

Health at the Intersection of Autism and Poverty

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MADELINE HALEY:

Hello everyone I will give it another minute or two and I know that the holiday time of year, people are doing a lot of things right now so I'll give it another minute.

All right I think that we can go ahead and get started. Hello everybody my name is Madeleine Haley and I am the project manager for AIR-P and I want to welcome you. Thank you for joining us today and because of the number of participants the audio will be muted throughout the call but you can submit questions via the chat box on the webinar or by the Q&A function on the webinar console. This entire webinar is recorded and will be available on our AIR-P website which I will put in the chat right now. There will also be a short evaluation survey at the close of the webinar which we invite you to provide feedback for on this webinar and suggestions for future webinars. So let's go ahead and get started. We first want to acknowledge the health resources and resources administration as a funding source for the AIR-P and it is my honor to introduce the speakers. Doctor Lindsay Shea who is the director of policy and analytic center at the autism Institute and AIR-P services leader and if you have been attending our webinars frequently she was also presenting at our November webinar. And Doctor Stacy Nonnemacher the clinical director of Bureau of support for autism and special populations at the Pennsylvania Department of human services. Please join me in welcoming Doctor Shea and Doctor Stacy Nonnemacher.

LINDSAY SHEA:

I'm very pleased that my colleague is here with me as well. It has been truly the thrill of a career to learn more about Medicaid and see it through Stacy Nonnemacher's eyes. Today we will talk to you about some of the research that I have been doing in the national claims data and drill down on state innovation in Medicaid. And that is certainly where Doctor Stacy Nonnemacher sits in terms of thinking about ways to move forward the Medicaid program to serve autistic individuals. To make sure we are all on the same page and to get the lay of the land, there are multiple ways that individuals can get insurance, health insurance specifically in the United States. We know that there are many individuals, 216 million Americans receive coverage through private insurance gained through employment. If you have a job, your employer may pay all or a portion of your insurance plan. Or if you gain insurance through the affordable care act marketplaces it counts as private health insurance. There are about 28 million Americans who have no health insurance or are paying out of pocket for their health insurance. There are 12 million Americans who are served by TRICARE or veterans administration which is for our individuals who are serving in the Armed Forces. Medicare is different from Medicaid and it is hard because they have very similar sounding names. Medicare is an entitlement program that Americans

receive when they turn age 65 or before age 65 if you have certain health conditions. Medicare is different also because it is administered by the federal government and versus Medicaid which is a partnership between states and the federal government. There are about 60 million Americans who have insurance or Medicare. Medicaid which is often thought of alongside the children's health insurance program which is run by states is a federal state partnership. The federal government has a certain set of rules that the states must comply with or meet a bare minimum standards set by the federal government and then within that partnership, states have flexibility to think about ways that they need to shape policies, programs within the state to meet the needs of unique populations, emerging populations or in general the individuals living in the state needing health coverage. There are about 73 million Americans who have coverage through Medicaid or CHIP programs we often see this paired with Medicaid data. As we move forward Medicaid is a program available across the life span for autistic individuals meeting certain criteria. We'll talk about how it has taken shape in Pennsylvania versus Medicare which is a program for older adults age 65 or older or with certain health conditions before age 65. Today we are focusing on Medicaid.

Medicaid has all sorts of names. Much of this depends on how states have branded their Medicaid programs. For example my colleagues who are here today from California often it is called Medi-Cal and in Tennessee, TennCare, and Delaware DMAP, SoonerCare in Oklahoma and even though we are trying to talk about a specific topic related to Medicaid it may actually have a different name depending on where you live or what your estate has decided to call the program within the state program Medicaid portfolio.

So eligibility we can probably think of and in general when we are using big national data, people in Medicaid, we think about how people gain access in three broad groups. The first is disability if an individual has a diagnosis in this case and relevant to our shared network of activities, an autism diagnosis. There are also other criteria. Example his level of care requirements, an individual must have certain service and support needs in certain areas to a certain degree in order to enroll in state Medicaid programs in addition to the diagnosis. Individuals can qualify to poverty. An individual may meet the requirements for Medicaid because their income is at a certain level and will you know the affordable care act standardized the requirements because states had highly variable poverty requirements for individuals to enroll through this category. The affordable care act raised the baseline in terms of how individuals in states determine how individuals might meet the criteria. And then there is 1/3 group of decayed eligibility criteria or programs that are offered through states that are based on state decisions that are approved by the federal government that meet the needs of the populations within the states. For example there are programs for individuals with HIV/AIDS, if you are pregnant you are automatically eligible and there are other very local based programs one of which is based in Pennsylvania that Doctor Stacy Nonnemacher will cover later today as well.

We look at who is covered by Medicaid and we look at those 73 million Americans, we see that they

are mostly children, 43%, about 1/3 are adults, 12% are individuals who are labeled in this data source from the Center on budget and policy are blind individuals and 8% being older adults. When we look at spending, the resources within the program, and their allocation, we see the blind and disabled group is 1/3 of the resources that are spent in Medicaid as compared to that slightly bigger portion for adults and a smaller portion for children despite the fact that the makeup more of the individuals enrolled in Medicaid. This makes it really important to pay attention to how Medicaid is structured. How do we think about ways to shape the policies and programs and support people like Doctor Stacy Nonnemacher thinking about state programs and ways to best serve populations with these limited resources.

In a recent publication that our team released using some of the newer Medicaid data nationally, we see that the number of individuals on the autism spectrum served within Medicaid in the nation has been increasing steadily. We have newer data and will be updating the figures soon but you can see on the adults, 18 to 24 the biggest growth is among transition age autistic individuals which is ages 18 to 24. In most cases it is a lifespan diagnosis, those individuals are going to as the age contribute to those lines in the lower component of this figure and increase it. We know that this group is overall growing, the most quickly among younger adults but that group is also going to age into older adulthood and how do we think about ways to support what they may need.

Another way to look at this is by year. When we take the raw data and put it on a line and see how these ages are moving forward, we have heard about a tsunami. We've heard about a title wave and there may be a way that I've certainly heard critiques of that because it suggests that there is a time at which it will wane or will no longer be present and the reality is, that individuals we see here in these differently colored lines are going to continue to age and that increase will move to the right and there are more younger individuals moving along. This corresponds with the CDC's latest estimates which indicated an increase in the prevalence of autism across 11 states in their populations. You know that Medicaid is an important payer for services for autistic individuals for a few reasons. Many states have taken care to generate new programs for children and adolescents on the autism spectrum. There are waivers which are specifically designated programs for children and we know that those waivers are intended to help support especially when we see that CDC headline of eight-year-olds. That is the population the CDC focuses on. To help those children gain access to services and supports that they are likely to need. We also know that individuals in the autism spectrum are likely to have relatively lower employment outcomes than even other peers with diagnoses. So when we think about how individuals get insurance, health insurance outside of private health insurance, which you gain through an employer from our previous slide, Medicaid becomes among the only option available to people across the lifespan. Medicaid is important not only for autistic individuals but for autistic individuals of all ages.

So what does Medicaid cover? There are a set of mandatory benefits which is the federal entity

overseeing Medicaid programs and they include inpatient services, outpatient services there is an entire bucket of early and periodic screening, diagnostic and treatment services. Nursing services, physician services, laboratory services, family-planning services and a constellation here of medical services that are linked to physical health and health outcomes all across the lifespan. Optional benefits that states may choose to include for the Medicaid populations are also a wide array of both medical options: prescription drugs, thinking about ventures, prosthetics and eyeglasses but also pivoting into the services received the frontline of options for autistic individuals including in childhood physical therapy, occupational therapy, speech therapy and also thinking about home and community-based services. Services that help people think about where they want to live in their community, how did they stay in the community, how do they engage in the community around them. That is a place that Pennsylvania has been exceptionally... Autistic individuals report that they prefer to access as they age.

When we think about these types of services, home and community-based services, long-term services and supports, these are services that are meant to keep individuals out of institutions. So as we look at trends in spending patterns, and enrollment in types of Medicaid programs, we can see the green line has decreased and in the 2000 became lower than the gray line which are services that are delivered in communities. What we really see here is the crossover of a majority of institutionally based services where individuals were served in inpatient settings versus a switch to more outpatient, community-based services. In 2016 we know that Medicaid spent 94 billion dollars on home and community-based services to enroll populations. How do home and community-based services consider and support meeting the health outcomes and needs of individuals on the autism spectrum? So home and community-based services can include many different kind of options. And Doctor Stacy Nonnemacher will talk more about home and community-based services in Pennsylvania, across the nation there are different ways that states think about providing home and community-based services. As you look at these examples and how they are often delivered through Medicaid waivers, it is also important to think what are the differences in how these services may be used across the lifespan? How do we think about the services that might be needed in childhood, adolescence and services that might be needed into adulthood. As we think about job coaching and how it may emerge during the transition to adulthood and during adolescence to prepare for that adult. Where a job is exceptionally important in thinking about ways people prefer to be in their communities. Thinking about supports for everyday activities and lives. Getting dressed, taking a shower, eating these are all services that directly linked to physical health outcomes because they keep people in their homes, communities and also help them meet the needs that they and we all have every day. To take care of ourselves.

One way that we thought about using the national data to consider service needs across the lifespan is to think about how in the last 22 years as we've seen the CDC's network continue to document the increasing prevalence of autism in the United States, how have states shifted their approach? We talked about how Medicaid is a partnership between the federal government and states and so in what

ways have states used the latitude on their end of that partnership to create new options specific to autism to allow for this increasing prevalence and for individuals to receive services. What you see on the left of this figure is where states started in 2004 (Reads) 11 states had waivers that only served intellectual disability and seven states had neither of those types of waivers. We do see changes in the middle part of the figure where you see the 10-year-old moving from the late great to the dark gray to the block, we can see that states increased the number of autism specific waivers that existed in hopes of serving this population and in hopes of addressing the needs of the population where we see an increasing prevalence.

We also map this out by state and so using color coding where Black states added autism specific waivers, darker gray added a waiver that serves both individuals with autism and ID and the likely states where there is no change. You can see how these states activated differently in order to try to meet the needs of this group. Of note there are three states that do not have the type of waiver that we thought about during the study. Vermont, Rhode Island and Arizona use a different type of mechanism to serve individuals.

As we think about the eligibility criteria for Medicaid, we can get a little more specific. We mentioned the affordable care act as a requirement for poverty to be at 133% of the federal poverty level and that equates to 16,971 for a single person in a year of.... Individuals in foster care pregnancy meet criteria for Medicaid. And when we've looked at the national data and sought to identify how people enroll in Medicaid, this is a table from a publication a few years ago using older data so this data is from earlier years 2000 to 2005 and found among autistic use aging into adulthood, more than one in four lost eligibility for Medicaid. They disenrolled. They no longer had access to that list of services that range from medical services, required by the federal government and those home and community-based services that really help to think about where individuals want to be and how they want to spend their time. Among those one in four disenrolled, about one and three were able to get back on to Medicaid and people who disenrolled and did not re-enroll in Medicaid were more likely to potentially face other aspects of health disparities for example individuals who are Black or Latin acts or (Indiscernible) as they aged into adulthood. It is important to understand where the gaps are happening so we can try to identify strategies to address them and retain access to Medicaid among individuals are more likely to need it. This is another recent paper using newer data using 2008 to 2012, sought to examine when exactly at what ages did autistic individuals aging into adulthood lose the access to Medicaid. Here we see spikes. Received literal points at 19 as well as age 21 where individuals were more likely to disenroll from Medicaid. There may be something important here about the transition to adulthood and people aging and getting older and about how states operate the programs. There are transitions during the aging into adulthood where individuals are assessed not only as a member of a family but then assessed as their own family unit. These changes could yield points of increased risk for individuals to lose access to Medicaid. It is an important way for us to think about the autism group which is the most at risk overall as well as during these two age groups in the study.

Another feature of Medicaid is to think about waiting list. There are many states where there are not enough resources to enroll individuals who may qualify for services. They put into place waiting list of individuals who are typically either known to be eligible for Medicaid or would be assessed for Medicaid eligibility prior to enrolling and they are waiting for the name waiting list. A number of individuals nationally who have been counted has been increasing and to date 2017 his last known count there was more than 700,000 individuals on waiting lists for home and community-based services through Medicaid. Of note there are also some states including some very large states that do not have waiting lists. They only enroll people when there are resources available to expand their Medicaid programs. So this waiting list numbers are startling large but we do not include any individuals who might also be waiting for services but have not yet been counted. We can see the largest proportion are individuals with intellectual or developmental disabilities, more than four 473,000 individuals of the last count in 2017 were waiting. So we did a study a few years ago with some autistic individuals who responded to it a needs survey. There were a variety of services and more than 1/4 indicated that they needed case management services. In the article we also saw reports of needing physical health services and resolve differences in risk for who needed the services across other known groups who were experiencing health disparities. It indicates that these areas thinking about waiting lists are needed.

So we have started to look at Co-occurring diagnoses, physical health condition specifically among individuals enrolled in Medicaid. This panel presentation you can see on the top there are a set of conditions for which autistic adults are less likely so they are at lower risk for having a co-occurring condition and there are set up conditions on the bottom where we see higher risks of this condition. We see elevated risk for epilepsy, Parkinson's, pituitary gland and other symptoms concerning nutrition metabolism all in places of increased risk for autistic adults in comparison to other groups. Individuals who do not have autism. This one is complicated but I will invite you to read the paper if you're interested. Another important element of the study was that the lead author was able to identify that there are racial and ethnic disparities related to risk for these co-occurring physical health conditions. So when we look across the different color dots individuals who have increased risk of a variety of conditions present new starting points for how we can consider how these diagnoses emerge, when they merge, how might we need to shift or change considering needs within Medicaid programs to meet these physical health condition. These are conditions many of which are neither could be life-threatening, like diabetes as well as conditions that are manageable. When services are delivered and provided to the individuals. This presents another starting point for us to understand where and how Medicaid is functioning and where it may need to continue to grow or evolve to meet the needs of these groups.

Other research not using the same data as founding there are high rates of prescription drug use and polypharmacy all across the US. We've also uses data to look at COVID-19 risk. This paper identified

that autistic adults that were enrolled were at higher risk for COVID-19. It indicates how beneficial it can be to study these issues within the Medicaid system for several reasons. First we have very large groups so we can see that many individuals who are enrolled in that allows us to do comparisons like those that we just displayed. It also allows us to take these findings and think about how can they be valuable to Medicaid today. How can we use these data to try and help support the system and thinking about change or when things are needed. How can we take the research and make it as meaningful as possible. With that in terms of making things as meaningful as possible I will hand the presentation over to Doctor Stacy Nonnemacher to talk a little bit about our great state of Pennsylvania and Medicaid programs.

STACY NONNEMACHER:

Thank you so much. I am so thrilled to be here to talk about the work we are doing here in Pennsylvania. We are lucky to have a brilliant mind like Doctor Lindsay Shea to be helping us in the administration of the adult programs we oversee. I will talk a lot about them in the next few slides. First just by way of a bit of context, it is helpful to know where we live within our Pennsylvania system. We are part of the government system that can sometimes be very complicated and we made it look less like a spiderweb here but it feels very spider webby as we go about doing our work but we do live within the Department of human services, the office of developmental programs with some of our other colleagues and partners, office of mental health, office of long-term living, children youth and family. If we drill down a little bit, in the office of developmental programs, there really are fear bureaus who we are overseeing specific programs in Pennsylvania. The Bureau of community supports a very long-standing barrel that oversees historic, intellectual disability waivers and our Bureau was established around 2006 established at the urging from stakeholders in Pennsylvania and in the beginning prior to bringing up these two adult programs, we were really established to consult to some of the other offices I mentioned who were serving people with autism. Whether they signed up or not right? They were serving kids with autism and behavioral health, in foster care and so we spent a lot of time early on consulting with those offices and we still continue to do that to this day but really where we put our effort and our vision was really to design these adult autism programs which I will focus on. Which we were so fortunate to build from the ground up. We built these two programs, adult autism waiver and the adult community autism program and had them approved around 2008 or 2009 but an interesting thing happened as part of our evolution that I think really is worth mentioning as I was listening to Lindsay talk about the national landscape. From 2009 until 2017, here in Pennsylvania four adults with autism the primary place of her receiving services was either in the mental health system or in the two adult autism programs that we had designed. They were not receiving services if they did not have a diagnosis they were not receiving services in these other programs. In 2017 we expanded eligibility criteria in those three waivers to include autism without ID. So the reason why bring this up, and I think it is important to this conversation is back to what Lindsay said about eligibility. This is one place where we have really had to think about what determines the federal rule for eligibility. What determines specifically what substantial functional limitation looks like which is part of that rule. Unlike

intellectual disabilities, we know with autism that (Indiscernible) does not predict functioning. We had to modify within our own existing processes those ID processes to account for this. So definitely some growing pains there in our state but again more opportunities as of 2017. Prior to 2017 again very limited... We had programs but we only had certain capacity within the programs so in 2017 we opened up all these other programs again, with some growing pains worked in there we were able to expand the opportunities for individuals with autism.

So before I jump into specifically what we have done in these programs, in the office we have a medical director who has been wonderful at initiating programs across the state, office wide and looking at some physical health in the state. The first one is our Fatal four initiative. These are the health issues of aspiration, dehydration, constipation and seizures. This is predicated on the concept that the more that support professionals know about these conditions and the more they are familiar with these medical conditions the more proactive they can be. So we know that if people can identify proactively when somebody is aspirating, dehydrating them we can treat them earlier. Since we started this large capacity building effort around the fatal four across Pennsylvania we have seen a decrease in incidents across those four areas. We also have what is called the health risk screening tool administered for those who are receiving residential services in Pennsylvania. If you don't know the HRS T is a screening tool that really is a risk management tool if you will. It looks at and detects health destabilization. Again more of a screening tool, a proactive way that we can keep our finger on the pulse in terms of making some real time care decisions specific to physical health. We also have within our regional offices in Pennsylvania, nursing staff. These nursing staff are really crucial to some of the things that we are seeing that cause red flags in our programs. Specific to physical health, medical needs. If we are identifying that a participant is struggling whether it is through the HR ST or other mechanisms that we have in Pennsylvania, we are able to bring in qualified nursing staff into the conversation to help us have these conversations about the quality of support that somebody is receiving. What providers may need to support someone better around their physical health needs and our nursing staff really will go above and beyond even if we are looking for them to do something like an on-site inspection to ensure that the home that the person is living in is supportive of their physical health needs. Or to provide any additional support that again the provider or the family or individual may need. Similarly, our office contract with what we call healthcare quality units. We have eight healthcare quality units in Pennsylvania and the primary function is at the request of providers, families or individuals they provide education and consultation specific to medical and physical health needs. They do diabetes training. They will issue health alerts like a flu health alert, heat advisory health alert and really is the arm of ODP, all things physical health overseen by our medical director in Pennsylvania.

I want to talk a little bit more about the two adult autism programs. As I said both were approved by the centers for Medicaid and Medicare services around 2009. At the time we were fortunate to design these from the ground up, what we knew about supporting this population. What we would do

differently for those of us including myself who had spent a lifetime supporting individuals in our ID programs. We also knew that there was a (Indiscernible) of research in supporting adults with autism. We are getting better as a field but we definitely have a long way to go. At the inception of our programs we were borrowing what we knew whether it was in the (Indiscernible) system or whether it was things that could be generalized that we knew were working in the ID system or the mental health system. We were (Indiscernible) the wheels of the bus as it was moving if you will. The adult community autism program which is the first one I'll talk about is a 1915 letter a managed care program. It is available to Pennsylvanians 21 and over and currently only available in four counties. Because it was new to us as a managed care program and new nationally as an adult autism program and again given the paucity of experience programs for us to learn from, we really wanted to start within these four counties. As Lindsay was going to the list of what Medicaid will cover both primary and optional, I couldn't help but think about the array of services that we decided here and Pennsylvania to include in the aCAP Program. They directly align with the needs assessment data that was highlighted earlier. You will see some of the employment pieces, a shameless pitch here that ACAP has some of the highest employment rates here in Pennsylvania in terms of employment of our participants in the program.

We do put a strong focus on all things home and community-based however, it really is a unique marriage of the home and community-based services and the physical health in this model. It is a participants health insurance and the provider that we have chosen to oversee the program was primarily or historically a home and community-based provider. They learned a lot about being a managed care provider and navigating the physical health services with the home and community-based services. Having that one provider oversee everything whether they are providing the services directly and they provide most of the home and community-based services directly or whether they are managing the provider network who is providing those services that this provider, the managed care provider is not providing directly. There really is a strong need then in a model like this to have very good case management, support coordination and assist with scheduling and maintaining medical appointments. We have heard anecdotally from families and individuals living independently what a huge burden that has lifted off of their shoulders. In our daily lives we are constantly navigating setting up appointments and keeping appointments and managing appointments and for some families and individuals who may have been struggling prior to coming into the program, this was really a big relief for them to have someone who was overseeing and navigating that for them. The one thing when I have conversations both internal to Pennsylvania and external that I like to highlight is really in a model like this, one of the primary benefits of a model like this is really the strong coordination which accounts for that holistic sometimes elusive supports that we talk about in HCBS and really truly can be done here in a CAP, one thing is to be able to be responsive. To be able to be timely in responding to what that participant needs and not have to go through layers as happens in some other waiver programs in order to get services changed, supports change, amounts changed, authorizations changed. This can happen easily and can happen on a moments notice within this program because it

is one provider who is overseeing everything. The director of health services that is part of the program has been a valuable addition to the provider administration and was identified as a need by the provider, not us as the administrative entity and they started including that as an executive position within this model. And he has been crucial to all things whether there are staff who need education on medical conditions that some participants may have and may need to navigate conversations with doctors or pharmacy as a registered nurse he is able to have those conversations. Another piece that Lindsay talked about polypharmacy was a significant concern for us when we were building these programs. We knew that oftentimes individuals with autism who are misunderstood may have had language but really struggling to communicate who was resorting to behavior to get their needs met were often medicated and heavily medicated. So at the outset of this program we rode into the agreement that the provider needed to have oversight of pharmacological and monitor that ongoing. The director of health services is really integral to us keeping our finger on the pulse with that with the participants in the program. The other piece is really just that are important to this program are those medical practitioners whether it is a family doctor or the PCP or if it's a specialty position they are really working very closely whether this was the director of health services or the support coordinator, so that we are able to better coordinate our goals, our treatments, our progress, everybody is bound by really one vision, one plan in this program. If the physician is part of the network of providers, they are contracted to be part of the team. Now in fee-for-service or a traditional 1915 C waiver model you will have a lot of different providers and lots of different positions outside of the waiver that sometimes gets like herding cats. Trying to get them to get together and stay consistent with treatment and same page with goals can get a little cumbersome. Like I said, there is community support at the hallmark of this program as well wanted to get folks into the community and wanting to get folks employed if that is their desire and what we knew and one of the pieces that we borrowed from what we knew were 12 children, transitioning is using a service like behavioral support services to guide using techniques like applied behavior analysis to help build skills, shape behavior, to help people to really be able to benefit from fully and meaningfully being engaged in the community. So I always like to, and we do a lot of work together but I like to highlight the cases from our programs and in this particular case, we have a gentleman that has been with the program for almost a decade and before coming to the program he had a bachelors degree in electrical engineering and graduated from college but he had experienced some significant deterioration and ended up in a state hospital for five years. He enrolled in our program and he returned home. And we are assisting his elderly parents with ongoing coordination of his medical care. Again from the physical and mental health, losing skills, mobility, cognitive functioning and saw a lot of specialists and ACAP was helpful to the parents and there was an increase in physical aggression the parents were living in fear and because the provider was able to see this early on, they were able to prevent and plan for transition to residential services. They could support him in a home of his own with behavioral specialist services, residential (Indiscernible) services, skill building services and focusing really on his goals being physical therapy and activity to minimize or prevent further decline in mobility, working on communication instead of physical aggression and property destruction, working to identify his own physical health needs when he was in

pain because sometimes the hypothesis was that he was engaging in this aggression because of that. The director of health services has been crucial to all of this in bringing the staff along so that they are able to more appropriately support him. That is just an example of that program and I will switch gears a little bit now and talk a little about the adult autism waiver which is a 1915 C waiver and this one is considered a fee-for-service waiver. It is very similar services, much the same home and community-based services but does not have all of the bells and whistles of the physical health services but I still want to talk about the unique services that we can bolster the physical health for individuals.

We have what's called specialized skill development suite under there there are three services we find these to be crucial services because they span early NAS estimated that we identify with an individual. If we are assessing that there is a need around physical health, we can design plans to teach skills. We can design plans to address behaviors that are interfering with optimal functioning and we also have outside of systematic skill building and behavioral support services to community support service. Those folks are implementing the plans that the clinical folks have developed to build the skills and to address behaviors interfering with optimal functioning. It is easier to get a flavor of what that looks like with some examples. In terms of systematic skill building, we had a gentleman come in through Adult Protective Services and hadn't been to a doctor in years and was overweight and had high blood pressure. The team really worked with him on making healthy decisions as well as identifying and choosing healthy meals and snacks and they encouraged him to try new seasonings aside from salt which he always used to flavor his food. It all sounds rather simple but integral to his overall physical health. The team also worked with him on scheduling and attending appointments because it was something that he struggled with. And this led to him getting proper medical care to meet many of his untreated medical needs. These services work very closely with one another and another example we see quite a few participants in our programs who have boarding behaviors. We have one gentleman and it had a direct physical impact on his health. They built a strategic behavioral support program to tackle some of the cleaning. So they started with the most frequently accessed areas and then they moved to places where guests would congregate because he wanted to be a host but he knew that the state of his home was not something that was welcoming as I remember him saying. The team also worked with him on the curb appeal and just being neighborly. And really when it was done in this really systematic way, from a behavioral perspective, we saw a significant decrease in his physical health systems again that decrease in chronic respiratory issues, a decrease in things like bedbugs and an increase in being included and socially engaging with neighbors because he was in the neighborhood. We also have folks who have gender identity needs. I know of two people who needed support including (Indiscernible) so they could learn from, be around and engage with people from their community and struggling with similar things. We are able to use those community support services to support individuals to find and attend those community support groups. So some of the typical physical health goals and supports that you would see in both of these programs not just a AW are around things like medication management, many folks living independently that struggle to manage their medications so whether that is a need in some sort of adaptive place to help them

remember to take the medications. Some have specific health conditions like diabetes, seizure disorders or rehabbing injuries. As well as as Lindsay pointed out, a need for nutritional consultation. We see a lot of that and exercising and staying active. Certainly as I mentioned several times just even the act of managing and attending medical appointments. This is a population who has oftentimes have some significant issues around executive functioning and planning the day. So in these programs determining the services is dependent on assessment protocol and part of the protocol is a risk identification tool that we created and we did that together along with some other colleagues. We are proud of the tool which is a quick screening to show the participant has increased risk in any area. So rest like law enforcement, chronic medical conditions, unstable living environment. The tool paired with other standardized tools gives the team a roadmap to what services and supports like the ones I talked about would be helpful to address the needs.

I'm going to turn it back to Lindsay now and hopefully that gave you a flavor of the two programs and with the case examples gave you a sense of some of the things we are able to do within the programs to address the physical health needs of individuals.

LINDSAY SHEA:

Was a great way to take on and see what is happening in states. So we actually went back and forth a little bit around trying to think about resources and that is challenging when we think nationally about Medicaid. There is the centers for Medicaid and Medicare services which has the guidelines for all Medicaid programs. The assert program partnered with the autistic self advocacy network to create a self advocate guide which contains a lot of information about how to navigate Medicaid within your own state and locally in the programs and services you might need. The administration for community living has state specific protection and advocacy systems in all states that individuals can tune into and ask questions and help to guide you towards Medicaid program. We have two links for you in the presentation and you could search for those resources as well. So of got a placeholder here for questions but did you want me to show the end slide?

MADLINE HALEY:

We are at time that would be perfect. I think if you're willing to stay on for a few extra minutes, you can answer the questions that are in the chat but I want to be respectful of everyone's time. So we have a feedback survey which I will also put in the chat. And then our social media handles and if you go to the next slide, we have our webinar for January 18 which will be in the new year which will be (Unknown name) and he will be part of that and I will send the link for that as well.

LINDSAY SHEA:

One question was are the services widely known by individuals who need them. Other families who may not know what services they have access to with Medicaid?

STACY NONNEMACHER:

In Pennsylvania the services within the programs you mentioned are known to those folks that become known to our county. We are a county administered program primarily in Pennsylvania so I think what you're asking, is for those individuals who are enrolled with the county they know what programs or services are available by programs? I'm not sure.

LINDSAY SHEA:

It is hard if the nature of your questions that people need to know about Medicaid programs to enroll in them. There are efforts by the state to make sure that there is outreach to a variety of communities and for example in Pennsylvania there is the asserted collaborative which makes lots of information about the programs known all across the state but I think there are probably variations in how states handle outreach about programs individuals can access and in some ways, there are initiatives so for example certain populations like graduating high school seniors can be targeted for enrollment in Medicaid programs to help make sure they retain access during those critical windows and the transition to adulthood. But there is certainly not a guarantee that all individuals in all places know about all Medicaid services available to them. It's a great point. And relevant to health outcomes as well. And it looks like we have another question around the services you are walking through. Today include occupational therapy?

STACY NONNEMACHER:

Yes they include occupational therapy as part of the physical health services in the program. In the adult autism waiver when we first started the program we did include and it was one of if not the most underutilized service in the program. I think at the last renewal we had zero participants were using OT so we did remove that from our service array but that is part of the estate plan as well so people can access occupational therapy that way.

MADLINE HALEY:

Thank you so much again Lindsay and Stacy and thank you everybody for attending have a great holiday and we will see you in 2022 with our January webinar. Thank you.

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