 schools and then on into the communities. This is really important work, but I am realizing that people aren't familiar with this new language we are throwing around, it seems, Pre-ETS. It rolls off our tongues so easily, but I am not sure that everybody is all caught up with the language. So, really it stands for pre-employment transition services for students with disabilities. And I just really wanted to start with our good foundation of transition. The importance of transition is for students with disabilities to learn skills to maximize their independence and self-sufficiency when they go out into their communities as adults. That's a good foundation, and the picture is a little boy I have worked with over have many years, and his mom gave me permission to share his picture with you.

So, there is again just some bullets for transition, very important to develop self-determination and advocacy skills. We are working on this, but what is the new part about Pre-ETS? It really comes from the Workforce Innovation and Opportunity Act of 2014, known as WIOA, another term that I'm finding people are just kind of slinging around and not really defining. The people that I, you know, study with and work with at VCU are familiar with these terms. People that work in voc rehab are familiar with these terms, but I'm finding that parents

aren't as familiar with the language as I would hope they would be. So I'm going to give a little bit of background on the WIOA law. The WIOA law was really designed to help job seekers access employment, education, training, and support services to really better succeed in the work markets, in order to match employers with skilled workers and to compete in the global economy. And that's really what we want for our loved ones, our students, our community members with autism to have. We want them to have competitive integrated employment and to be competitive in the global community. So this law really speaks to me. I really appreciate it. It is an extension of the Rehabilitation Act of 1973, so it just expands that Rehabilitation Act and brings it even more in focus for our students with disabilities and really focuses, once again, on competitive integrated employment.

So, if you start with definitions, the law has a lot of terms within it. Who is a student? So, they use the word student. They use the word youth. So let's look at student first.

So, student is an individual between the ages of 16 and 21 who is currently enrolled in an educational program and has -- you know, getting IDEA services under an IEP or getting services under a 504 through the Americans with Disabilities Act, and then a youth with a disability is a broader term under the WIOA law. The range is broader. It's ages 14-24, but it really doesn't look at Pre-ETS, because a youth with disability doesn't need to be in school or getting special education services or disability services in school. This is very confusing to me, and I'm still a little bit confused. I have to keep going back and reading it. So, anyway, let's move on to the next.

So, what are the required pre-employment transition services? There are five that are required, very, very helpful. Job exploration counseling, work-based learning experiences, counseling or other opportunities for enrollment in comprehensive transition or postsecondary educational programs at institutes of higher education. And Dr. Getzel talked about that with her program with ACE-IT, and workplace readiness training and instruction in self-advocacy. I feel like these are things that people have been doing, but now they are written down and they are required, and it is a good thing.

And then there's several additional Pre-ETS that are authorized but not required, and these also are good. Improving transition from school to education or employment, they are helping agencies provide support for the required Pre-ETS. They are providing instruction to voc rehab counselors, school transition personnel, or other people supporting our students. Disseminating information, providing evidence-based findings to support policy and practice and personnel preparation. All of these things are very, very important, and I'm glad they are included.

But when we look at what is coordination, and I like this picture, because it's like remember the person that we are helping and the whole purpose of Pre-ETS and transition planning and coordination is so that our students with disabilities, with autism, can go out into the world, increase their independence, increase their employment, so they want to keep the focus on the person.

So, interagency coordination and collaboration, what I would really like is this is now -- it's now mandated, which I guess we had to come to that, but it's a good thing. We are really focusing on getting the agencies, the K-12 agencies, voc rehab, the independent learning centers, the private places, everybody needs to coordinate and work together. So the Pre-ETS funding can be used for this coordination, which is really good, and the coordination can include attending an IEP meeting or a person-centered planning meeting, working with local workforce development boards, the one-stop centers, employers, to try to really hone in and

develop internships, summer employment, apprenticeships, just to name a few options that are available.

And then, again, to research. I'm on a student research team at VCU that's looking at what's going on, and I can tell you from what I hear, that's what's going on. People are still looking at what's going on. It's coming together, but every state needs to develop their plan, and they are working on it. I have nothing to report right now, as far as what is going on, but there's some good questions here. What are stakeholders doing to implement the Pre-ETS services for students? What interagency collaboration and coordination is working? What's not working? What additional supports and researches are working? What's needed? Lots of questions.

I want to share with you this good resource that we have found, and I have gone back to many times, Workforce Innovation Act Technical Assistance Center, and the URL is www.wintac.org. So it might be just one more resource for you to go to. And I have got my references here, if you want to take a look at it, and I'm happy to answer your questions at the end. And thank you very much.

>> Thank you, Michelle. That was a great talk.

And again, we are getting some questions that I'll put in the parking lot until our Q&A session.

And next, we'll turn to Julie. So, take it away.

>> All right. Can everybody hear me?

>> Sounds good.

>> Okay, great.

So I'm going to be talking a little bit about what we have learned from our research about ways to improve transition outcomes for youth on the autism spectrum. So back in 2004, I started my postdoctoral training at the University of Wisconsin, working on one of the largest longitudinal studies of families of adolescents and adults on the autism spectrum. And these families, especially for families of adolescents, one question came up over and over again, and these are questions that we all hear. What is going to happen when my child leaves high school, what can I expect, what will his or her life be like? Because I wanted to find answers for the families, because I was curious back in the time of 2004-2006, I wanted to find out what research we had that was so critical for support of families, and it was really nothing. In the last decade or so, decade and a half, we have tried to understand, first of all, what happens when individuals with autism spectrum disorder and their families leave high school, and how can we make the transition process smoother and better support adults in meeting their full potential. Now, many other people have been working on this and doing great work, as we are hearing about today, and the findings from a number of studies in the US and outside of the US, across cohorts, tell us a number of ways that people on the autism spectrum struggle oftentimes during the transition to adulthood and beyond.

And, for example, we see that many adults on the autism spectrum have difficulties. Again, as we have heard about today, not only accessing postsecondary education, but being successful in those positions once they get there. Social relationships can be a challenge. Financial independence can be a challenge. We see higher rates of physical and mental health problems for many people on the autism spectrum, and employment can be a challenge in a number of different ways, not only getting an employment position, but maintaining that position once one gets a position, and also we see really high rates of adults who are on the autism spectrum that are underemployed, who have jobs that are not meeting their potential in terms of what they would be able to do work-wise.

So how can we improve transition outcomes? What are some of the changeable factors related to transition outcomes? And I think from the research world, at least, we are really on the front end of understanding this. Most of the work has been around employment, although Liz put it out, a few studies also related to postsecondary education, we also know a little bit about that as well. And many of the factors that predict employment and independence are things that we can't really do much about, especially once somebody gets into adulthood. So some of the most consistent predictors of employment and independence are someone's IQ and the amount of language, the extent of language that they had when they were five, and this is really helpful to know in terms of understanding who may need more support in adulthood, but it doesn't really give us an area to make change, especially once somebody gets into adolescence and adulthood, but we have a few factors that we have identified from our research that we think are promising avenues to improving adult outcomes.

Now, these are not the only factors. Liz presented, I think, a really nice set of factors, and we'll see some overlap with what Liz presented and also some new ideas in this presentation.

So the first thing that I'm going to talk about is adaptive behavior in daily living skills, and something that Liz talked about and also came up a bit in Michelle's presentation, and just so we are all on the same page here, when I'm talking about adaptive behavior, I'm really thinking about the things that people do to function in their everyday lives, and a component of this being daily living skills, which are really the practical everyday tasks of living, right? So these are things like being able to get one's self from A to B, whether that's public transportation or another way, being able to -- personal hygiene could be a piece of this, cooking simple foods could be a piece of this, these tasks of daily living, essentially. And we see that many individuals on the autism spectrum have a real challenge with daily living skills, so this is a really nice study by Amy Duncan and Summer Bishop. Amy is at Cincinnati Children's Hospital. Summer Bishop is at University of California San Francisco. They took a large sample of individuals on the autism spectrum and broke them up by their IQ scores, so we see individuals with IQ scores between 85-99, 100-114, and then greater than 114. And we looked at their daily livings, and as IQs go up, generally, daily living skills go up in a comparable way, but that's not what we see here and in a few other studies as well. The higher somebody's IQ is, the more of a lag we see between their IQ and their daily living skills. Now, in our work, daily living skills and adaptive behavior is really one of the most consistent, changeable factors that we find that predict employment and other indicators of independence, but in schools, we are not doing a great job, I think, across the board of really working on and promoting daily living skills. And again, Liz brought up some of the great work that they are doing, and some of their programs focused around employment and daily living skills. What we tend to see oftentimes is that if somebody with autism is more on a track to get a special ed diploma and perhaps staying in school past when they turn 18, they may be getting some daily living skills instruction, but if somebody on the autism spectrum, a student is, quote, "mainstreamed," spending all of their time in gen ed settings, the focus is oftentimes completely on academics and they get no training in daily living skills at all.

I really think research holds great promise in improving transition outcomes. This is something that parents can also work on at home as well, which I think is nice. So the first factor that I think can really improve outcomes is working on daily living skills.

Second thing that I'm going to talk about is co-occurring mental health problems, particularly anxiety and depression, which are a significant challenge for many adults on the autism spectrum. And this is just data from a fairly small study that I did with Dr. Gotham, who is also

at Vanderbilt, and we have had a number of indicators of mood symptoms and anxiety symptoms in a sample of about 40 youth on the autism spectrum who were in their last year of high school, and we looked at what was the percentage of students with no anxiety or mood symptoms, little no -- about 25% of the sample had highly significant anxiety symptoms, 25% had mood symptoms, and only 1% overlapped between the two. Meaning 50% had mood or anxiety symptoms, and only about a third had little or no symptoms. This is consistent with other studies that show an exceedingly high level of symptoms with adults on the autism spectrum, and this can significantly limit their ability to transition into work or secondary education in their communities.

This is a huge issue. It can be really hard to find providers who are willing to treat youth and adults on the autism spectrum, and it's even harder to find providers who can do this in a competent way. There have been very few evidence-based treatments for mental health issues in autism, especially depression, but I'm really hopeful that this is going to change. Mental health issues in particular have really, I think, come to the forefront in terms of recognition for advocacy organizations and research funders, who are really beginning to realize the extraordinary mental health need of these adults, and I really am hopeful that that's going to spur change, both in terms of treatment but also providers who can competently treat individuals with autism.

So the second factor with that is effectively treating co-occurrence of mental health problems.

The second thing I'm going to talk about is access to services. At least in my experience, with adults with autism, the most consistent finding is probably that adults with autism are not getting the services that they need to reach maximum potential. A number of studies have found this in the US, out of the US, and across the age spectrum in helping adults into transition.

The adult service system is woefully underfunded, and in many areas, the services just aren't there. The extent to which services aren't there, I think, differs by state. But I have yet to talk to anybody who says, oh, yeah, we have gotten what we need for my son or daughter, and it's a real challenge to get adult services. One issue is that the system is underfunded. This is a problem, and we clearly need advocacy for funding to increase for adult services. Even if the services are available, the adult disability service system is so cumbersome and so difficult to maneuver that it can be a real challenge to access these services. We see adult disability services related to housing, employment, special needs -- many of these are services that are administered by different agencies that don't talk to each other, but yet they are independent, if you get too much of this, you get less of this, and to get this you need this. And putting it all together, it's incredibly difficult for families to navigate. In recent interviews, we asked families if they had received any information about adult services that could support their son or daughter after they leave high school, and the answer for many families was no. Maybe the best-case scenario was that families had been given a brochure or some handouts, but really, families were getting little to no support in getting ready to understand how to access these services.

So we developed a program to train families on how to access adult services on behalf of their son or daughter. It's a 12-week program where each week focuses on a different aspect of the adult service program system. What makes this program different is we really focus on how the different pieces fit together, and we take a real nuts and bolts approach about the practical information about who needs to get the service. It says, for example, here's the line

on the SSI application and here's what you actually have to write to be considered for SSI.

We have preliminary findings from testing out this program that we are excited about. So we recruited a sample of 40 families on the transition age autism spectrum. We assigned half of them right away, and the other half had to wait for 12 months before they could get to program, and we looked at differences in their son or daughter's post-school activities. For families who were in the intervention program, we saw that six months later they were getting an average of a service and a half more before the program. For the control program, they were getting a half service more at this point in time. 60% of the intervention group increased in the number of services that they were getting compared to the control group.

We have a small percentage of our sample, and we have to be really careful here because the numbers get small, who had left high school at the time six months were up, and we looked at what they were doing, and in the little sample we found that all of the sons or daughters who had taken the program were working in college compared to the 50% of the control group. So, clearly, we need to do more. We have recently gotten some funding to develop a national model for the program and test it in three sites, but these give us some preliminary suggestion that just getting families information about services in a digestible way may be enough to move the needle a little bit in terms of service access in transition outcomes.

Okay. So what can we do to improve adult outcomes? Again, I want to say that this is not an exhaustive list, and I think Liz presented some nice research showing things that can happen inside of the schools and some other factors that I think we can talk about in our discussion.

In terms of what we see in our research, one of the things that I think we can do to improve adult outcomes is really focus on teaching daily living skills for individuals with autism across the spectrum of functioning. Currently, in many places, if somebody on the autism spectrum has a higher IQ or they are, you know, fully included, they may get none of this training, but our research is suggesting that it is really important, potentially even more important than like social skills training or other things that individuals getting on a more regular basis.

The second thing is to focus on effective treatment of co-occurring mental health problems, and, again, I think that the door is going to open wider on this over the next 5-10 years, and I think it's going to be critically important to helping people reach their maximum potential.

And the last is working on increasing access to adult services. And of course, more services would be nice, and we need to keep advocating for that. But we also have much more to learn about how to make our system more efficient, and how to better integrate across services.

As Michelle talked about, bringing discussions of adult services into transition planning meetings is really important. This is being addressed by legislation, and I think this is going to help a lot, and I think until we figure out ways to simplify the adult service system, having more kind of quote/unquote, "case managers" or people that can help families navigate complexities of the adult service system with mental health. And that's all I have. Thank you very much.

>> Great, thanks, Julie.

We are going to open it up to questions now, and Sara, I believe you're kind of controlling the link on that end, although while that's getting set up, there are several questions in the chat that I want to highlight and give you all a chance to respond to. And the first came in response to some of Liz's content. Amy and Orion asked about the public services offered and how that would work for home schools. And Sara, it looks like we need to get Liz and Michelle's mics open too.

>> Hi, this is Liz. I believe the class I'm thinking you're talking about is Get Ready for College?

>> Yeah, I suspect that's right.

>> There are a number of classes -- okay, yeah. Anyone can access that in home, in the school. There are a variety of ways that it could be implemented, meaning that it can be school-based, where maybe an instructor helps facilitate students going through the course, or it could be taken at home, so it's available anywhere.

>> Okay. And, Rose Martello asked if the programs are for postsecondary ed or -- (operator speaking) --

>> ACE-IT in College, they do earn a School of Education certificate. But, yes, they do audit classes, so we are one of the comprehensive transition programs, CPTs, and we started the program through a federal grant that we were able to obtain back when the first round of funding of these programs happened. Again, it's very employment driven. It is very focused on increasing independence and things like that, but they are in classes, taking regular course work with assistance that their education coach and we provide, with quite a bit of support through employment specialists that we have as part of the program as well.

>> Great, thanks. To remind everybody, if you have a question that you would like to ask of our presenters, press star and then pound on your phone, and then we'll unmute you. And we'll give you just a few minutes to chime in before moving to the next question.

>> It doesn't look like there --

>> I'm sorry, Sara? What was that?

>> It doesn't look like there are any questions at this moment.

>> All right. I'll move on to some of the other ones that were put in the chat box. This was, I believe, a question for Michelle. Does this program take into account supporting job retention? Often employers are accommodating in the short term, but after multiple incidents over a period of time, they lose patience.

I believe the question is in reference to Pre-ETS in general.

>> I don't think it really focuses on job retention. I think it's more about the services that are put in place earlier than they are -- previously they were put in place when students transitioned out of high school into voc rehab, but the Pre-ETS are starting those pre-employment transition services in high school, at a younger age, so I am not sure that they are looking at one-on-one jobs. Is that what the question is?

>> I think --

>> But they are looking at establishing -- yeah.

>> Yeah, and I think there's a problem that (simultaneous speech) --

Sorry. Go ahead.

>> No, you go ahead.

>> I was just going to say, this is a problem that we are starting to confront with our Pre-ETS program as well, is how are we going to support students over time. And if they do have persistent things that we need to continue to educate them over, at a certain point, employers might just throw up their hands and say, you know, "I'm done," and I think it's really getting at that potential problem. And that relates to a question I had regarding Pre-ETS, is have you done any work on how to work with employers to help them -- I don't know -- deal with that reality if it comes up, or do you know of any programs that do that?

>> You know, I don't. I think people are working on this individually. Liz may have some more insight into that.

>> Yeah. Michelle really sort of hit the nail on the head. In terms of Pre-ETS, you're looking at really an infusion of more, in terms of the transition services process through Pre-ETS, sort of -

- even though -- one, even though the federal laws I don't think really talked to each other when they developed these laws, but they really are looking at those early services that are needed to hopefully create better awareness, work experience, and that ideally, once a student moves through -- not all students will need support for employment, but the idea is the student with pre-ETS experience is then transferred to a vocational rehab counselor for long-term support.

But you raised, Eric and the caller, an important question. But as Michelle was pointing out, I think some of these things are still trying to be worked out in understanding that, but pre-ETS really is sort of what it stands for, sort of those pre-employment transition services, getting hopefully students out in the community more, which is needed to get them out more and to look at what are their career interests and have more of those types of exposure.

>> Yeah, great, thank you.

I'll turn to another question from Rose, and I believe that this one, it was presented during Julie's talk. She asks, given the common IQ test that we have in practice today are designed for people in a white/eurocentric culture and are designed to be assessed largely with verbal communication, kids from bilingual homes, kids from non-European backgrounds -- I wonder if there's a tool to assess children's capacity for independent living skills.

>> This is a real problem with our IQ test. The question is always are we adequately tapping into what people are able to do, and for people on the autism spectrum, this can be an even greater challenge. The study I presented I think was full-scale IQ scores. Oftentimes we'll use nonverbal IQ scores, which allows us at least to get away from tests having a verbal load. It's a great point that I don't really have an answer to. In our research, whether we are talking about somebody sort of how much they are engaged socially, whether we are talking about somebody from comes from a different racial or ethnic background, maybe some items are more or less relevant -- these are significant limitations to our measures that I think limit the conclusions that we can draw at the end of the day. So, no answer to that, but just, yes, that's a really important point.

>> And I agree, it's really kind of an unfortunate situation.

We are just running out of time, so I'll just do one more quick question. Let's see. Pat Osborn asked I would like to hear more about disclosure of disability when seeking disability employment. If, when, what? And I guess that is open to all of the presenters.

>> So I'll start first. You know, we have been interested in this issue, and there is -- in terms of the research, there may be one qualitative paper out there, but I don't know of a lot of evidence to suggest whether to disclose or not to disclose, because I think it's really nuanced. I think it's a really tricky issue, and it depends on certain circumstances, because if you don't disclose, then you can't ask for accommodations and supports, not in the same way at least, and I certainly have a lot of anecdotal evidence of people who end up losing jobs or things that don't go well because they don't disclose their disability, and then they -- you know, sort of the employer's hands are tied in some ways, in terms of making accommodations and supports without that knowledge.

But I think there's also a really valid concern about people getting their foot in the door if they disclose their disability and how that might bias somebody, especially on the front end, for jobs. And so I think it's a really, really important issue. I don't know that we know much about it systematically from the research, and my guess is that it's going to be pretty individualistic on a case-by-case basis, but I would be really interested to hear what Liz and Michelle have to say about that.

>> So, this is Liz. From our experience, we have dealt a lot with disclosure in the workplace, and Julie is right in terms of sort of the research-research part of this. It is very individualized. We really work with individuals. Part of the problem that we have seen over the years is that individuals, including individuals with ASD, cannot articulate sort of what their particular support needs are. However, what we really encourage and what we really work with students on, and adults, is that if they are going to disclose, they disclose within the context of "I need these particular types of supports to help me do this, this, and this," so it's a matter of not coming in and saying, "Look, I have got all of these things going on, and I need the support." It's a matter of really taking a strength-based approach toward disclosure, which, again, during an interview, you'd talk about your knowledge, skills, and that kind of thing. But when accommodations come up or it's something that the individual decides they are going to do, we really do that with them. We really work with them within the context of, I have told you about all of these types of skills, and what really helps me achieve this high level or do that within -- these are particular accommodations I need.

>> Great. Thank you both. And I noticed that we have gone over a little bit, so we are going to have to wrap up, but I wanted to thank all of you for your time as presenters today and thank everybody who joined and AUCD for hosting this really important topic.

I realize there's several other questions that we have not been able to get to, and I apologize about that. However, hopefully our presenters would be open to ongoing discussions through email or other venues as their time allows. So, again, thank you to everybody, and I hope you have a good rest of your day.