

**The Lewin Group**  
**Serving Adults on the Autism Spectrum**  
**February 28, 2018**  
**2:00 p.m. EST**

**Jessie Micholuk:** Good afternoon everyone. Welcome to the Disability Competent Care Webinar on *Serving Adults on the Autism Spectrum*. My name is Jessie Micholuk, and I'll be getting us started today. Should you have any questions now or throughout the presentation, please feel free to enter them into the Q&A feature on your platform. We'll be addressing your content-related questions during the discussion portion of this webinar.

The Lewin Group under contract with the CMS Medicare-Medicaid Coordination Office (MMCO), partnered with Christopher Duff and other disability practice experts to develop the 2018 Disability-Competent Care webinar series. This webinar series builds on the 2017 DCC Webinar Series that introduced the Model of Care and its 7 Foundational Pillars. You can view this series and related resources at the Resources for Integrated Care website.

As I mentioned, the webinar will be interactive with 45 minutes of presenter-led discussion, followed by a 15-minute presenter and participant question-and-answer session. We'll also be including video replay and the slide presentation at our website listed on your screen.

We're pleased to be able to offer Continuing Education Units (CEUs) and Continuing Medical Education (CME) for this webinar. The accreditation is listed on your screen now. To receive the credit, the post-test must be completed through the CMS Learning Management System with a score of 80% or higher by midnight on March 19, 2018. Further information on this process is available at the Resources for Integrated Care website, and we'll be including that after the presentation as well.

This webinar is supported through Medicare-Medicaid Coordination Office (MMCO) to help beneficiaries enrolled in Medicare and Medicaid to have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to Medicare-Medicaid enrollees, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar. To learn more about current efforts and resources, you can visit the Resources for Integrated Care website.

I will now hand the presentation over to your moderator, Christopher Duff.

**Christopher Duff:** Thank you, Jessie. I would also like to welcome everyone to the second webinar in the 2018 series. I am a Disability Practice and Policy Consultant, who has been working the Lewin Group to develop a Disability-Competent Care Model and related webinars and materials. I am especially excited about this webinar, for I have minimal experience in working with autistic persons, and I have learned a great deal in working with the presenters along the way. I will be joined today by two speakers that I will introduce in the order of their presentations.

First will be Dr. Christina Nicolaidis. She is a Professor and Senior Scholar in Social Determinants of Health at Portland State University and Adjunct Associate Professor at Oregon State and Science University. As a general internist and health services researcher, she has focused most of her career on improving the health care of marginalized populations, including autistic adults.

Dr. Nicolaidis is the Co-Founder and Co-Director of the Academic Autism Spectrum Partnership and Research and Education that goes by the acronym AASPIRE. It is a national NIH-funded partnership that brings together academics, autistic adults, family members and disability and health service providers to conduct research to improve health and well being for autistic individuals.

She is also Editor in Chief of a new academic journal, Autism in Health in Adulthood. Dr. Nicolaidis brings her personal experience, perspective as a clinician, as a parent of an autistic teenager, as an employer, friend and ally of autistic adults.

Following her, Joe Cappuccini will present on behalf of Mahsa Hesari. Mahsa created the slides and is the Program Supervisor in the Behavioral Health Department at L.A. Care Health Plan. Mahsa received a BA in Psychology and an MA in Behavioral Clinical Psychology from California State University-Northridge and is a Board-Certified Behavior Analyst.

She has worked with autistic persons and their families for most of her career as a direct provider of a range of services with autistic persons and their families before she joined L.A. Care in 2015. Based on her experience as a provider, she developed L.A. Care's Autism Services Program and currently supervises the staff, overseeing the services and managing the Autism Provider Network.

The learning objectives are fairly straightforward. We are focusing today on autism, a common though not well understood population by those of us in the health care field or plans, as demonstrated by the number of requests we have had over the last few years for this topic.

Dr. Nicolaidis will start off the presentation today with an introduction to autism, its prevalence and related conditions. She will talk about the barriers and disparities experienced by autistic adults and participant experiences and strategies for providers. She will introduce a great tool she and her colleagues developed to help participants and providers with their health care experience.

Joe will follow Dr. Nicolaidis' presentation where he will share their experience developing and overseeing their Autism Spectrum Program at L.A. Care. This includes information about Functional Behavioral Assessments, the Evidenced-Based Treatment for Children, and their Behavioral Health Provider Network tool. He will conclude with information about how they prepare for transitioning their members on the Autism Spectrum into the appropriate adult services.

Before handing this over to Dr. Nicolaidis, I wanted to make a note on the differing perspectives and even philosophical approaches you will hear from our two presenters in their work with autistic persons and their families. Though their approaches vary to a degree, they both believe in

the youth of interventions to help autistic persons communicate, function independently, learn effectively, obtain high-quality health care and live healthy, productive lives. Autistic persons are not broken or needing to be fixed. Their concept is core to Dr. Nicolaidis' model and is certainly core to the DCC model, which focuses on living with a disability and aimed at training and support for functional independence.

At this point, I would like to hand it over to Dr. Nicolaidis for her presentation.

**Christina Nicolaidis:** Great, hello, thank you for having me. Before we start, I just want to make a few minor notes about language. First of all, you'll hear me use the term autism and Autism Spectrum Disorder relatively interchangeably. Both terms really talk about a complex neurodevelopmental disability that affects social communication, sensory processing and scope of interests.

You also might be surprised that I'm not using person-first language. Please understand that that is not out of either ignorance or disrespect, but by respecting the wishes of my autism partners, many of whom prefer identity-first language; for example, autistic adults versus person-first language. What they have explained to me is that person-first language is wonderful when you're trying to separate the person from an unwanted medical condition; for example, person with HIV, person with cancer. But that can feel stigmatizing to somebody who considers autism a part of their identity, much in the same way that we wouldn't say person with femaleness or person with Whiteness or person with homosexuality. They also feel that on the Autism Spectrum is an acceptable alternative.

Just to be clear, the DSM, the Diagnostic Statistic Manual, has been changing rapidly over the last decade and that sometimes causes confusion to providers and to the community. The latest version, DSM-5, has combined what used to be called Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder not otherwise specified into this one big term called Autism Spectrum Disorder.

One problem with the word "spectrum" is that autism actually doesn't really manifest on a linear spectrum. It's actually kind of across multiple spectra. You might find that somebody is very strong in their verbal skills, but has a really hard time with their adaptive functioning. Or somebody might have challenges with a need for consistency, but not so much with something else. What I've also found is that these challenges really change depending on environmental stimuli, supports and stressors. Somebody might be able to function quite well in one environment and then put them in another environment, often the one we're seeing them in that they're sick and there has been a crisis, and they'll function very differently.

We are also talking about adults, and they mature over time. No adult is like they were as children, and certainly what we find is that as autistic children turn into autistic adults they mature just like the rest of us do. They also learn many coping skills and that will also affect how they function and how they present.

Just in terms of the DSM, I just want to basically say there are two big buckets that we care about. One is what the DSM considers persistent deficits in social communication and social

interaction. These are things that might as an adult manifest in challenges and understanding nonverbal communication, or figuring out when it's their turn to speak, or in understanding the social queues that might present in their work environment or in other situations.

The second big bucket is what the DSM considers restricted repetitive patterns of behaviors, interests and other activities. That's where we find people will have potentially stereotyped or repetitive motor movements or what we call "stims." They might have a great need for consistency or insistence on sameness, what the DSM calls highly restricted fixated interests of abnormal intensity or focus, what many of us in academia consider our specialties. But you'll find that adults will often have a high degree of knowledge and interest in one or two narrow areas.

Then, very importantly hyper- or hypo-reactivity to sensory inputs and that can often really make or break our interactions with autistic individuals of understanding how key the sensory aspects are of the condition.

Over the past few decades, the prevalence of autism seems to have skyrocketed. Most people believe that that isn't actually because something has truly changed, but because we keep changing our definitions and our understanding of what autism actually is. People in the Baby Boomer generation didn't even have a chance to be considered autistic as children, because it wasn't even in the DSM. We didn't even have Asperger's in the DSM until 1995.

As you can see, we've mostly been looking at today's version of autism in the children who were born in the 1990s, early 2000s. That group of children has grown up now and is entering adulthood, but that doesn't mean that there haven't always been autistic adults there. A large well-conducted population-based study that really just went and did new diagnoses door to door, found approximately 1% prevalence of autism in the adult population with no change in age. What we do know is that there's a continued under-diagnosis of autism in women of any age and in people of color, and that we'll see probably change I'm hoping over the next few years.

As a health care provider, especially as an adult health care provider, I'm rarely in the position of treating autism per se. What I'm often treating or looking out for are associated conditions. There is growing literature on conditions that are associated with autism, which include epilepsy especially in participants with co-occurring intellectual disabilities; gastroesophageal reflux disease and multiple other gastrointestinal conditions, feeding and nutrition problems, metabolic syndromes and a very, very high prevalence of anxiety, depression, sleep disorders and unfortunately suicidality.

We're also starting to get new information as well as many anecdotal concerns around post-traumatic stress symptoms associated with the childhood treatments we're giving; for example, such as applied behavioral analysis. We also know that autistic individuals have a higher risk of experiencing violence and abuse. Unfortunately, all of this put together amounts to a reduced life expectancy, which we find is largely driven by seizures and suicide, as well as poor care for the many other co-occurring conditions.

The things to think about are not to stereotype people on the spectrum. If you look at current media, we have quite a lot of images of what it is to be autistic. There's an adage around, if you've met one autistic person, you've met one autistic person, and there is really quite a lot of variation.

The other thing is that though we're talking about autism in a clinical context, we do have to remember that autistic traits can be both strengths and challenges. As I mentioned earlier, what can be considered an abnormality of a restrictive interest can actually be great expertise in an area, or it could for example help somebody manage their chronic illnesses because they use their consistency for good.

Similarly, I often find that people expect that autistic individuals will not only have these stereotypical traits, but will also have the savant-type qualities. Again, that is not true; some do, but certainly some don't and that can be harmful.

Finally, though autism is defined as a social communication disability, it doesn't actually mean that people shy away from social interactions. They just have very different interactions and many may maintain strong friendships and relationships. I can tell you my closest friend in the world is an autistic adult. Though, it might be a really bad idea to take her to a cocktail party, that doesn't mean that she can't actually have true friendships, and really be there as much as a support to me as I am to her.

I'd like to move a little bit more now to health care. As a health care provider, I am very well aware of how challenging it can be for me to provide optimal care to my patients on the Autism Spectrum.

Before we even talk about autism, we need to just talk about disability. I can't imagine that anyone listening to this talk today doesn't know that social issues greatly impact health and health care. The large literature that shows a disability status and health disparities are often associated with poor performance on measures that are linked to value-based purchasing program payments.

We know that people with disabilities in general experience worse health outcomes; experience difficulties or delays in receiving necessary health care; have limited knowledge or access to sexual health information; and sadly again as we're talking about adults we find that there's this huge "services cliff" as children with disabilities transition from adolescence to adulthood.

In my own work, my colleagues and I did a survey quite a number of years ago in 2013, comparing autistic adults to non-autistic adults with and without other disabilities. We found that autistic adults reported greater unmet health care needs. In particular, they reported greater unmet physical health needs, mental health needs and prescription medication needs. They also had a greater use of the emergency department, which to me really signifies a failure of our primary care system. We also found that they had lower use of preventative services, such as a Pap smear and overall lower satisfaction with patient/provider communication and with their own ability to manage their health care, or what we call health care self-efficacy.

Also in another study that my colleagues and I did, we found that people without disabilities experienced fewer barriers to health care in general compared to autistic people and people with other disabilities. Then when we specifically looked at autistic people, they reported different barriers to health care than people with other disabilities and a greater number of them. Overall, their utilization reflected a different pattern of health care usage.

In our study at least the top barriers that autistic people described or endorsed were fear and anxiety, feeling that they can't process information fast enough in real-time, concerns about cost. They were concerned that facilities caused all sorts of sensory issues that then impacted their ability to actually interact with their providers. Then they not surprisingly mentioned great difficulty in communicating with providers.

For this next section I'm going to focus on a qualitative study my colleagues and I did and really trying to understand more in depth the experiences of autistic adults, their supporters and their primary care providers.

We heard lots of stories. Some were positive, some were quite negative, but overall what we found is what the success of a health care interaction really depended on an interplay between different factors. We grouped the factors into multiple levels.

First of all, there were the typical participant-level factors, things that we would expect with autism; their verbal communication skills, their atypical nonverbal communication, their sensory sensitivities, their challenges with body awareness, the slow-processing speed, things that again we had heard of before.

What we found, however, is that those things really mattered in relation to what the provider was doing. We had a number of provider-level factors, such as the knowledge and incorrect assumptions about autism; the provider's willingness to provide accommodations; and the provider's skill in incorporating Care partners.

Of course, all of this happens in the larger context of system-level factors, which included the availability of formal or informal supports; the complexities of our health care system; and accessibility and stigma. Then of course, all of this also gets impacted by the very well-known socioeconomic factors. All of our participants, but especially dually eligible participants may also experience additional barriers. For example, things like transportation, housing, nutrition and so on.

I'm just going to highlight a few of the things that to me really were very telling. First of all, I keep making note of the sensory sensitivities. This is a quote from one of our study participants. She says, "The lights in the office are very bright and that is exacerbated by the white walls. Sometimes the waiting rooms are crowded and I cannot filter out the background of people talking or shuffling magazines. I feel disoriented by being led down long hallways to different rooms. I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions. But he refills my usual meds, and I go on my way."

We also heard quite a lot about body awareness, which again as a provider is important for me to remember. When they ask if the pain is shooting or stabbing or burning, it's like I don't know. It just feels funny. Or the problem is it's difficult for me to isolate specific sources of pain and identify duration and intensity. It's sort of like the equivalent of white noise.

I was unfortunately very saddened to hear how many times providers failed to accommodate patients or understand their autism. As this participant said, "I've used my Alphasmart when my speech is too slow or difficult to understand for medical appointments. Some of the doctors have been really great, but others have acted really condescending when I used it, sometimes assuming I needed a parent present. So I try to go without even when my speech is poorer shape."

As another participant said, "Usually, when I demonstrate a large vocabulary or some fundamentals, my needs, especially around communication are then ignored. My choice is then to pretend to be less intelligent and accept their infantilism, or to be confused, frustrated and stressed out."

Similarly, another participant said, "I prefer and find it easier to communicate in text. But with every doctor I speak to, they wave away the note-card and look at me to ask the same question I have just answered and interpret my confusion as my being non-compliant with the medicine. I wish health care providers would read the notes I make for them."

Or as another participant said, or this one was actually a supporter talking about trying to support her adult son in health care interactions. "But they talk to him in the same words that they'd use if they were talking to me. If they're going to talk to him, they need to say it how he can understand it."

Then largely what we often found is that the various communication problems due to the breakdowns of offering accommodations patients often felt that they had been deprived of their patient autonomy. For example, as this participant said, "Just because I might need more information to understand things, it doesn't mean that they can or should just talk to me like a child or leave me without knowledge of my own health. My body is my body and my experiences and wishes about my body are MINE TO MAKE!"

I largely work one on one with patients in my exam room. However, much of what is happening is really outside of my exam room. I'm hoping that at least some of those of you on this call can actually help with the larger system. We've heard story after story about how difficult it is, really for anyone to manage our crazy health system, but especially for somebody with executive functioning challenges or other things related to autism. As this young woman explained, "I wish they understood how easy it is to get confused with all the administrative hoops a patient has to jump through to get help. It sounds pathetic at my age, but I need someone to hold my hand. I don't know what I'm doing. But nobody understands that I need that, and there is definitely nobody willing to do it."

So, we've heard a lot from patients about their concerns with the health care system. As a provider, I can tell you part of it is also that we just don't get the training. I don't think I had a

word about autism anywhere in my medical school, residency or fellowship experience and that is not unusual. A study done down at Kaiser Permanente in Northern California found that 77% of health care providers rated their skills in providing care to autistic adults as poor or only fair. Multiple other studies have shown that providers really don't have the skills, training or confidence in taking care of their adult patients.

The other thing I can say as a provider is very challenging is that people on the spectrum really vary so greatly, so it's very hard to have a short little training and say, okay, this is what you have to do to take care of an autistic adult. When, in fact, one of my patients may be an engineer and another one of my patients may be nonverbal and living with 24-hour support. So, it's really important for us to think about individualized patient-level accommodations, which is what we'll be talking about further in the talk today.

Given the context that we can't just make accommodations that work for everybody, I still wanted to give some examples of things that health providers and health systems can do. For example, before a visit it's perfectly reasonable to ask staff to inform the participant about what's likely to happen during the visit. Enable the participant to procure pictures of the office and our staff. For my own child when he was younger, I would just go the day before or the week before and take pictures of things. Just having to be able to show him the pictures made such a difference in him being able to tolerate a visit.

Generally, I know time is money and I know time is really challenging and I struggle with time, but we often do need to schedule longer appointments. We also avoid rescheduling appointments. Something that might be just a minor deal to somebody else may be really a huge problem to a participant who really needs consistency.

In the waiting room, notify the participant about how long they'll wait and check in with them. Then, encourage participants to prepare notes in advance about what they wish to discuss. Identify and document participant's sensory sensitivities. For example, when a medical assistant is rooming a patient, they can room them in a room that has natural lighting as opposed to the fluorescent lights which are such a problem for many of our autistic participants.

Similarly, during a visit providers can do things to help. For example, make a problem list with a participant. Show equipment to a participant before using it, or do a trial run of difficult exams and procedures. I make all sorts of recommendations and actually show them what you want them to do before they leave the office. Give time to process what's been said. Sometimes it's in the visit. Sometimes we actually need to break visits into multiple visits and, then again, accommodating sensory sensitivities.

I'm going to move on to talking about the AASPIRE Health Care Toolkit, which is something we've been working on as a team now for several years. The AASPIRE Health Care Toolkit was created as a part of this ongoing research project with my research team AASPIRE. We've used a community-based participatory research approach, whereby we as researchers work with autistic adults, people who support individuals on the autism spectrum, and with health care providers and disability providers in every phase of the research project. We've created a toolkit that is

basically separated into two different parts. One is for patients and supporters and the other is for health care providers.

The provider part of the website is meant for both providers and staff. Certainly, I'm hoping it would be helpful for people who are working outside the health care system in supporting people with their health care. It offers materials, resources and practical information to help providers offer high quality primary care. That part of the toolkit is broken down into four segments, including autism information, diagnosis information and referrals. A lot of details around specific strategies and accommodations we can do to care for participants on the autism spectrum. Then are some sections about legal and ethical considerations and various resources.

The patient and supporter part of the website is really intended to help patients advocate for themselves as best as possible and be activated to manage the health system. It offers information and detailed instructions, all of which has been edited very carefully by my team of autistic partners to really make sure that the language is accessible and specific enough to deal with the language pragmatic issues that often come up with autism. That part of the toolkit has sections around navigating the health system, staying healthy, informing participants about their rights in health care. Again, there's general information about autism and about computer and Internet access, and links to reliable medical information.

Also in the toolkit are a number of forms and worksheets. These are things that in our studies we found participants really value. There are worksheets around making an appointment; around what to bring to a health care visit; how to describe their symptoms; how to make sure that they're following up with all of the things that have been recommended.

Then the centerpiece of the toolkit is what we call is what we call out Autism Health Care Accommodations Toolkit, or AHAT for short. This is a tool that helps participants get the accommodations they need. The participant or their supporter fills out a survey focusing on how they communicate, what supporters there are in their lives, and all sorts of possibilities around accommodations and strategies.

The computer then takes this information and creates a personalized report for providers. What's interesting is that it actually took us way more time to find a report that providers would read than anything else. We do feel like we've gotten something that is very provider-friendly in terms of focusing on the actionable things they can most do to facilitate care.

This is an example of the format of it. You'll see there are particular topics and then are bulleted lists of very practical things a provider might do for this particular patient, which may be different than what they would need to do for a different patient.

We tested our toolkit with 170 autistic adults and we found that the vast majority found that the material was important, useful and easy to understand. What I was most excited about is a month after using the toolkits participants reported fewer barriers to health care, greater health care self-efficacy and improved participant-provider communication. Of course, that was just pre/post test, and we're now currently doing a controlled study within three health systems to see how this will work in integrating it into health systems.

Ultimately, the idea is that participants can use the AHAT to consider their accommodation needs and how to communicate about them and how to improve their self-advocacy. This also helps providers understand and be more receptive to reasonable accommodations. We've been very careful to make sure that the reports are easily shared with providers and staff or case managers or anyone else who may use them.

We've talked about a lot of things today. I think the most important take-home points is autism is really common in adulthood and, again, estimated to be about 1% of the population. Even though many of those are undiagnosed, the large cohort of diagnosed children is now reaching adulthood. There are many opportunities for the health care system to improve our capability to provide adequate care for adults on the autism spectrum.

There are tools and as I said I would love for you guys to use the tools that we've made. They've been publicly funded and are available for free because we really do believe it's important to have greater health care experiences for our autistic participants. Of course, there are still lots and lots of work to be done. I'm hoping that we can push out a whole system to improve the health and the well being of autistic adults.

Ultimately, addressing the health care needs can make a really huge difference in the lives of autistic individuals. I very much appreciate you listening. I also appreciate the incredible work that's been done by my AASPIRE team, including both of our academic partners and our autistic partners. Thank you.

**Christopher Duff:** Dr. Nicolaidis, I would also like to thank you for your excellent presentation. Before I hand it over to Joe Cappuccini from L.A. Care, I just wanted to talk about Slide 44 if you would move on. I wanted to address the insurance side in order to make it broader than just California. These are comments about benefits related for autistic persons. All states are mandated to provide ASD services to those under 21 diagnosed with autism. There are some variants by state in terms of the breadth of services and I'm referring to Medicaid benefits here.

If a participant continues to need ASD services after the age of 21, they are generally referred to adult DD/ID Service Centers and/or providers and the coverage can vary by individual states. Assuming the ASD benefit is incorporated in the MCO contracts, such as those participants in the dual-eligibility demonstrations, they are generally served by the health plan's Behavioral Health Network.

I'll now hand it over to Joe Cappuccini from L.A. Care, who will speak on Slide 44 and forward.

**Joe Cappuccini:** Christopher, thank you very much. As a reminder I'm speaking as proxy for Mahsa, who is the subject matter expert here at L.A. Care. Christopher, thank you for inviting us and, Dr. Nicolaidis, thank you very much for your interesting information, I found your passion and your delivery was very attention getting. I want to thank you for that.

I want to go back to the previous slide, if you would for a moment please, and I want to kind of subsidize something that Christopher had mentioned. First, let's go ahead and cover the first

bullet point. Up to the age of 21, yes, the Autism Spectrum Disorder services are considered Medicaid-covered benefits managed by the health plan.

I want to add an additional bit of information that, Christopher, we did not include on this particular slide. That is if the member needs more ASD-like services; for example, applied behavioral analysis, the beneficiary is referred to local Disability Service Centers. For instance here in L.A., we refer to that or we call those local Disability Service Centers, Regional Centers. I just wanted to kind of backfill that slide that Christopher had alluded to previously.

Thank you for that and let's now go to the next slide, and I'll give you an overview of who we are here at L.A. Care Health Plan. We are the largest, national publicly operated Medicaid health plan and we've been servicing Los Angeles County specifically since 1997. We've identified our mission to provide access to quality health care for L.A. County's vulnerable and low-income communities, as well as residents in order to support the safety net required to achieve those purposes. It's our legacy that we have built by developing new programs, fostering innovative partnerships and exploring ways to provide better care at a reduced cost.

When we talk about L.A. Care's ASD program, in late summer of 2014 we had identified the need for a specific program to meet the needs of providers, as well as Medicaid participants as they assumed the responsibility of autism services. As you already know, most current ASD program staff are former ASD practitioners, so a variety of perspectives allows our staff to better understand and meet the needs and challenges of the participants.

Just to review some of the key elements of the ASD program, we do apply open communication. It is an evolving and updating resources and processes, and it is requiring a continuous trainings as far as attention to updates, both medical and regulatory.

The about L.A. Care staff within the ASD program include five board-certified behavior analysts whose responsibility it is to review the treatment plans, determine the eligibility, as well as ensuring the coordination of care. We have one dedicated Care Coordinator who addresses the emails, as well as the phone calls coming from the community, the hospitals, the vendors, as well as other multiple entities.

We have one Regional Center liaison who addresses any issues and concerns that are related to Regional Center Services, as well as Physician Provider Groups (or what we call PPGs) such as occupational and physical therapy, speech-language pathologist services, etc.

We have assembled a dedicated team, a specialized provider network team that focuses on onboarding the new physician provider groups and supporting them with business and administrative matters. We do that on our end.

As far as functional behavioral assessment is concerned, once we receive the request for autism services and receipt of diagnosis from a physician or a licensed psychologist, the participant is then referred to an Applied Behavioral Analyst and a specialist for a standard functional behavioral assessment, which includes indirect assessment as well as direct assessment. The interviewing of the caregiver where that behavior occurs, the observing of the participant in their

own environment, and then working with the participant to find out the strengths and weaknesses in their communication or motor skills, their play skills, and their adaptive and social skills.

As we continue through the behavioral assessment, the goals are designed to operationally define the behavior and measuring the baseline level by identifying the frequency of the behavior (how often it happens), the duration of the behavior (how long it lasts), and then the intensity of the behavior (it is mild, moderate or severe).

We also continue the assessment to determine the reasons why the participant is engaging in the problem behaviors, also known as "identifying the function of the behavior." Then, we design evidence-based treatment plans to address the identified problem behaviors and/or developmental delays. Then we continue on by recommending goals and ABA-based treatments to the health plan.

As far as evidenced-based treatments for autism are concerned, Applied Behavioral Analysis is a scientific discipline concerned with the understanding and improvement of human behavior in homes, clinics, schools and many other settings. The goal is to develop effective ABA-based treatments that will support improving problem behaviors socially significant in the members' lives.

The following behavioral health treatments are the primary behavioral interventions that have been identified as evidence-based. They are first, Comprehensive Treatments. These treatments are usually provided intensively at home or in Center-based programs for an average of 36 months.

Then there are Focus-Based Treatments, and those are designed to address specific behaviors, including aggression, self-injury, disruptive or other challenging behaviors. They commonly include caregiver training and average 10 to 25 hours a week for a short period of time. Now, it's important to note that these treatments are all gathered under the ABA umbrella.

As an ASD provider network, about L.A. Care's ABA-provider network consists of over 70 in-network ABA providers, an additional Memorandum of Understanding (or MOU-based ABA providers) and licensed psychologists for second opinions. All of the ABA participants referred to by providers have access to a local psychological service, or Beacon, for testing and other mental health services, such as talk therapy, medication, etc.

Care coordination, which is one of the key elements of our ASD program at L.A. Care, it's our in-house staff who ensures the integration between providers and services such as occupational and physical therapy services, and speech-language pathology services. Both services are provided as medically necessary.

We transition participants to adult services. Prior to a participant turning 21, the needs are identified for continuing services. A Care Coordinator will refer the individual to a local Disability Service Center. If adult behavior health services are required; for example, talk therapy or marriage/family therapy, psychiatric supports, that participant is referred to the plan's Behavioral Health Network to determine the eligibility and identify the providers. Providers can

then engage with local Disability Service Centers or health plans in order to determine the eligibility for those adults who previously received autistic services as children.

A question had been posed to us, as well as others, what did we learn? The lessons that L.A. Care learned transitioning a participant to adult services are to initiate early planning in order to eliminate and minimize the gaps in service. We do that by identifying ongoing participant needs after the age of 21. We find a way to refer the participant to the appropriate service networks (DSC or the Behavioral Health Network), and we facilitate the transfer of the participant records. We take ownership of that.

During the early planning, we prepare the participant and their families for differing eligibility criteria and benefits between the DSCs and us at L.A. Care. Oftentimes, we run into questions and concerns about differing eligibility criteria and benefits, and then we and the DSC have identified personnel to facilitate that transition; a conduit, a liaison, someone who may translate insurance-heavy lingo into easy-to-understand layman language. We do a pretty good job of it to start, but it's always nice to have that third party.

Additionally, more lessons that we've learned as far as developing the program, gain management and leadership support. Buy-in from above is crucial to the program's success and we have it here. Our leadership identified dedicated staff to help us develop and deliver the autism program we've just discussed.

Additionally, policies and procedures were designed that clinically, ethically and medically put the participant first. Why? Because we want to ensure flexibility to accommodate that participant's needs. We want to be open and we strive to be open to new information, such as clinical information, guidelines, policies, regulations, ad infinitum.

We're constantly developing and updating effective workflows, processes, as well as staff training to optimize consistency. That being said, on behalf of Mahsa, myself and all of the dedicated staff in our Behavioral Health Department at L.A. Care, we want to thank you for the information and your time and attention.

**Christopher Duff:** Thank you, Joe, I appreciate that very much and very well presented. I would like to now apologize to the larger group that we have successfully eaten up over half the time for the Q&A, but please keep them coming in, because we will respond to you. If we don't get to them all online here, we will respond to you separately. I promise that.

An interesting question has come in that I wanted to ask. It's from an ambulance service in Washington State. This is the second time we've gotten questions from an ambulance service, so I'm pleased that they're beginning to get engaged with this. Do tools exist to help educate ambulance providers, or EMS professionals in accommodating autistic adults and kids given urgent situations? I think that's a question best for Dr. Nicolaidis.

**Christina Nicolaidis:** Thank you for that question, and this has come up multiple times. I'm not aware right now of tools specifically aimed at emergency personnel. I have to say, I was an EMT

for years and years before going to medical school. I really completely appreciate this and understand how much it's needed.

I would say that much of what's in the toolkit for primary care really could be also helpful for emergency personnel. This was a research study, so we had to be very specific, and we did it specifically for the primary care system. However, I would say 80% of the information would also be useful for people in the EMS system. That being said, I think it's an important need and we certainly have it on our list of things to do to try to make supplements that are specifically for EMS.

**Christopher Duff:** Great, thank you very much. Marissa from Anthem Health Plan asked if you can provide a little more detail as to why diagnoses of women, including those of color, have a lower diagnostic rate than those of men.

**Christina Nicolaidis:** It's a really interesting question. I don't know that we have a 100% answer. Part of it is the logical thing that diagnoses in general, especially for people of color, are going to be lower because of lower access rates; because of the many, many social determinants of health where we find that there are disparities in health care practices for people of color.

I work with Dr. Zuckerman, who specifically focuses on Latina individuals, and we've found that there is both an issue of access to health care, and then there's also potentially within the community different ideas or even awareness of what autism may be. So there is a combination of factors.

When it comes to girls that is trickier, and my personal opinion is that much of our image of autism has been focused on how it presents in males. We find that there are some gender differences. When you've created a definition that is based on the characteristics that are more commonly seen in males, it then kind of becomes a self-fulfilling prophecy where we don't see it as easily and we don't recognize it as easily in girls. We find that girls who are diagnosed have more severe intellectual disabilities. They are diagnosed at older ages.

Again, many of us are very interested in this topic and are working on it and there's new research on it. My own speculation would be that 10 years from now we're going to have a very different definition of what autism even is for any gender. It will, hopefully, also be a little more inclusive of how it presents in women, but it is an ongoing issue of great concern right now in the research world.

**Christopher Duff:** Thank you both very much for the presentation. I appreciate it. I have learned a lot just speaking for myself. At this point, I need to hand it over to Jessie to wrap things up.

**Jessie Micholuk:** Thank you, Chris, and yes thank you to our presenters today, Dr. Nicolaidis and particularly her AASPIRE Team, the funders of which are listed on this slide here. Of course, to our presenters from L.A. Care, Mahsa Hesari, thank you for your work and Joe Cappuccini for the presentation today.

I also want to remind people to keep sending your questions in. We will be sure to address all of them with the help from our presenters going forward so we can get you that accurate information and have those posted.

Also, we have another webinar next week on ***Palliative and Hospice Care for Adults with Disabilities***. Please join us at the same time.

For more information on obtaining those CEUs and CMUs for today, you can follow the link to CMS Learning Management System, and we have all that information at our Resources for Integrated Care website.

As always, your feedback is very important and essential to developing new trainings and resources. There will be a brief survey that will appear automatically on your screen when this webinar ends. You can send any additional comments that you have as always to our inbox at [RIC@lewin.com](mailto:RIC@lewin.com). Thank you again everyone for your time today and have a great rest of your day.