

Resources for Integrated Care
Intellectual and Developmental Disabilities and Behavioral Health: Leveraging Person-Centered Approaches
September 27, 2023

Leslie Bishop (Facilitator)

Hello everyone. My name is Leslie Bishop, and I am with the Lewin Group. I am honored to serve as your event facilitator today. Before we begin, we would like to orient you to the platform.

Audio should automatically stream through your computer's speakers. Please make sure that your computer is connected to reliable Internet and that the speakers are turned up. If you are experiencing any difficulties with your connection, please turn off your network VPN for the duration of this event, there is no phone dial in option. The recording will be available after the event.

In the center of your screen, you will see the slides for today's presentation. Below the slide presentation are resources you may download including a PDF of today's slides along with a *Question and Answer (Q&A)* box where you can enter questions for our presenters or chat with the webinar team if you need support.

Our team will also send helpful messages via the Q&A box. Closed captions are available if you select the *Resources* icon, you can move the windows around to fit your screen. If you minimize a box and want to bring it back, you can click on the associated icon on the bottom of your screen.

Welcome to the webinar, *Intellectual and Developmental Disabilities (I/DD) and Behavioral Health: Leveraging Person-Centered Approaches*. We are grateful you took the time to join us today and are looking forward to sharing promising practices to support behavioral health needs for individuals with I/DD.

Today's session will include presentations from our esteemed presenters, a panel discussion and we will close with time for questions and answers.

The recording and a copy of today's slides will be available at www.resourcesforintegratedcare.com.

Continuing education credits are available at no additional cost to participants. We strongly encourage you to check with your specific regulatory boards or other agencies to confirm that courses taken from these accrediting bodies will be accepted by that entity. Social workers may obtain one continuing education unit (CEU) through the National Association of Social Workers. For those interested in continuing education, you must complete the pretest at the beginning of the webinar as well as complete the post-test with a passing score by 11:59 PM tomorrow, September 28.

This webinar is supported through the Medicare Medicaid Coordination Office (MMCO) at the Centers for Medicare and Medicaid Services (CMS). MMCO is helping beneficiaries

dually eligible for Medicare and Medicaid have access to seamless, high-quality healthcare that includes the full range of covered services in both programs.

To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, 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, please visit our website or follow us on Twitter, recently rebranded as X; our handle is @Integrate_Care. You will also find us on LinkedIn.

The road map for our time together today is as follows. We will start by collecting some information from the audience via two polls. We will then provide some background information about the prior 2022 Resources for Integrated Care (RIC) webinar and resources about individuals with I/DD. Then our esteemed presenters will share the following presentations. Dr. Andrea Witwer will present about intellectual and developmental disabilities and behavioral health conditions management complexity. Olivia Ayers will then present on supporting the system in the I/DD and behavioral healthcare landscape. After these presentations, our panelists will offer their perspectives in a guided panel discussion.

Before we engage in some audience Q&A, if you have questions, please type them into the *Ask a Question* box and we will go as we go and we will answer as many as we can. We will close by sharing additional resources and requesting your feedback on the information shared today.

At this time, I'd like to introduce our presenters and panelists. Dr. Andrea Witwer is an Associate Professor in the Department of Psychiatry and Behavioral Health and Psychology at The Ohio State University and is a Director of Training for the Nisonger Center, University Center of Excellence in Developmental Disabilities.

Dr. Witwer has extensive experience providing interdisciplinary clinical services and conducting research in the field of I/DD, including publications regarding cooccurring emotional, behavioral, and psychiatric disorders, and those with autism spectrum disorder and other developmental disabilities.

Olivia Ayers is a Licensed Clinical Social Worker and the Clinical Director at Elevate, a Certified Community Behavioral Health Clinic which applies the Provider Prevention and Support Services Initiative to address the needs of individuals with I/DD and behavioral health conditions.

Olivia directs all clinical services offered to individuals served and ensures that evidence-based models are being implemented for crisis intervention, care coordination and staff development, long-term services and supports providers to promote cost-effective, high quality care delivery.

Dr. Patricia Nobbie is a mother of an adult child with Down Syndrome and has worked in support of people with developmental disabilities for nearly four decades.

Her work spans the public sector at both the state and federal level and the private sector, serving on several advisory boards for projects exploring healthcare accessibility for people with I/DD and mental health conditions.

She will be joining us for the panel discussion where she can speak to her experiences as a caregiver and advocate.

Thank you to all our presenters for sharing their time with us today.

As noted earlier, we are going to poll the audience before we launch into today's presentations. The goal of these questions is to get a better sense of our audience members today. To ensure all participants are able to participate in this poll, I will read each response option aloud. If you participate, you can chat in your response or click the button corresponding to your response.

You should see a pop up on your screen asking which of the following best describes your professional area.

The options you may select from are health plan case manager or care coordinator, health plan customer service, health plan administration or management, medicine, nursing, physician's assistant or other provider, pharmacy, social work, advocacy, or other.

I'll get it just a moment so we can see the top responses come in here. Okay. It looks like we are gathering our results and we'll move to the next slide.

Our second poll asks in what care setting do you work?

Response options include health plan, ambulatory care setting, long term care facility, home care agency, community-based organization, consumer organization, academic or research, or other.

And we'd like to thank everyone for their responses. We will be moving on. Thank you all for your participation in those brief polls.

This event will accomplish the following learning objectives: Recognize the impact that siloed systems of care have on efforts to implement effective care coordination and care planning strategies. Apply person-centred approaches for identifying behavioral health conditions in individuals of I/DD and understand the lived experience of individuals with both diagnoses. Recall holistic care coordination strategies that support the unique needs of and improve outcomes for adults with I/DD and behavioral health conditions. And identify the roles that community-based organizations can play to address social determinants of health and strengthen provider networks.

I'd like to set the stage by reorienting the audience to the prior RIC webinar event and existing RIC resources to support individuals with I/DD. Effective care coordination and appropriate medication management are important for improving outcomes for individuals with I/DD and mental health conditions. RIC has several existing resources that can support these aims.

In the 2022 webinar *Strategies for Improving Care Coordination for Individuals with I/DD*, expert presenters discussed strategies for effective care coordination and process improvement to meet the holistic needs of individuals with I/DD.

Also, the spotlight on Partners Health Plan provides insights into effective medication management and the challenges posed by polypharmacy in the population of dually eligible individuals with I/DD.

I am looking forward to some engaging presentations from this impressive group. So, without further ado, I will turn things over to Dr. Witwer from the Nisonger Center at The Ohio State University who will share insights on managing the complexity of co-occurring I/DD and behavioral health conditions.

Dr. Andrea Witwer

Thank you, Leslie, and thank you everyone for joining us today as we talk about this really important topic. I'm going to start on the next slide and talk about the background and prevalence. Just really, why is this an important topic that we should be discussing?

We think about the prevalence of intellectual and developmental disabilities as well as mental health conditions. We know there's an estimated 7.39 million people in the United States that have some type of intellectual or developmental disability as of 2019, with more than 70% of them being children.

When we look at the prevalence of intellectual and developmental disabilities among adults, we estimate it at 7.9 per 1,000 adults.

When we look at it in comparison then we look at mental health conditions, we see that those prevalence rates of co-occurring, intellectual and development disabilities with mental illness, there's a really wide variability.

But what we do know is that they're higher in those with I/DD as compared to those without an intellectual and developmental disability. So, rates of mental illness among people with I/DD vary from 10 to 60%, averaging somewhere around 30% compared to 8 to 18% among all adults.

So, this is definitely something that's disproportionately impacting adults with intellectual developmental disabilities. Same when we think about autism, autistic individuals have 5.2 times greater odds of having at least one psychiatric diagnosis compared to those without any type of developmental disabilities.

And even compared to their peers with intellectual and developmental disabilities, they're at almost two times greater odds. They have an almost two times greater odds of having at least one psychiatric diagnosis. Next slide. Well, so we think about why is this?

We know that adults and individuals of intellectual and development disabilities across their lifespan are more likely than those without disabilities to experience a lot of risk factors for mental illness.

This includes, but isn't limited to, stressful family experiences and situations, stigma, abuse, neglect, unemployment, and lack of supportive friendships. They also experience trauma and develop post-traumatic stress disorder symptoms from traumatic events.

They're more likely to have an undiagnosed psychiatric disorder and to receive psychiatric medications without a psychiatric corresponding diagnosis. They're also more likely than people without disabilities to experience hospitalization for an adverse medication event.

Next slide. When we look specifically at the research related to dually eligible individuals with intellectual development disabilities, one study looking at those dually eligible individuals found that almost 59% had at least one mental health condition.

So this is a group with a highly disproportionate number with intellectual development disabilities.

Another study found that any primary psychiatric diagnosis and a claim for an adult with I/DD resulted in a 40% greater risk of having an emergency room visit as compared to those without a primary psychiatric diagnosis.

Another data review found that individuals categorized in the top 10% of persistently high healthcare spending were more likely to have an intellectual and developmental disability compared to those who only occasionally had high healthcare spending.

So this is very important. We have this interaction of mental health paired with this group that already is at risk for these persistently high healthcare spending needs. And these data just really emphasize the importance that we're meeting those needs of mental health and meeting mental health needs of these individuals. Next slide.

We think about the potential impacts of mental health conditions beyond emergency room visits, which we've talked about. We also see increased parental and caregiver stress, increased use of psychotropic medication, and poorer long-term outcomes and functioning in general.

We also see an increased risk for exclusion, which can be compounded for people with behavior labelled as challenging such as self-injury and aggression. We see these individuals may be left out of community services, they may be placed in larger scale, congregate or secure accommodations, and may be subjective to abuse and restricted practices. So lots of widespread impacts of mental health.

Next slide. So, how do we navigate the system? What are the experiences that adults with I/DD and care providers have and working within the system? Let's go to the next slide.

We know that often in states, mental health and the I/DD systems are not always integrated. Often, they're in separate locations.

And so this poor integration between behavioral health and physical health symptoms and I/DD systems really causes it to be really difficult to meet those complex healthcare needs. It can often lead to a poor integration and this poor integration can lead to a lack of awareness among providers within this system.

What we'll often hear is that the I/DD system and the mental health system each perceive that there are more resources available within the other system. So, it's this idea of not maybe knowing the other system to know what resources are available.

We often find I/DD providers may lack that mental health knowledge to really meet those needs and identify the sources of behavioral and mental health treatment.

Then we often on the other side will see mental health providers that could exclude adults with I/DD just based on their intellectual and developmental disability diagnosis, preventing access to things like intensive outpatient or group therapy.

Next slide. We did some work within our state asking the perspective of providers on what this siloing of systems, what some of the results are. And what they shared with us was that the, "ways to get mental health and developmental disability systems to work together would be useful." So if we could really find a way, this provider shared that, "it's sad that after all these years we still have people who are in the wrong system."

Mental health says their issues are developmental disability, and developmental disability says their issues are mental health. And we have folks that are stuck in the middle with limited help. Another shared it's hard to find someone who's comfortable with both mental health and I/DD diagnoses.

Usually it's one or the other, despite the fact that very little changes in terms of treatment of these individuals. So, I feel like it's just training to become more comfortable that is necessary.

Another provider shared that, "mental health seems unwilling or lacks the time, which I think is an important piece to work with me or to attend team meetings where their expertise is invaluable to the team." Which I think then goes into that last quote, which is where those, "direct support care staff need to have access to behavioral health consultation."

So they're making sure that they're meeting those mental health needs of adults with intellectual disabilities and individuals with intellectual disabilities when they're working with them on a daily basis.

Next slide, we also talked to adults with intellectual and developmental disabilities, and they shared their insights really talking about the value of providers collaborating and working towards a common goal and the benefits of inviting family and other supporters and team members to appointments.

The one gentleman shared, "I think it's a big thing when they all talk together, they all know what can be the issue, so they can work together to a solution." Being able to work from the mental health, from the developmental disability side, "you know, so everyone's not trying to do different things."

Let's have a cohesive team that can work towards that common goal. We heard many examples of how that does work and these adults shared value in that very much. Next

slide. To talk about the challenges with the systems, but let's talk a little bit about how do we identify mental health conditions in the population and what does treatment look like.

So on the next slide, we want to think about how we identify treatment, identify mental health conditions. So, prior to initiating treatment, mental health conditions had to be identified. We can't get folks the help that they need if we aren't able to identify it.

And what's really important here is that the data and information need to come from a whole-team approach. We need to get information from the individual themselves, talk to their parent or caregivers, providers, educators, or the work staff at their work placement and other support professionals. Really working together to understand if there are changes in the individual's behavior, mood, etc., so that we can start to work towards identifying those mental health conditions.

The problem is there are challenges on that basic level of identifying symptoms. So on the next slide we'll talk about the first one which is diagnostic overshadowing. Diagnostic overshadowing is a negative bias that impacts a clinician's judgment regarding cooccurring disorders in individuals who have an intellectual and developmental disabilities.

It occurs when a health professional, or really any professional, makes an assumption that a person with I/DD's behavior is part of their disability without exploring factors such as that it might be due to a mental health, or a biological determinant separate from that individual's disability.

So really what happens is that psychiatric symptoms in this diagnostic overshadowing concept are all attributed to the developmental disabilities. In addition to identify it getting in the way of identifying psychiatric conditions, it can also get in the way of how the case is conceptualized and the treatment planning that goes on, next slide.

So here's a case example to just kind of help illustrate what happens with diagnostic overshadowing. So we had a referral for a young woman who was 18 years old who was referred for diagnostic clarification.

She was referred by her psychiatrist, had a previous diagnosis of autism as a young child, used short phrases to communicate, and had a diagnosis of mild intellectual disability. The family had recently raised concerns about increases in agitation, disorganized speech, which was different from baseline, and additional odd behavior, as if she was seeing things that weren't there.

When I spoke with the treating clinician that referred her to me, the individual felt that this was all just part of the autism spectrum disorder. And it really when we started to talk to the family, it was a failure of the clinician to understand the change in baseline and the unique symptoms were really part of psychosis.

So just this idea of thinking, well, all of these different behaviors, these odd behaviors are part of a diagnosis that is a part of the developmental disability really let that psychiatrist to not be able to more effectively and quickly treat the individual.

Next slide. We also know there are other barriers to an accurate description of symptoms. Individuals with intellectual disability or language and communication impairment can have difficulty interpreting their internal states or may have difficulty reporting them to others. So, we often rely on secondary reporters to communicate symptoms.

And we know, I think of yourself, your parents, your spouse, whomever doesn't always know how you're feeling. It's the best we can do. We often see when we ask individuals with disabilities themselves, we can see some self-report biases that we have to think about where they may just agree with everything that we say, or they might just pick one response and keep going.

So it's definitely not an easy task. Next slide. So, what can we do? Talk about how hard it is. Let's think about what we can do, and it really is watching the individual for changes in behavior.

So things that can be red flags are an increase in agitation or energy level, or a decrease in energy level. Someone who loses interest in activities that they were previously interested in, sleep problems, sleeping too much or too little, weight gain, too lot, too much or too little.

These observable symptoms can often be that first warning sign for us. We want to also listen to the individual. Are they reporting feeling, such as sadness or feeling tired or grumpy? Are they worried? Clingy?

Things that we might see as being part of an anxiety or a depressive disorder, and tracking their mood, often there are a number of different team members involved.

We can look and see patterns. We can see that an individual has felt like this. Decreased energy, decreased appetite, decreased motor level for the last two weeks, then we really maybe should be worried about a major depressive disorder.

Then after you have this information, it's really great to reach out to the primary care physician. They can help you work through this process and or request a referral for a mental health evaluation. Next slide. We want to think first about recognition.

It can be difficult for providers and caregivers to recognize the presentation of mental health and especially when we think about individuals with disabilities maybe can't always advocate for their own needs. So, that recognition is really a concern.

Caregivers and support people play a really important role in helping to identify the changes. They're really the ones that are often the most aware of the individual's pattern and their typical disposition and can see those changes in baseline.

And I think it's really important for us to really be paying attention early on. When we hear we talked to mental health providers, they often report the belief that often they see family members are not seeking help until they're not able to manage until things get to a crisis level.

So if we could be able to really get at it early, we can get to get the individual the help they need before they need emergency services.

Next slide. A model that I like to use when identifying behavior changes is the HELP model. I'm going to walk you through in the next few slides what that means. But when we think about it, this is a model that like everybody to apply when working with a concern.

We want to first look and say, okay, is the eating an issue because of a health condition or a medical condition? Have there been changes in the environment? Have the supports changed? Have the expectations changed? What's going on in the individual's life? Have there been new life experiences? Has there been a trauma? Has there been a change in social support?

We want to go through all of those things and address each of them and then look at the psychiatric disorder. We also then want to think of all of this within the context of the individual's strengths, their vulnerabilities, what might have happened to bring things on, and what might be going on to keep these challenges going.

So on the next slide, when we think about physical health, we really want to look at medical conditions, hearing or ear infections, how self-injury, irritability if your ear hurts, gastrointestinal distress, urinary issues, and menstrual cramps.

All of these things can cause changes in behavior and can be addressed to help make things better for that individual and may help to ameliorate their difficulties. Same thing with dental conditions. Often dental is not always paid attention too closely. There could be cavities or dental pain that needs to be taken care of.

Also things such as thyroid dysfunction, seizures, or vitamin D deficiency. All of these things can be associated with behavioral changes, and you also want to look at those environmental factors. Has there been a death or a separation from a parent, a family member, or a caregiver? An important one is a change in support staff or a long-time support person that's no longer involved. This can be very traumatic and feel like a loss to individuals, including a roommate change.

We also want to look at those expectations to make sure that the family and support staff has appropriate expectations and if the individual have access to activities and social connectedness. All the things that we know promote positive mental health.

Next slide please. Another important piece that we really want to think about is trauma.

Research shows that individuals with I/DD are at significantly more risk for adverse childhood experiences and other forms of abuse and neglect as compared to the general population. For example, studies have found that individuals with a disability are four times more likely to be a victim of crime and 3.4 more times to be neglected. Approximately half will experience 10 or more traumatic events in their life.

Another important thing for us to realize is that events can be experienced as traumatic for individuals with I/DD, and they may not always be the things that one might think of as traditionally traumatic.

This could be events such as the loss or the moving away of a staff member, undergoing a medical procedure, or even the loss of control in specific situations or with a specific person can be very traumatic for an individual with I/DD. Next slide please.

There are a number of vulnerabilities on the systemic, personal, and societal level that can increase the risk for traumatic events. Some of them we may not be able to address, but others we can. So, we look at those systemic ones.

We see high levels of stress within families and that can be multi directional and increased risk as well as the greater reliance on caregivers. Sometimes the trained compliance to authority figures. Also think about personal vulnerabilities.

An individual is restricted and their abilities to communicate not have access to the tools that they need to express their wants and desires.

They may have difficulty predicting high-risk situations and may not always understand that an abusive situation is abusive. I think there are also societal vulnerabilities that we've seen in the literature. An important one is a lower likelihood of education about human sexuality.

So, we think about things we can address a number of these on here. Stigma and societal assumptions of folks with intellectual disabilities. These are things we can work towards addressing at all of these different levels.

Next slide please. So, how can providers and support staff support mental health? We know that the use of mental health services does not match the prevalence of mental health.

So, we really need to work towards identifying the folks that need that treatment and those folks that are working with them every day can identify those changes in behavior. Be supportive when someone starts talking about referral to services, are asking for help, assist with arranging transportation, that can be a huge barrier for some folks and making sure that an individual has adequate transportation to their medical appointments and their mental health appointments.

And then really involving providers and support staff in therapy as it's appropriate. That psychoeducation and the work on generalizing therapy can be a very powerful tool. Next slide please.

And it's important that we get folks to treatment because there is a growing body of literature supporting the benefits of psychotherapy for adults with intellectual disability. We see research supporting dialectical behavioral therapy, cognitive behavioral therapy, and mindfulness.

Overall, the research base is really rapidly expanding, and we're really starting to understand and realize that individuals with I/DD, children and adolescents and adults can benefit from psychotherapy.

There was a study that was done by the World Health Organization where they reviewed 92 studies. They found nine that met the criteria for inclusion in their meta-analysis and basically found that psychotherapy can produce change, and at least two out of three of the

measures they included changed. This is something we want to make sure we get folks linked with.

Next slide. So once you get someone linked with therapy, what does that mean for us? You should see a clinician that will make recommendations specific to that individual and their mental health needs. That individualized treatment is something that we should be looking for with the clients that we serve.

Treatment should be multifaceted. We want to think of it as not just medication. Medication can be a very powerful and important tool. However, it's not the only tool. We look at combination of psychotherapy and then behavior support as needed.

You should also see with your clinicians, recommendations on environmental, educational, and work supports that can help to support that individual's positive mental health and help to reduce relapse.

The other thing that can also be very important and is something to advocate for is to have a plan in place for emergency situations so that all the team members can meet the mental health of the needs of the individual when they are in crisis.

So, you can see it's very important from the recognition phase all the way through to meeting with the clinician that we have this team approach.

It's through this team approach that we can really make sure that we're providing that person-centered and integrated care for the adults with intellectual disabilities.

So, thank you very much. And with that, I will turn it over.

Leslie Bishop (Facilitator)

Thank you very much Dr. Witwer for sharing these valuable insights. I'm going to move ahead to Olivia's slide presentation.

Next, I would like to introduce our next speaker, Olivia Ayers, the Clinical Director at Elevate Certified Community Behavioral Health Clinic. Olivia will share information about systems of care for individuals with I/DD and behavioral health conditions. Olivia, the floor is yours.

Olivia Ayers

Thank you so much Leslie. So as Leslie mentioned, I am going to be spending some time with you all talking about how we support the systems that we are working with. Next slide please.

So, I work for the START network, I work out of Iowa and the START model is an evidence-based model that is based around supporting the system and individuals with an intellectual and developmental disability.

So, I'm going to spend some time with you all today talking about the START model and specific aspects of the model that can be integrated for a positive and effective systemic support.

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We can see here that the START model's guiding principles include things like a strengths-based approach. So, this really pulls from positive psychology, wellness-based also pulls from positive psychology. But this is really about the thought that the absence of a crisis does not mean that there is wellness there. We use the biopsychosocial model, trauma, informed care, cultural competency, and a person- and family-centered approach. Next slide please.

In the Public Health Model, this is a piece of what is used in the START model that I just want to touch on some of these levels because we'll be referring to these throughout the presentation today.

So we have a primary level. These are when services are provided to the community to build their capacity. So, it's building your capacity to serve individuals today, but also, it's building that knowledge base so that you can serve individuals in the future that you may not have even met yet.

Secondary services, this is an area where service providers tend to spend most of their time. This includes direct services. So, when we're providing a direct service to the system or to the individual that we're supporting, those would be considered a secondary service.

And the last one is tertiary. So, these are emergency services. They are typically very costly and those include things like using the emergency department, being hospitalized, ambulance, things like that.

We can go to the next slide please. This is an image of the Public Health Model. So, when we are in primary services, we are proactively supporting the system members to support individuals they are currently serving and will serve in the future. And we have the potential to defuse crisis before we even meet the individual.

So, we can learn things that defuse crisis. So, when we meet new people or the people that we're serving right now, we can actually start to defuse those crises very proactively. And then you can see how the services funnel all the way down to tertiary services.

And this is where the resources are very limited. We are reacting to crisis events that have already occurred and the options for successful intervention are narrowing.

So, that's why we see our inverted pyramid where we start to get really small there in the tertiary services. Our goal is to get out of the tertiary level and to stay in that primary and secondary interventions.

So when you support an individual or a system, the system can also be the ones that are in a crisis. When we're supporting a system in crisis, we have to respond to the tertiary need. Those are a lot.

There's a lot of safety factors that go into tertiary services, so we want to respond to those. And as we're doing that, we need to be learning from the crisis and planning for what we're going to do the next time.

So, following that crisis event, have a team meeting and talk about what happened, how did the system react, and what are we going to try next time when we move forward. What did

we learn that works and what did we learn did not work, so that we can continue to adjust that and get ourselves out of the tertiary services. Next slide please.

And this takes us to another important aspect of the START model, the biopsychosocial model. The biopsychosocial model considers biological, psychological, and social factors. So, it's really a holistic model of support.

We want to learn and assess the individual's biopsychosocial baseline so that we can identify potential crisis early on and keep ourselves and those individuals out of that tertiary service usage.

So, for example, I served an individual that appeared to be very depressed and as a result she was put on many antidepressants medication. She had been hospitalized at a psychiatric facility on multiple occasions.

And when we really used this model and considered the biopsychosocial reasons for a change in her baseline. Through lots of services, we were able to identify she actually had extremely low vitamin D levels. And once we were able to get the vitamin D levels back on track and in that normal range, the depressive symptoms started to go away.

And so then we were able to work with the physician prescribing medications to start slowly decreasing those because now we know more, and we know that she doesn't need all of those. Next slide, please.

So, assessing biopsychosocial factors ensures that we catch what we might have otherwise missed.

If I come about services only through my therapist perspective and I miss that there's low vitamin D levels, I'm not going to see the progress that I'm hoping to see for that individual. A biopsychosocial lens helps us to prevent unnecessary interventions and guides us to the best possible interventions.

So when we unnecessarily provide antidepressant medications, because that's what we thought we needed to do, if we use this model, we can identify when we don't need that and reduce some of those interventions.

So, another example, we served an individual that began hitting his head on walls. He started hitting staff and yelling, declining to engage in activities and he was completely nonverbal. So, this individual was taken to the emergency department. Many times he was hospitalized at a psychiatric facility many times, and he was given antipsychotic medications after many, many months of this behavior going on. We later found that he was having severe migraines and that he really just needed support for those migraines.

We also identified how can we identify a migraine is coming. So, when he started to pace and tap his head with his hand, that was how we knew a migraine was coming and we can administer a PRN (as the situation demands) medication.

So, we had this crisis that was happening over and over, and we kept trying to figure it out. We had consultations, we did observations, we had team meetings and after trying many,

many things, we identified migraines and then we were able to really proactively plan with the primary care provider to keep that individual out of those tertiary services.

So, we had this backup plan in place. His primary care physician was willing to put in a standing order for a migraine medication that he could get at the emergency department without an administrator to the emergency department or going to his office, if the office was open.

And that was able to avoid tertiary services and also provide a lot of healing to the individual experiencing those migraines. Next slide please. This is going to take us to the three A's as we call it in the START model, Access, Appropriateness, and Accountability.

Access is really assuring that all the services are inclusive and that they're community based, and they're offered in a timely manner. So, when that person needs them, appropriateness is ensuring that we have the right system members. So, if somebody has a seizure disorder, but we recognize they don't have a neurologist on their team, we're missing an important system member and we want to bring that member into the team.

Appropriateness is also ensuring there is linkage between providers to ensure that everybody is aware of the treatment plan. There's accountability to ensuring everybody knows the roles of each person within the system.

Outcomes should be clear, and data-informed to provide high-quality and cost-effective services. So, something that we can do is really supporting a system in utilizing these three A's. Next slide, please.

So, positive psychology is a wellness- and strengths-based approach to services. This means the absence of crisis is not wellness. Positive psychology pushes us to supporting individuals not just in decreasing their crisis, but also increasing their quality of life and their overall wellness. Positive psychology gives us a strengths-based foundation.

So, this means we know and incorporate the person's strengths, skills, and interests in helping us to defuse a crisis, but also incorporating those into their day-to-day life to ensure that they have a good quality of life.

Using person-, family-, or system-centered language is really crucial for creating an environment that is solution focused and uses a positive outlook. So, you can see on the slide there's a few examples here.

So, we might say a person is complaining of a headache versus they're reporting that their head hurts. This is a more workable problem. We can offer a PRN medication, or we can reach out to a primary care provider if we need to.

Attention-seeking versus they're seeking connections. It's not as simple as they're just attention-seeking, but they are seeking relationship and connection with people. How can we proactively ensure that they have that time for connecting with people to make sure that those needs are met.

Saying somebody's non-compliant versus their choice is....

So, instead of saying they won't take their medication, saying their choice is to not take their 4:00 PM medications, and the system can explore options and reasons as to why that might be.

A difficult family member versus this individual's mother is the strongest advocate I have ever met or this family member or this friend is invested in the individual's wellbeing.

That makes that individual an important part of our system and it makes any problems that we're having much more workable so that we can support those. Next slide please.

So, Seligman and colleagues reviewed research on other individuals that were studying happiness. And this is where the PERMA+ model came into play. What they found was that individuals reporting high levels of happiness had a few things in their life. They all shared PERMA+ in that research.

So, they focused on having positive emotions daily; they were engaged in something daily. They really tried to experience the world around them through that engagement. They had strong relationships and connections; they felt meaning. So, meaning is being a part of something that feels bigger than yourself. They also experienced accomplishment.

And then the [plus] was added later for overall health. So, things like exercise and eating healthy, those types of things. So, this is of course important that the individuals we're serving have access to PERMA+ on a daily basis.

But when we're supporting a system, our system also needs PERMA+ in their life. They need an opportunity to experience a positive emotion. They need to feel that meaning like they are a part of something bigger.

We need to have relationships, connections, and accomplishment. They may complete a task that leads to some accomplishment.

So, that's another thing we can do to support our systems is we can mindfully choose to incorporate aspects of PERMA+ into our team meetings or into our even our emails to give that little boost of happiness and support to our system members. Next slide please.

Character strengths are also a large part of the positive psychology model. All people have character strengths that can be observed, celebrated, and built on to use a strength-based approach to our care. We can use character strength. To strength-spot is what we call it and start other persons on the system.

So, you might notice that somebody within your system of care has a strength of humor and how they use humor to defuse crisis and to bring joy and happiness to others.

You might note that to them, for example, my top character strength is hope. This is hope for the future, and it's the belief that I have some control over my future and getting to the end goal. So, when somebody on my team needs hope and encouragement, they need time to focus on what they can control versus what they cannot control and what can be done to work towards a better future for them, their system, the individual; I'm their person.

So knowing your system's strengths, their strength of character can be really helpful in identifying which system members will be the most successful at completing a certain action step and how to build each other up through using each other's strengths of character. Next slide please.

Systems functioning. Every system is looking for homeostasis. This is achieved through the system's unspoken rules, group norms. Each system you support will have its own set of unspoken rules.

Part of what you are doing in care coordination is learning those rules so that you can join with them and we can start to shift small things that will really help pull us out of that tertiary services and build up quality of life for the system and for the individual that's being served.

Resistance is a common reported concern for individuals within a system, so changes whether the change is good or bad, it shakes up the homeostasis. Resistance doesn't come from a place of wanting to be difficult, it comes from a place of stress and anxiety.

So, we need to understand why there's some resistance, validate that it can be stressful, it can be scary to change things up, and that's what's going to help the system have the support that they need to be able to make the changes that need to be made. Next slide please.

Another thing that we want to do is develop a common goal with the system. So, this can be very general. Typically, when you're first entering a system, the common goal is very general.

So an example of that could be, we all want Suzie to be healthy and happy. Everybody can agree to that goal that our system has for the individual we're serving.

The reason a common goal can be so, so vital for a system, even though we have such a simple goal here, is especially when we start to see that homeostasis getting shaken up a little bit.

We might see conflict where we have individuals within our system that are really on an opposite end of the spectrum and we're having a hard time agreeing on what to do to move forward.

Something that can make us not feel like it's us against them, but that it is a group effort. We are a team, and we are all here for the same reason is a common goal. So when you have those two different, strong, opinions, you can remind the group of their common goal. We all want Suzie to be healthy and happy. We all have the same end goal.

We're just talking about getting there in a different way, and that can help bring back some more cohesion to the group to be able to make decisions together. We want to join with the system, so understanding those unspoken rules and joining with the system's common goal.

Once you have joined with the system, this is where you can really find the opportunities to bring in some new ideas to the team to start shifting some thinking and perspective on the services that we're providing. Next slide please.

Active listening is vital for ensuring a system feels heard. Our nonverbals are really important, so be mindful of things like your facial expression, those minimal encouragers like head nods and those, “uh-huhs,” your language, tone of voice, and things like that. But there are four big aspects to active listening that I want to cover with you today.

The first one is paraphrasing. Paraphrasing is saying the same thing back with slightly different words and we use this intervention to allow the person to really hear what they're saying and process how other people are hearing that information so that we can make adjustments from there if we need to.

Summarizing is another skill of active listening. This is reiterating the highlights. We've probably all been in meetings or situations where we are either the person or somebody in the meeting is sharing a lot of information and we may be going down 10 different roads.

But today's meeting was to do crisis follow up and so you can do a summary of the highlights of that information and that helps us to keep the focus. What we're doing here today is this. If we go down 10 different roads at the same time, we won't be able to provide the same quality care and intense amount of care that the individual needs.

So you want to focus on that one direction. Clarification is additional explanation. You're just asking for more information, and this is really helpful for your group cohesion. So, things like developing a common goal, crisis planning, and future interventions, those are all really helpful with clarification and then reflection. This is rephrasing information, and this allows the person to hear their thoughts in a slightly new light.

This really connects well to my previous slide where we talked about things like the differences between saying the person is complaining or saying the person is reporting something. Even just rephrasing it slightly can really change the light and the feel of the sentence. Next slide please.

Interdisciplinary consultation, so using a biopsychosocial approach is an important, is very important because we know biopsychosocial factors really intertwine with each other.

We can become focused on our own area of expertise and then we can start to miss important information. An interdisciplinary team can really help to ensure that biopsychosocial is considered and supported.

Now, some individuals have access to an interdisciplinary team. With my team, we actually have an interdisciplinary team within our group of people. And so we provide every single individual we serve with interdisciplinary consultation, typically multiple times, because we find so much value in it that we employ people that can do this.

But even if you don't have access to something like that, where it's very easy to get at, you can still ask for consultation from medical professionals, from psychological professionals, and from somebody that really knows the individual's social life.

There are some examples on this slide of who those different people may be, but getting together and being able to talk through what is going on is really your best practice for using the biopsychosocial model and identifying vulnerabilities. Next slide please.

So at this point, I am transitioning a little bit more slightly off the START model, although this does relate to it and we're going to talk a little bit more about polypharmacy. So polypharmacy, just to make sure we're all on the same page with what that is, is the simultaneous use of multiple drugs that treat a single ailment or condition. Next slide please.

So when we are missing biopsychosocial factors, this is a big contributing factor to polypharmacy. High levels of physical aggression, property destruction, suicidal ideations and or attempts, all of these things can result in polypharmacy in hopes of decreasing this unsafe behavior and hopefully decreasing the need for tertiary services. Polypharmacy does not treat the root cause, though.

So, if we are treating depression with multiple antidepressant medications, but we're missing that the root cause is that there is extreme low vitamin D we're not going to see the improvements that we're hoping to see in that individual with the treatment model that we're using. Next slide please.

So, there's lots of literature out there on polypharmacy. And O'dwyer et al. completed a study and found that most adults with intellectual disability that were over the age of 40 were experiencing what was labelled as excessive. O'dwyer et al. defined "excessive," as 10 or more medications. What that means is that this population that was studied and these people were on 10 or more medications, all to treat the exact same thing. That's a lot of medication to treat the same ailment or condition.

Individuals with intellectual disability are three times more likely to experience polypharmacy than the neurotypical population is. Medications are often being used off-label, so off-label means that the medication is being used for something other than its intended purpose that's written on the bottle and what people would typically prescribe the medication for.

So, for example, a person with an intellectual disability may be on multiple antipsychotic medications without any diagnosis or any symptoms of psychosis. And that medication that is being prescribed off-label is typically used to decrease an unwanted challenge like physical aggression.

But prescribing off-label medications is not FDA (Food and Drug Administration) approved because we don't know what the effects of using a medication without its intended purpose will be. Next slide please. Polypharmacy is correlated with things like falling, adverse drug interactions, mortality, and the use of hospitalization actually increases.

So, even though the intent of polypharmacy is to decrease the tertiary service usage and unsafe behaviors, it's actually increasing hospitalizations. It's also increasing the length of stay that somebody is in the hospital and the readmission for hospitalizations occurs sooner after their original discharge.

So, we're actually seeing a pretty big increase in the need for tertiary service usage. Polypharmacy is associated with increased healthcare costs and impairing the individuals overall functioning. Polypharmacy can lead to very complex drug interactions that can be fatal in nature.

Just in our program, we have consulted with pharmacists, which is a wonderful resource, and we love to consult with them and they have called us in, you know 10 or 15 minutes later and said we got to get these two medications stopped because these could actually be fatal for this individual.

And then we can address that with the prescribing providers. But if there's no communication between them, things like that can accidentally occur. Polypharmacy is not only decreasing life expectancy, but it is also decreasing the quality of life. Next slide, please.

And, sedation. Many medications that cause sedation are used in the ID population. Sedation is effective in decreasing crisis most of the time, although the absence of crisis is not wellness. And sedation through medication often leads to other costs such as a decline in their quality of life and increase hospitalizations with longer hospital stays. Next slide please.

So, knowledge really is power, encourage the system to know why medications are being prescribed. We can watch for common side effects that relate to those medications. So, if the individual didn't have constipation concerns prior to new medications being started and now they do, that could be a side effect of a medication.

And we want to report that to the physician that's prescribing this medication so they can assess whether this is something that they want to continue with or not. We also want to assess if the medication is working. If we're supporting an individual that is prescribed medication for the purpose of decreasing physical aggression and we see no progress in that area, we want to make sure we're reporting that so that again, the prescriber can reassess and decide if they want to remove that medication, if they want to try something else, if they want to increase the dosage.

There's lots of different things that the prescriber may try to support the individual. And taking this kind of information, the side effects you're noticing, if there's any changes in the behavior, is a really great way of supporting an interdisciplinary team. So taking that to different parts of your system to get their thought process on why this might be happening can be very helpful in figuring out those things like, oh, this individual has a migraine, but they're nonverbal and weren't able to tell us that, we can find that faster and support that vulnerability faster.

Next slide please. So, this last slide is really more of a resource for you all. If you are not looking at the medications that individuals you're serving are on, I encourage you to take a look at those, learning a little bit more about what medications they're on and side effects and things like that can be really helpful for you when you're trying to do what we just talked about in our last slide when you're trying to assess for changes and potential side effects.

And if you look through this list, these are all medications that cause sedation. If you look through this list and you are familiar with some of the medications that individuals you're serving are on, it's very, very likely these look very familiar to you.

Many of these medications are commonly used in individuals that have an intellectual disability for sedation purposes. And I believe that that is all I have for today.

Leslie Bishop (Facilitator)

Great. Thank you for sharing your knowledge and so many valuable resources Olivia. Thank you again to our speakers for sharing their thoughts and improving care for individuals with I/DD and behavioral health.

You should now see a pop up on your screen with our final poll asking if you would be interested in a follow up webinar related to the topic of I/DD and behavioral health. The options you may select from are, yes, pertaining to polypharmacy, yes, pertaining to integrated care, yes, pertaining to care management, and then yes, pertaining to with a blank space which is open for free text.

And we encourage you to use the Q&A function to capture your response. It sounds like there is not a priority, but pertaining to care management seems to be a high response from folks.

So thank you all for answering that poll. We will now move into our panel discussion, and we'll welcome Dr. Pat Nobbie in addition to our esteemed speakers. My colleague John Jansa is joining to facilitate the panel discussion and audience Q&A. John, I will turn things over to you.

John Jansa (Moderator)

Thank you very much, Leslie. If we can go ahead and proceed to the next slide. Perfect. The first question is for you, Dr. Nobbie, what kind of support do family members or caregivers who support an individual with I/DD and a behavioral health condition need?

Dr. Pat Nobbie

Thank you, John. So families need consistency and individuals with I/DD and a behavioral health condition need a predictable routine. When that routine fails, the care and support falls on the family. Consistency means knowing who is supporting them outside of the family, and that those support people really know the individual.

The other thing I think caregivers need is crisis prevention strategies and training so they can avoid escalation of the incident, which could result in an inpatient or ED transfer or worse, having to call the police. Effective communication is part of all of this.

John Jansa (Moderator)

Great, Thank you Dr. Nobbie. Let's go ahead to the next slide. And again, this question is for you, Dr. Nobbie. How can a plan or health plan integrate family and caregivers into an individual's care team? And also, how can that plan support the entire care team?

Dr. Pat Nobbie

Great, so family members or the primary, unpaid caregivers are part of the care team. Planning cannot proceed without them, particularly for individuals with the communication challenge. The family caregiver is the proxy for information.

For example, when my daughter Mia was hospitalized this winter, she got asked with every clinical contact, what is your pain level on a scale of one to ten, with one being no pain. And she would always say 10 because in her understanding there was either pain or no pain. But I knew she wasn't on level 10 pain, which would have required a heavy painkiller prescription, which she did not need. I had to educate the clinicians on how to ask that question or interpret it differently.

That's not to say that people with I/DD in a behavioral health condition have no agency. They do, and the task for the care team is to support that agency and decision making as much as possible, drawing on the knowledge that the family caregiver has about the individual situation.

Technically speaking, if a person has a Medicaid home and community-based setting service or support, they are able to invite whoever they want to a care plan meeting. This may provide another perspective because families can sometimes limit a person's opportunities out of concern for their health or safety.

John Jansa (Moderator)

Thank you, Dr. Nobbie. Thank you so much for sharing those insights. Let's go ahead and move to the next slide as we bring in our two speakers.

So this question is for all three of the panelists. In your experience, what is the most helpful action a health plan can take to support individuals with I/DD in a behavioral health condition and their support network?

And again, Dr. Nobbie will begin with you.

Dr. Pat Nobbie

So I think the most important thing is to listen. The individual and their family and, or their care partners have a history and an experience that preceded health plan involvement. Either they have learned to adapt, or they will need support to learn ways to accommodate the needs of the individual differently. But what they have lived is helpful to the care coordinators to build on and also use modes of communication that work for the individual.

John Jansa (Moderator)

Thank you, Dr. Nobbie. Dr. Witwer, do you mind offering your perspective on this?

Dr. Andrea Witwer

Yeah, sure. I think it's helpful for care plans to provide time for the team of care providers to meet. Also, we know that things like patient navigators can be incredibly helpful in these instances.

John Jansa (Moderator)

Thank you, Dr. Witwer. And Olivia, how would you like to add to the response for this question?

Olivia Ayers

Yeah, I think a biopsychosocial approach is really crucial. So, explore biopsychosocial vulnerabilities and potential reasoning for changes in functioning or the behavior. Consider the individuals abilities and their vulnerabilities. So, the individuals cognitive and adaptive functioning, their communication abilities, and mental health functioning are all important aspects of the person. To ensure that we are incorporating those and goals should be truly person-centered and achievable based on their current functioning.

In conjunction, health plans should consider the current system members and especially the primary caregivers to ensure what is being asked is doable for the current systems functioning and that the system feels supported through those recommendations and changes.

John Jansa (Moderator)

Great. Thank you all. And let's move to the next slide.

So the fourth panel question is for all three of you, again.

What are the key indicators, such as environmental, physical, or behavioral that could prompt action to prevent adverse outcomes or prevent ER utilization or inpatient hospitalization and address social determinants of health and Dr. Nobbie, you're free to go ahead first.

Dr. Pat Nobbie

Thanks John. So, if an individual has a behavior support plan and indicators can be set for elements of that plan and if an incident, a behavioral incident exceeds that indicator or gets close, then other interventions or actions need to take place.

For example, you know learning what environmental incidents trigger a behavioral crisis and learning how to deescalate that incident or experience might prevent an ED utilization or an inpatient stay. The Council on Quality and Leadership did a study on the relationship between ongoing staff development and the incidence of the things mentioned here, adverse outcomes, ED utilization, etcetera.

More staff development. The lower the incidence of adverse events such as accidents, falls, abuse and neglect, ED utilization and medication errors.

They've also found a positive relationship between individuals being able to choose where to live and having robust community supports to less adverse incidents and where social determinants of health have an impact on their quality of life. These studies are more about the relationships of paid staff to the individuals that they support. But the experiences that were studied also encompass what family caregivers do, and these are our indicators that should be considered.

John Jansa (Moderator)

Thank you Dr. Nobbie. And Dr. Witwer, do you mind sharing your thoughts on these strategies?

Dr. Andrea Witwer

Yeah. In order to identify those key indicators, it's important to ensure that the team identify early any changes in behavior. We want to also look for changes in engagement and activities of living or mood, and we want the team to be sure to communicate changes to the treatment planning team.

It's also key to have a way to track behavior and other side effects to minimize adverse medication outcomes of side effects of those medications. We also want the team to take into account the individual's environment, their access to social engagement and other activities that promote health, healthy living. Be sure to take into account any adverse experiences in the person's life and realize that many of the things that we don't think of as traumatic may be experienced as such by individuals with I/DD.

John Jansa (Moderator)

Thank you so much, Dr. Witwer. Olivia, I'll turn it over to you for your response.

Olivia Ayers

Yeah, I think just to add what's been shared already, knowing that individual's baseline through that biopsychosocial lens is really helpful. Data tracking is so important. So, looking at what we call ABC tracking, so looking at that and exceeded the behavior and the consequence. So, what happened before, during, and after an incident can really help us to assess the changes that are contributing to those behaviors.

And that's what's going to help us to plan in the future for what we're going to do next time, tracking things that could impact them biopsychosocially. Like, if we're serving an individual that has had constipation concerns in the past and that's led to tertiary services, we might need to do some valve movement tracking.

And then the other thing I'll say about tracking is as much detail as possible is best for all data gathered. And it's really important that if it if you have a lot of different staff that they're all tracking that data in the same manner. So, set a very detailed and clear explanation of what's being tracked. Make the data tracker as easy to use as possible so that staff are able to use that. There's a lot of work that can be done during the development of the tracker that really saves the staff a lot of time. And this is so helpful for physicians and prescribers of medication to assess what the next best steps are.

John Jansa (Moderator)

Thank you so much. Let's go ahead and move on to the next slide, which has our last question again directed to all three of our panelists.

Can you talk about how community-based organizations support meeting the needs of individuals with I/DD and a behavioral health diagnosis?

Again, Dr. Nobbie, we'll start with your response.

Dr. Pat Nobbie

Yes, thanks. So, socialized isolation has been talked about as equivalent to smoking 15 cigarettes every day. It's considered a significant health risk. It's also a safety risk. All people need connections, and community-based organizations, including faith communities, can support the individual and their families and caregivers to develop connections outside the home. My daughter works. She goes to swimming, she bowls, she attends church and helps with Sunday school class, and she has a social life with a group of adults that does various activities once a month. And she does all of this without me.

If Mia doesn't show up in any of these places where she is expected, someone is calling or texting me to ask where she is and is she okay? Her being out and about in the community is an important part of her health and safety.

John Jansa (Moderator)

Thank you very much Dr. Nobbie for sharing that. Dr. Witwer, do you mind sharing your thoughts?

Dr. Andrea Witwer

Sure. And just really building on what Dr. Nobbie has said, there are a number of community-based supports that adults at I/DD can use. These can help to promote positive mental health as she illustrated looking at things like meaningful employment, community engagement and social connectedness.

John Jansa (Moderator)

Thank you Dr. Witwer. And Olivia, I'll turn it to you for your response to this question.

Olivia Ayers

Yes, thank you. The system coming together to offer support, brainstorm, and make decisions together is a really important way to support the individual that's being served.

Being attuned is also a key way that the community organizations are supporting, so being attuned to changes in baseline helps the team identify those early warning signs that something's not quite right and action can be taken proactively being open and curious. So, think through a biopsychosocial lens to mitigate the overshadowing of vulnerabilities.

And finally, creativity is crucial for community organizations supporting this population. Creativity is important for meeting everyone's needs with the resources that they have available to them. So, creativity is also important for incorporating things like that PERMA+ model that we talked about and ensuring that some PERMA for each individual being served is incorporated to their daily life.

John Jansa (Moderator)

October 24, 2023

Thank you, Olivia. Let's go ahead and move to the next slide.

And I'll just want to start off by saying a big thank you to Dr. Witwer, Olivia, and Dr. Nobbie for that engaging panel discussion. With that, we do have a few minutes for questions from the audience.

So at this time, if you have questions for our speakers, you can submit them using the Q&A box located below the presentation. Just type in your comment at the bottom of the Q&A box and then press Submit to send.

We did get a lot of great questions from people who when they were registering for our webinar. And so, we have some time to start with some of those questions and I will make clear to our panel who these are targeted to, but I'm open to anyone on the panel to answer.

Olivia, I will start with you. You brought up a point talking about intervention and supporting for an individual with I/DD and behavioral health who was nonverbal. The question comes down to what interventions are effective in diagnosis and treatment for individuals with I/DD who are nonverbal?

Olivia Ayers

That's such a good question and is really tricky. I feel like this is still very much a conversation that happens amongst clinicians to try and figure this out, I have found that *DM-ID 2*, it's the diagnostic manual for intellectual disability two, I believe is what that is. I've found that really, really helpful. It is a diagnostic manual that is based off the *DSM-5* diagnostic criteria. So, you'll see the same things from there, but it's a much bigger manual.

And within there, they actually talk about how you might see symptoms related to different diagnosis show up a little differently in individuals that have an intellectual or developmental disability. So, they like, for example, and when you look at depression and what are the symptoms, how do you diagnose depression? If you use this manual, it actually speaks to, there's a whole chapter on how physical aggression can actually be seen in an individual that has intellectual disability.

And they speak to the nonverbal piece of that too, where it's this nonverbal communication and how it's coming out to express a concern. So, I found that resource to be very helpful.

Data tracking is amazing for clinicians that are trying to figure this out, especially because they're not spending as much time day-to-day with these individuals. So, if you can track things, especially things like eating and changes in sleep patterns, those are very, very helpful to start to narrow things down and figure out what might be going on.

And then that behavior tracking is also helpful. So, I mentioned ABC tracking in the panel discussion that we just had. That's really just trying to track like what happened before there was a concern in the behavior. So, was it, you know, was it a trigger of a really chaotic environment or something like that? What was the behavior that is being tracked?

And then what was the consequence of what happened afterwards? Even if we don't use that word consequence, that can be really helpful to guide us in thinking biopsychosocially.

October 24, 2023

So, we're constantly seeing this challenge occur around the person's 4:00 PM medication path. Let's assess that what's going on at the 4:00 PM medication path before we diagnose or give medication.

So I think that those three things are very, very helpful especially for individuals that are nonverbal.

John Jansa (Moderator)

Great, I actually want to move on to a question for the whole panel and then for the remainder of these questions. These are again open to all three.

A question was raised through registration that asked well, excuse me, we know there are challenges in recruiting and retaining direct support professionals to work with individuals with I/DD. Are there any particular considerations or strategies to build that workforce for individuals with co-occurring I/DD and behavioral health needs?

This is a huge issue we know within the community and within the larger healthcare community. Would anyone like to take a first pass at considerations or strategies to building the workforce?

Dr. Andrea Witwer

This is Andrea (Dr. Witwer). I can talk to that a little bit. I know that's something we've dealt with a lot in our state, have been thinking about. I think there's two ways to approach it.

One of them is thinking about how do we build the workforce and really looking at pipeline development, starting to like train and recruit in high school, vocational training programs. I know there's a lot of those working on having a ladder of promotion for direct support professionals where they see kind of a progression and a career out of being a direct support professional. I think those are ways to get folks interested in the field.

The other piece of it, I think, is making sure that we find ways to help them feel supported, especially when we think about meeting the needs of those with co-occurring mental health conditions. There's been some research that's really looked at. Can we use things like *Mindfulness Based Stress Reduction* to help meet the stress needs of direct support professionals? When they've done that with some groups, they've found that their interactions with staff, with their clients is better and burnout reduces. So, really trying to kind of look at ways to reduce burnout of the staff we have.

We know that when they have more education around how to address challenging behavior, preventative strategies, how to support mental health, they feel more supported and are more likely to potentially change positions.

Dr. Pat Nobbie

And John I'd like to jump in here and just echo what Dr. Witwer said, and I mentioned I referenced this before with the CQL study because there is a relationship between how well

staff feels supported and how respected they feel and an impact on the on the people that they support.

I also think you know working on self-directed programs or participant directed programs as they're sometimes called, gives families a little bit more control over schedules accommodating the staff that supports their individuals. It's more individualized in some states that allow budget authority, enable you to pay a little bit higher rate for the staff and so that tends to keep them on.

Mia has actually had the same direct support person for almost 20 years since she graduated from high school and that's just part of our effort to support her and her family as well as you know, communicating with her what Mia needs and what my family needs. I think self-direction programs have a lot of opportunity.

Olivia Ayers

And this is Olivia. I cannot agree more with both of our previous speakers. So yes, to all of those things.

I think, in addition to that, some other things to try is thinking about the work culture. So, again, we can pull a lot from the presentation that we had today. Are we identifying what their strengths of character are and utilizing them?

If we have somebody on our team that is super creative, how can we ensure that they have an opportunity to engage in that strength of creativity on a regular basis or that PERMA+ model? Are we ensuring that there's opportunities for PERMA throughout their day-to-day work and those things are going to make a really big difference in their overall happiness with their employment?

And then I think just in addition to that, just being very mindful of a supportive environment, they're learning a lot of things and there's a lot of challenges and things that just kind of pop up that we can't necessarily train for everything.

And so it can feel really scary and contribute to burnout when things happen, and we feel like we don't know what to do because nobody's ever told us what to do about when this unique situation occurs.

So I think just having that very supportive environment, offering lots of grace, we're not expecting perfection, but knowing who to go to, when you need to talk through something that's happened and make a plan for the next time.

John Jansa (Moderator)

Those are great. I think we have time for one more question. How can or what tools can support networks use to best track and document behaviors and medication side effects and then put those tools to use in support of the individual?

Dr. Andrea Witwer

Yeah, I think there are a lot of great resources, some of them at the end of our PowerPoint, when you have *My Health* and *My Health Navigator Passport*, I forget the name of it, where they can have just all of their existing health, you know, concerns, their preferences that then they can fill out ahead of time with family members, with them, you know, having that ability to kind of speak themselves and use that to share with clinicians that can help with some of that consistency.

These are my medical diagnoses; these are my medications. Often different people will transport individuals to appointments. So, having something that they take with them that has a cohesive story, I think can be a really important piece.

And then I know that Olivia has referenced ABC charts, which are also a really incredibly helpful tool to use when you're trying to track things like behavior changes and patterns of behavior.

Dr. Pat Nobbie

Yeah. And I'll just jump in and say, you know the parent, or the primary caregiver is a really important source of information for things that might not necessarily show up in a chart like a fear, you know, fear of heights, how different antibiotics work.

I shared an example of my daughter you know when she was in the hospital and I was with her that she started hallucinating when they gave her, you know Oxycontin painkiller. And it really scared me because she's usually very coherent and this was so out of character and so you know we had to determine that morphine was a better solution because it didn't affect her that way.

So listening to families and not discounting what they're seeing and documenting or recording or you know have their experiences is, I think is really important in a medical care setting in particular. But especially having a way for that individual to communicate that to their doctors on their own and helping you figure out ways to support people to do that is also really important.

Olivia Ayers

Absolutely. This is Olivia. I would just add to that saying that some of that I believe are open access assessments such as the *Recent Stressors Questionnaire*. That's a beautiful, very easy assessment that can be very helpful.

There's a PERMA+ assessment that can also be very helpful and are good trackers of changes in baseline and that's really what I think prescribers are looking for to help them assess what's going on. So those are great additional resources.

I'm also a big proponent of making your own rather than some of the assessments and trackers can be quite costly. So, making a tracker based off what you need for that individual. If you're worried about an individual's sedation, we can actually make a tracker. And there might be somebody on your team that has one of their strengths of character, that is fantastic at organization and can make one of them for your team to use.

So I think using your system to come up with, we're really just looking at these one or two things and here's just some simple boxes to check that you can make pretty quickly, either writing it out by hand or even putting it into a Word document or an Excel sheet, just depending on your skill level with all of these different resources can be a really great way of tracking some data.

And when we do those and just make our own homemade version, we I really like to ask the provider. So, if the primary care [provider] wants us to specifically be looking for something, some side effect, we usually ask. They may not ask us proactively, but if we ask them, "what would you like to know about this new medication that we're starting or a change in behavior," they typically have quite a few things they would love to know. So, we just use that to build off of the tracker. So, I also think that making your own is a good option sometimes.

John Jansa (Moderator)

Great. Well, thank you. Thank you all three of you for sharing your insight and your responses to those questions. We'll close out the question portion and the Q&A portion and I'll turn it back over to Leslie to take us through the finish line.

Leslie Bishop (Facilitator)

Thank you, John. Before wrapping up, we wanted to take this opportunity to share some exciting information with you.

In September of 2022, the Administration for Community Living awarded a five-year cooperative agreement to develop a Technical Assistance and Resource Center to better support the needs of individuals with I/DD who also have mental health support needs.

It is estimated that individuals with I/DD experience mental health conditions at a high prevalence rate. Access to both clinical mental health treatment and well changed community supports has been a challenge nationally in most states, resulting in crisis situations with people languishing in hospitals and ERs.

This center aims to spur systems change at a state systems level to address these issues while also bolstering clinical and community provider capacity, including direct support professionals. To make meaningful change. ACL recognized the importance of fostering an initiative with meaningful cross system commitment.

The leadership of the LINK Center includes key partners that can effectuate change at the state level while informing federal policy. The National Association of State Directors of Developmental Disability Services and the National Association of State Mental Health Program Directors represent the state agencies responsible for delivering services. The National Association for the Dually Diagnosed is a professional organization with knowledge and resources.

In addition, the LINK Center partners with several other organizations bringing together lived experiences, research, practice, and policy partners, including an active steering committee comprised of people with lived experience. ACL is involving other federal

agencies such as the Substance Abuse and Mental Health Services Administration and the Administration for Children and Families, among others, to ensure that individuals with I/DD and their families are included in key policy discussions related to mental health, crisis response, suicide prevention, and others.

At this time, if you have any additional questions or comments, please e-mail RIC@lewin.com. The slides for today's presentation and a recording in a transcript will be available on the Resources for Integrated Care website shortly.

As a reminder, please take the post-test if you're interested in earning NASWCEU's. You must take the post-test by 11:59 PM on Thursday, September 28th, with a passing score, but you can take the post-test multiple times to earn the score.

Please complete our brief evaluation of our webinar so that we can continue to deliver high quality presentations. We would also like to invite you to provide feedback on other RIC products as well as suggestions to inform the development of potential new resources by using the link included on this slide.

Our speakers highlighted several key resources for you all today, which you will find on the following slides, along with other resources available on the RIC website, including a *Care Transitions* toolkit to support individuals with I/DD, which is also available in Spanish.

Thank you again to all of our speakers for sharing these resources and for your engaging and informative presentations. Thank you to our audience members for your participation. Have a wonderful afternoon.