Video transcript

IHC Academy: Healthcare Discrepancies Experienced by Individuals with IDD / Woods System of Care

Guest speakers: Wendy Aita and Liz Hayden

Rebecca Martin: I'm Rebecca Martin, and I am a graduate assistant working with the Edward J. Bloustein School of Policy and Planning to coordinate these IHC trainings, and I'm excited to be hosting here today. We have the IHC Academy presentation from Dr. Wendy Aita from the RISN Center and Liz Hayden from Woods. We're excited about it. Before we get started I just have a couple of things I need to tell you. One, I'd like to let you know that we're going to be recording today's session so we can post it for people who are not able to attend live, so I wanted to let you know that. I also, if you are, if you would benefit from having access to the presentation slides, which have been made accessible, you can access them from a link that I'll put in the chat in a few moments. Please feel free to add any questions that you might have to the chat as we go along today. We'll have a question and answer period at the end of the presentations. And given your interest in today's training we'd like to send you updates about future IHC training opportunities. If you would like to opt out of receiving information about the IHC program and training opportunities, you can indicate that in the chat or email me, and I'll put my email address in the chat as well. And then I'd like to thank Tatiana for being here as our ASL interpreter. Today feel free to pin her if you would like to do so. And then before we begin I'd like to take a moment to express our deep appreciation to Peri Nearon and her team at the New Jersey Division of Disability Services for making this training series and the IHC grant program possible. And without further ado, I will turn it over to Dr. Wendy Aita, who's the co-director of the RISN Center.

Dr. Aita: Good afternoon. Thanks everyone for being here. I'm going to try to share my screen so we can get started.

Are you able to see? Okay, great.

So hello, my name is Dr. Wendy Aita. I'm a clinical psychologist. I'm the co-director of the RISN Center, and today I'm going to be talking to you about discrepancies in healthcare experienced by individuals with intellectual or developmental disabilities. For those who don't know, the Rowan Integrated Special Needs or RISN Center is in South Jersey. We're on the campus of Rowan College of South Jersey, and we're a primary care practice for individuals with special healthcare needs with embedded behavioral health services. We want to thank the Inclusive Healthy Communities and Division of Developmental Disability Services for the grant funding. We have been fortunate enough to be both Cohort 1 and Cohort 2 grant recipients, and I'll be talking a little bit about what we've been doing with the grant money and the work that we're doing here.

So our objectives today, very quickly because I know it's a short time that we're together, is I'm going to talk a little bit about healthcare discrepancies for individuals with disabilities, list out some barriers to healthcare, and then discuss our current research initiatives and our IHC grant. So just for, just to get started, a disability, so we have some common vocabulary, is a physical or mental impairment that substantially limits one or more major life activities or a record of such. And this is part of the American with Disabilities Act. An intellectual disability is a developmental disability that begins before the age of 18 which shows deficits in both intellectual and adaptive functioning, and within our population about one to three percent total have an intellectual or developmental disability. When we talk about health disparities, we're talking about avoidable differences or inequities that individuals experience in healthcare because they are part of a different group. And specifically we're going to be talking about those disparities as related to disabilities.

With a disability and the health disparities related to it, we are seeing that these vulnerable populations have poorer access, and that's part of one of the really foundations that we have here at the RISN Center. How do we improve access to quality healthcare for individuals who are within a vulnerable population? We know that people with ID experience four times a higher rate of mortality that could be preventable, higher rates of chronic conditions, difficulty accessing care, and a much higher rate of hospitalization than their neurotypical peers. People with ID also remain one of the most medically underserved population within the world. We have to kind of keep a couple of things in mind when we're talking about this. Just having an intellectual disability does not mean that you have poor health, although there are some comorbid or coexisting health discrepancies for people with different disabilities like, for example, individuals with Down Syndrome often have congenital heart defects. It doesn't necessarily mean that everybody with a disability has poorer health. And part of this is also because we have healthcare professionals who are not adequately trained in how to work with people with disabilities and diagnostic overshadowing is a concept in which health symptoms are attributed to their disability. So, for example, somebody who is having a behavioral difficulty we attribute it to being part of their autism rather than looking for an underlying pain or medical condition that might be related to the behavior that we're seeing.

We know that overall, even though we are very happy to know that people with disabilities are living longer and later, and that's part of the reason why some healthcare providers don't know how to work with people with disabilities is typically it had been pediatrics, pediatricians who knew who had all of the experience because people with disabilities were passing away at a younger age. Now that is not the case, and people are living much more into their 50s and 60s. However, we still do have discrepancies with mortality. They do, individuals with disabilities do die earlier. I wanted to talk a little bit about intersectionality. Although we're talking today about being part of the disability community as being one of the, one of the groups in which are receiving poorer access, we have to be able to look at this within multiple lenses. Disability is one group in which people might belong to that might lead to poor access. However, many of the individuals with disability also fit into other categories such as gender, race, their disability status, or their gender identity or sexual orientation. So all of these things overlay upon one another, and the more groups you belong to the more likely you are to have a health disparity or receive poorer access to care. We are very focused on inclusive help. How do we make sure that everyone is given the type of treatment in the way in which they need to receive it? And we're not looking just at giving everyone equal treatment because that's not necessarily being proactive in helping people achieve the best healthcare access that they can. We have to have healthcare equity and that might mean providing something a little bit different for each person based upon where their needs are.

When we are looking at it, and our inclusive Healthy Communities program is looking at women's healthcare, so that's why I'm getting a little bit more specific about some of the disparities in women's healthcare. We know that women with intellectual disabilities have the same gynecological health issues as people who don't have a disability. However, we know that they are less likely to get these healthcare needs met, and that's for a lot of different reasons. Sometimes it's related to their caregivers or bias or stigma that individuals with disabilities don't need to have women's healthcare exams. Sometimes it's related to the provider level thinking, well, you know, they're not comfortable with this type of an exam so I'm not going to do it or maybe they're not … the thought that perhaps they're not sexually active and if they're not sexually active they don't need to have this type of healthcare. Within breast cancer and disabilities, we know that compared to women without disabilities they have an equal or greater risk of breast cancer except in regard to Down Syndrome where they actually have a lower incidence of breast cancer. However, women with physical disabilities are less likely to have breast cancer screenings and that puts them at more risk of developing late stage cancer. One study found that individuals with cerebral palsy were three times more likely to die of breast cancer than the general population and, only 61 percent of women with a disability within a higher age category had had a mammogram within the past two years as compared to women without a disability.

And so what are the barriers that are getting in the way to individuals getting the healthcare access they need? We know there can be architectural barriers, medical equipment barriers, communication and other barriers as well. So, for example, many doctors offices don't have an ability to get even a basic weight on individuals with disabilities. They need accessible scales. They need a way of being able to get a weight, and we know that oftentimes individuals with disabilities have a higher rate of obesity so getting a good weight is important. Having a floor lift to be able to lift somebody out of their wheelchair in order to get a weight or to be able to have better access to their medical healthcare. Having accessible mammograms. When you get a mammogram, you have to stand up, and if you don't have the ability to have a mammogram in a seated position and having the specialized equipment, that is a barrier to access. There are other barriers to access as well that are related on to the individual level and the community level. There are beliefs, and like I spoke before about stigmas or the feeling that women who are not sexually active don't need to have a reproductive healthcare exam, but they're also sometimes financial difficulties. Finding a provider who takes Medicaid can often be a big challenge for this population and being able to find an accessible office in addition. We're going to focus a little bit more specifically though on attitudinal barriers, inadequate provider knowledge, emotional and behavioral barriers that are related to our current IHC project.

So the problem we were able to identify is that although people, women, with IDD report similar rates of sexual activity as women without disability, they are receiving, number one, limited reproductive healthcare education and sexual education. Oftentimes they're only getting what they get in school, and that is oftentimes very focused on avoiding sexual activity. And women with intellectual disability we know that they're capable of engaging in consenting for sexual activity, but they're not getting anything more than formal education and that leads them to be either at a higher risk of victimization. Or we are also kind of focusing on a fear bias when we're teaching sexual education and teaching women or women and men with disabilities that sex is something to be feared, that people are going to take advantage of you.

Cervical screening should be routine for anyone with a cervix from the age of 25 and above. And we kind of changed that wording a little bit, and this is part of our initiative right now, is we do have many of our individuals who come to our office identify as transgender. And being able to have a cervical cancer exam is very difficult for them. We've heard stories of, you know, you go to your OB GYN office, and you do not identify as a woman. There's already a barrier of feeling uncomfortable with having to have this exam anyway, and then you're outed in front of everyone when they call you to come back, and everybody sees that you're walking back and you identify as a man but you still have to have a gynecological exam. So we're trying to find better ways of improving access in the way in which people need to receive that access.

For many women with intellectual disabilities the experience of the exam can be painful. It may bring about thoughts or triggers of episodes of past abuse, and quite honestly if we're not getting a look we often don't know that people have been abused. Many women are not able to tell us that they have been abused in the past. We, you know, absolutely see women who do not use words to communicate or are non-verbal, and this might be the only way that we're able to see that. And that one study found that women with ID who are actually being screened can be as low as 15 percent. There was a 2019 UK study that was recently done that found that 88 percent of women with disabilities say that it's harder to have the … get access to the screening. Sixty-three percent said that they were unable to get the screening because of their disability, and 49 percent said that they chose not to have it for reasons such as bad experiences or being also being told they don't need one. So what we also wanted to do was try to address this disparity by looking at it from a provider level as well as an individual level. In addition, there are some emotional and behavioral challenges, and we try to address them. Non-compliance with basic healthcare can be very high secondary to anxiety for individuals with autism or intellectual disability. The literature shows that about one-third of patients have compliance problems during medical procedures, and that might be lab work, it might be related to EKGs, it might be related to the women's health exam, and this is related to fear and anxiety.

So our goal was to improve access by providing patient education and preparation if you don't know what's going to happen you can't be prepared for it, and you're going to have much more anxiety. And that's for all of us. You know, when our individuals come in and I work with them, I say I can guarantee you nobody raises their hand and says, great, I can't wait to go for my reproductive healthcare examination, right? Nobody's excited about that. It was interesting we had Special Olympics come in yesterday from New Jersey to kind of view our office, and we were talking about Pap Camp, which we'll get to in a little bit, and they were like, hey, everybody needs Pap Camp. We all want to go to this. You know, you don't need to have a disability to want to do that. So we want to provide them the education to know what's going to happen in their exam, give them a sense of control, treat any anxiety or previous trauma, address their sensory issues, and then help the provider be more patient or know about alternate procedures.

We did a survey in our Cohort 1, and we did find out a couple of things. One thing is that when we went to our IRB, and we said we wanted to ask women with disabilities about sex, they were like, what? Sex and disability in the same sentence? They were like, no, we can't include anybody without … who were not their own guardians. So we did have a limitation there. Overall, we found though that of the women who did complete our survey, they had limited knowledge about sex or birth control, they were not talking to their providers, sometimes their provider didn't even ask them questions, they only asked the person who was accompanying them the questions, they were not having their breasts or Pap exams consistently, and anxiety, worry and trauma were a significant barrier. So in the first cohort, we developed a content module – it's a 32-page booklet – to try to address some of these things that would include information related to women's health including their sexual reproductive health, discuss consensual and non-consensual sexual activity knowing that there is a high rate of abuse within this population, teach them how to become their own self-advocates with their caregivers and their medical professionals, and include the importance of these preventative medical care. So we took … the Arc had had an old booklet that was done in the 1990s called Women's Health and What Every Woman Should Know, and we updated that into an interactive booklet that – and I'm going to show you just a little bit about the booklet – that includes things like how do you make an appointment. And we were very cognizant of trying to present all of the information at various levels. So within the booklet there might be access to social stories because some people need to have a social story to get them prepared. There might be access to videos, there might be access to other printed materials, but we went through from making an appointment all the way through. And we talk about what we call the five P's, on privacy, pleasure, permission, planning for pregnancy, and prevention of STDs. And we talk about that not only in relation to relationships, like, you know, we're always talking about consent, but that our providers should be asking permission every single time they want to be able to examine somebody. For individuals with caregivers it's very important that they also respect the individual's privacy. You know, very oftentimes they're like, oh yeah, you know, you want to take a look at that, just pull down their pants. And we're like, no, we need to ask permission. So to trying to work with women on understanding their own self-advocacy and what they should be expecting and what they can ask of the provider or their physician.

We also know that inclusion matters. We found that there were no good pictures or illustrations of individuals with disabilities getting the exams, so we hired a medical illustrator who could create some color and inclusive materials for us, and, you know, here are some of the other materials that we were able to pull together. And so being able to see somebody who looks like you is just very, very important. In our Cohort 2 … so Cohort 1 we created the booklet, Cohort 2 we wanted to continue this work by addressing knowledge gaps within providers, working on decreasing stigma, and modeling and creating a true plan that we could help to identify a personal care plan for every person who needed to have this exam and address some of their issues in a fun way, in a way that could be replicated in different primary care offices and gynecological offices.

So that leads us to Pap Camp, and this is our Cohort 2, one of our big directions. We are developing Pap Camp, which is having a group of women, like five or six together, come together to learn about what will happen when they go for their gynecological exam and with the idea that they're going to come out with a personalized plan that they can take to their providers saying these are my needs. This is … I need this sensory need. I need some extra time. I need whatever it takes. We do have … this is a little bit about what the [indistinct] Pap Camp, and here are the activity topics. And this is actually … these are some cards. We're putting together a booklet of flip cards, they're like 4x6 so they can fit into somebody's backpack or their purse. They can bring it along with them, and there are activities within there that will then lead to a plan for them when they go. So, you know, we talk about permission and consent within it. We talk about ways in which you can calm your body, ways in which you can calm your mind. So it includes things like progressive muscle relaxation, imagery. There's a QR code that they'll be able to go and find different types of meditations that they might want to watch. We have an occupational therapist working with us on the sensory issues and how to include calming activities related to that. How to deal with some negative thoughts and how to change them into positive thoughts or use distraction. You know, sometimes we play I Spy. And then, what kind of supports do you need? Do you want somebody to come in with you? Do you want somebody to leave the room when they're there with you? And ultimately they walk away with a little packet which includes like a stress ball and we teach deep breathing so they're going to come away with some bubbles. We teach them how to breathe in and then breathe out slowly. They go away with cool socks. They get to pick their color of socks. And ultimately our goal is to make this less scary, make this more comfortable, and to be able to give them a platform to be able to talk with their, with their care provider. So I include, there's aromatherapy. I forgot the aromatherapy. There's some grounding techniques, but an individual advice plan is what they come away with from Pap Camp. And then our ultimate goal is then being able to take that on the road to different offices, and so we have some partner offices where we're going to teach their nursing staff how to run Pap Camp so that they can run Pap Camp also.

We also are focusing on provider knowledge. So we are putting together some, and we have already done some of this, some provider training to both primary care providers and OB GYN providers that helps them to understand what accessibility options are necessary, how to address sensory issues, anxiety, and past trauma so that they are a bit more aware to come in with a trauma focused lens as well as to know what kind of accommodations might be necessary. We did do a survey of some providers, and we found that they also were saying that they lacked training. They had not had specific training in working with different populations so our goal is to take this to local, state, and the national level to be able to provide training for providers. We were just recently at Autism New Jersey talking about this. We are going to be at the American Academy of Developmental Medicine and Dentistry talking about providing access and how to adjust practices to be able to provide these types of evaluations. And I don't know where I am on time. Hopefully I'm good. Am I good Rebecca?

Rebecca Martin: Yes, you're right where you need to be.

Wendy Aita: Perfect, okay, so what I'm gonna do now is I'm gonna stop sharing, and I am going to lead into Liz Hayden who is going to be taking part and doing the presentation for the second half before we have our question and answer session.

Liz Hayden: Thank you so much. So Rebecca's gonna put up the slides, but in the meantime my name is Liz Hayden and I'm the vice president for strategy development at Woods Services, which is headquartered in Langhorne, Pennsylvania. And I wanted to talk a little bit … you can go to the second slide. Rebecca is going to very kindly advance the slides for me. So I wanted to talk a little bit about our involvement in the Inclusive Healthy Communities grant program, and also similar to Wendy to express our appreciation as an agency for the planning grant that we received in Cohort 1, which provided a really great launchpad for us to not only do the project that we worked on that I'll talk about in a few minutes, but also to continue developing the work that we're doing in terms of expanding access to primary care and integrated care for folks with intellectual disability, autism, and other complex conditions. So next slide, please.

So I'm going to be talking a little bit about why we formed our system of care for Wood Services and talk a little bit about our integrated care model, which formed the basis of our IHC Cohort 1 project and we're continuing to build on, talk a little bit about the details of that project and where we're going with it, the importance of partnerships that we've developed, to continue to develop, and then some future directions. So next slide. So a little bit about Woods and our system of care. So Woods system of care is comprised of our organization and six affiliate organizations, which in the for-profit world would probably be called subsidiaries. So we have locations throughout Pennsylvania, and New Jersey and by far the largest populations that we serve are in New Jersey, and so we have very strong and long-time roots in New Jersey, which is why we were very interested in the IHC grant as we were developing a new program that was starting to be developed when the grant came along. So we serve about 23,000 folks – children, adolescents, adults, older adults, the whole gamut of ages throughout mostly southeastern Pennsylvania and the whole state of New Jersey, I think most counties, and have a broad range of partners. We are affiliate partners in that. So next slide, please. So Woods serves many, many, many folks with different kinds of conditions and different walks of life. We tend to serve folks who have really complex needs, and so they may have multiple conditions that require specialty care, combination of different things, and with needs that change, you know, throughout their lives or may have episodic needs. So generally speaking we do serve some of the most complex folks who really have trouble accessing care and the right kind of care that they need. So that is why we wanted to develop our system. Next slide, please.

So Wendy had talked quite a bit about some of the health disparities and disparities in access to care very comprehensively, and I just wanted to highlight one more thing that I feel like has probably been on our minds for a while. The COVID-19 pandemic really highlighted the disparities, I think, for everyone that people might not have been so aware of before in terms of different populations in this country who really suffered disproportionately through the pandemic, including older adults as an example. So people with intellectual disabilities really had, were at the upper end of that scale, so here are a few stats that I've included here. The data progressed throughout the pandemic that, you know, basically stayed the same. So the people were much more likely to get COVID, be hospitalized, have negative outcomes, or die from COVID. So one of the things we also have focused on and everyone's talking about is part of the reason for those disparities in the access to care is the healthcare workforce, which became increasingly burned out throughout the pandemic. That didn't help, but there were already shortages. And thinking about the healthcare workforce very broadly, so not just primary care, not just physicians, nurse practitioners, physician's assistance specialists, but also the folks that do sort of the day-to-day jobs of providing support so that people can live as independently as possible. So one of the things that we were really actively advocating for throughout the pandemic was, for example, making sure that the folks that we serve and the healthcare workforce and caregivers had access to vaccines when they became available right out of the gate. That was not in the plan originally, and it took a lot of advocacy to change that. So I think, you know, it's something that's top of mind for us in terms of advocating for changes in systems and making sure that we consider that our population that we serve we keep that front and center. So next slide, please.

So we have a lot of programs and services across our system of care. So I won't list them all, but what we do is continue to identify programs and services that might fill gaps as we identify needs that families tell us about or individuals tell us about or we can identify through data or funders. So that's an ongoing quest to continue building our system of care and adding services where and when they're needed so people can access where and when they need those services. Next slide, please. So what is our approach? So we have an integrated approach that we feel like we approach the whole person and that means being patient-centered first and foremost. So lots of the things that Wendy talked about really resonate with our approach, which is, you know, asking, listening, and looking at the whole person and not just looking at the disability or looking at the one condition but really considering the whole person in our approach. We also pair healthcare with addressing the social determinants of health so a number of Woods and a number of our affiliate organizations provide comprehensive services, including housing supports so people can live as independently as possible, all different kinds of supports that address the social determinants so that people can have healthier lives and live the way that they would like to live and get the jobs that they would like to get and live where they would like to live. So we try to integrate all of those things together in our model. We've continued to develop our services in a geographic kind of concentration sort of way so that people can access the services in close proximity so that's an ongoing, that's always a challenge, but we continue to try to build that. So next slide, please.

So some of our … I just wanted to show this example because our organizations and our system of care provide a few, provide some similar services but maybe in different locations. But the major point I wanted to get across is that some folks need supports throughout their lifetime.

Those supports may change as needs change, and certainly for anybody as, you know, go from being an infant to a little kid to entering adulthood and then becoming a senior changes are happening and your needs change and your interests change. So we have services that kind of address those interests and needs throughout the lifespan and that was really critical for us. So next slide, please. So I've sort of talked a little bit about our system of care and why we feel like this is an important approach. But we find that systems are fragmented. I think everybody might have something to say about the healthcare system that we have in this country and how it's sometimes hard to access things in a seamless way. So our attempt with our system is to try to shore up a system that is fragmented and approve the services along the way, improve the quality, and expand the services so that access is increased. And the other reason why a system of care is important for us is that funding models are changing. So there's this buzzword "alternative payment models," which basically means that healthcare is increasingly being paid for outcomes not just stuff that you get or things that people do. So the healthcare outcomes are the whole point. And so why shouldn't we get paid if we are helping to improve those outcomes and look at the whole picture as opposed to just getting paid for, you know, what might be a 15-minute visit doing X, Y, and Z? So having a system helps us function in that changing system a little bit better. So next slide, please.

So getting to our IHC project for cohort one, we were building on the work that we've been doing for a long time, and we had identified, you know, like everyone else is very familiar with the gaps in care, gaps in access, health disparities of the population that we serve. And we see it everywhere across Pennsylvania, New Jersey among the people that we serve. And people tell us, and families tell us, and we can see it in the data that we that we have access to. So we were looking at three things which is that the access to care issue, health disparities, unnecessary ER visits and hospitalizations, which if you can prevent them through increasing preventive care, how great is that? So much less traumatizing for people and less costly because those are the most expensive service, among the most expensive services, and everyone wants to avoid those.

So similar to what Wendy was talking about, we know that there aren't enough trained primary care providers to work in interdisciplinary teams, which are often really required to be able to coordinate across specialty care. And also, the fact is many providers don't take Medicaid or do not want to see patients who have complex needs. And there are some recent studies that have just been published about surveying – I think they were physicians who were surveyed – who expressed that they don't feel competent to serve this population, with folks with intellectual disability or autism, communication challenges. Also, patient visits can take longer if there are these barriers. And Medicaid reimbursement is not high enough to pay for a 45-minute visit that might need to address a few things and so that becomes a barrier on the system side for increasing the number of primary care providers to provide care. And then getting back to the earlier side of the professional trajectory, Health profession schools don't provide a lot of training, if any, to serve, help people be confident in serving folks with disabilities, any kind of disability. So next slide. So why Salem County, which was the locus of our IHC project? We had been talking with Salem Medical Center for a while when the IHC opportunity came up. We had already set in place a partnership we had talked about developing an integrated primary care practice in that location.

One of our affiliates had quite a number of folks that they serve in that area. It's not a very populous area, and while there are some services there was not the access to care for primary care for this population. And then Salem Medical Center ran their data, and they looked at their hospital data and they said, yes, there is a need, and so we felt that this was a good location and we had the partners in place to develop this project. So in the end we were able to develop a primary care practice not to the extent that we had initially planned. As we, as the project moved along we realized the population is fairly small, but the needs are very high. So we do have primary care, and we do have the partners in place that have a really a continuum of services both with Salem Medical Center and also with our affiliate partners. So next slide, please.

So I talked a little bit about this earlier, but the integrated practice that we had envisioned and implemented was based on a model that we had been operating in Pennsylvania just over the New Jersey border for quite a while. Woods had always provided healthcare. We reorganized that a few years ago, and at the same time we were able to partner with Pennsylvania's largest Medicaid insurer to do a patient-centered medical home pilot. And what that is a mechanism by which an insurer can look at the outcomes over a period of time and say, yes, you are doing good prevention, you're avoiding ER visits that are not necessary, and hospitalizations, and people's health is, your managing chronic diseases, and the health outcomes are there. And so our pilot showed some really promising results. This is about four years ago. Every year we've gotten better because we're looking at our data and saying, okay, we need to put this in place or that in place as we see the needs changing or something different that we need to do in in the in the healthcare practice. So this was kind of the foundation for what we wanted to launch in Salem County. So next slide, please.

So we were struggling a little bit with this concept that this is our Medical Center, so on one side the center is all primary care and then specialty care so we have a number of medical offices, we have adaptive equipment, we have all of the things that Wendy talked about that we feel are kind of basic, and on the other side we have dental care. However, it's not really feasible to pick this building up and move it to a bunch of other locations or build a whole bunch of health centers like this. It is just not feasible to do that. So we need to have … take the best of the model and the services and then combine them in different ways in different locations with different partners. That is, that's really the only feasible way to expand the model. As long as we have the hallmarks of the model, which is that patient-centered care and the interdisciplinary teams, and we have the right partners in place, then we can still deliver the model in the way that is effective. So next slide. So some examples of partnerships: the structure that we had in Salem County is different from the next project that we're working on now. So this is a joint venture. We actually had a set of services that were developed, including mental health outpatient services, a crisis stabilization unit, and then the primary care piece. So those partnerships are really critical. And one of the reasons that the partnerships help us along the way are sort of two levels: One is partnering with other health systems helps us bring in more specialists as we identify the need for those, and also we can bring in students or residents or folks who are really interested in learning more about this population and kind of help train the next generation of providers for the future. So you could go to the next slide. The next slide.

So Wendy talked quite a bit about some of these pieces, too, in terms of the training that providers need to know so we implemented training for primary care provider who is in Salem County and focused on these types of things: So learning strategies for communicating, you know, talking to the patient and not necessarily the caregiver depending on on what the needs are, focusing on the whole person and then the adapted environment. That's quite a challenge for existing practices, but something that's very critical. And then really being able to work in teams across disciplines, which I think primary providers do pretty well often, but sometimes this is even more expanded. And then the next slide. So some of the takeaways from our project were just we knew going in how important partnerships were. They're all different, and you run into things that you can't control. In our case working with the large hospital in a health system. It slows things down. So things don't happen in a very quick way when you're dealing with large institutions. We also know that provider training at all levels is needed, so every kind of provider at every level is really critical. We found that data is not great. It's hard to find data and information health data sets that inform issues for people with intellectual disability, and this population needs to be included in planning and in data sets so that better decisions can be made around healthcare. And advocacy is critical. Next slide. And I know I'm getting down to time so if you could go to the … this one. Perfect.

So what we're doing now moving forward building on the IHC project is expanding to a location in Hamilton with another large health system, and that's a totally different kind of partnership and structure, very much more populated area, higher needs. We kind of tested some things in Salem County. But we do feel like this is a really good strategy. However, we also want to press forward with continued training of students and existing providers. And I think that's absolutely critical because it's not feasible to open a practice in every single location where there might be a need. I think it's much more efficient to train existing providers and help increase access that way. And then the other piece is advocacy around policy and systems change both from the payment side, the funding side, connecting systems and services, continuing to press for those things to be less fragmented, include people with disabilities and planning and data systems so that decisions can be made around those pieces of information and …Mercer County is the answer to the question in the chat, it just popped up on my screen … and then training and supporting healthcare providers as well as the direct care workforce, which is so critical to supporting our … all the populations that we serve. So those are, that's it in a nutshell. Thank you.

Rebecca Martin: Thank you very much, and thank you to Wendy. I think you both gave us a really great understanding of your IHC projects and some of the systemic barriers and challenges that have come up in the work that you do. I would like to open up the opportunity for people to ask questions. If you would like to unmute and ask yourself, please feel free to do that. And if not, please feel free to put questions in the chat, and I'm happy to ask them for you.

Let's see, I have one question in the chat that I think we can start off with, which is how do we stop the merry-go-round of ER and early hospital discharge resulting in preventable re-hospitalization?

Wendy Aita: Yeah, I think, so one thing that we have found is that, well, first of all we know that there are sometimes legislative action that requires going to the ER, and, you know, so for example, Danielle's Law requires that anybody who has an injury has to go to the emergency room when that might be preventable. We know that when you get to the emergency room, it's often very traumatizing, it's scary, and providers, if they are not aware of how to work with individuals with disability, end up ordering all kinds of tests because they don't know what to do. So how do you stop some of that? I think on a legislative level and something that we are really hoping to be able to work with some health systems on is to be able to have a telehealth option first before somebody goes to the hospital – like, check in with their primary care doctor. so for our patients a check-in before anybody goes to the hospital to see if it's necessary, making sure that there's good access to medical records so we're not redoing things. You know, we've had patients who, you know, come back to us after being at the hospital and just had the same test run that we had run two weeks before, right? They're doing the exact same thing all over again. So we don't have good communication within hospital emergency room records in making sure that everybody's been working on the same system. I think that's a significant problem. And we need the data. As Liz was saying, it's very hard to make changes without the data, and when you go to a hospital having an intellectual disability doesn't get put in your problem list. Very often the problem that gets put in is the problem that you're showing up at the ER for. So when we want to try to make some of these changes, how do we make changes in the way that, you know, people are either admitted or discharged from the hospital. We have to be able to study it, and then in order to be able to study it we have to be able to identify people to start with. So finding a way of sharing information, I think, would help. We do work with our patients here on having a portable package that goes along with them. We work with families, so I'm creating that on, you know, records that have recently been done, listed medications, have these things at the forefront when you have to go to the hospital so that, you know, all of the information is in one place. But if we're going to be able to make some of these changes, we need to know what the statistics are. And until we can make sure that we start identifying things like autism or intellectual disability or cerebral palsy because, man, if you're going into the hospital for a head injury your CP might not even get in the chart. And we have to be able to pull that data in order to be able to make systemic change and do the type of education that's necessary.

Liz Hayden: And I will piggyback with one thing. I think everything that you've said Wendy and some of the things that we do at Woods especially on the prevention side. Sometimes we are mandated to send people to the ER, but then how do you avoid a hospitalization? So one of the things that we did was we did – and this is really fortunate that this hospital was really welcoming of this – we did a training for ER providers, and they were really excited about it because they felt like they were building up their skills to be able to more sensitively help people in the ER including they actually set up a sensory area, which I guess they had space to do that and the ability to do that. So that's kind of amazing to me. But that was a win because after that people were not admitted to the hospital as frequently following that. So that was a success. Now, is that feasible? I don't know the feasibility of training all ER departments, but it could be a strategy. It could work other places.

Rebecca Martin: Thank you. We have another question in the chat, which is have you seen provider pushback due to the increased or perceived increased workload due to additional needs of the population. And how do you get more providers even on board to work with Medicaid?

Liz Hayden: I can say one thing about that. The provider pushback is that people just don't accept patients. So the answer is, well, yes, there is a provider pushback. It's finding those providers who want to accept. So one of the things is working with the insurers to increase rates for primary care, which is only a little tiny bump up which can help offset the time that is needed to be spent and that is a huge incentive so that's working on the back side, the back end, with, on the payment side, to make sure that incentives are there to compensate for that time. You know, if people are trying to see, you know, have a 15-minute visit, which is just about what you typically get, you know, $14 isn't going to cover that. So that's something that we work on and it does, it does make a difference. I don't know, Wendy, if you have more to add to that.

Wendy Aita: Yeah, so in terms of provider pushback, one thing that we are very fortunate at having here at Rowan is that we have two medical schools. And in our building we have upstairs a brand new cohort of medical students. What we know is that you don't know what you don't know and if you haven't been exposed to individuals with disabilities then your perception of them can be that they're too difficult. And actually there was a course when Dr. Lecompte and I came to Rowan that was called Dealing with the Difficult Patient. And we're like, what? So we took over the course and now it is called Etiquette in Treating Individuals with Different Abilities, because if you identify this group as being difficult you're already setting up a preconceived notion that this is, you know, going to be just too much, too much for me to deal with. So our goal is, you know, we're only one medical center. We aren't going to be the special doctors for every special payment patient in the state of New Jersey. We need more foot soldiers. So what we do is we bring in our internal medicine residents, our family medicine residents, and they round with us. Our medical students upstairs come in, and they sit in on our patient, in our patient sessions. We get them involved in Special Olympics, because there you are seeing our patients thrive in the things that they love to do. So being able to have exposure is so very, very important, and that's how we create more doctors who are willing to work with our patients, because it's that perception of they're going to be too difficult, or I don't know enough about this, or I don't know what to do when I walk in. And if you can get trainees, you know, we did COVID injections, and sometimes, you know, we had to go and do them in the car because of behavioral challenges. So our medical students were doing that, and they were like pumped. They're like this is really awesome. I love to be able to do this. So we're hoping to get in on the ground level of bringing in our medical students. There's … I know we've had some positive exposure presentations before in the state of New Jersey, but that same individual who does the positive exposure – and his name is not on the tip of my tongue right now – but what he does is he takes photographs of people with different genetic conditions or disabilities thriving in their life. And he developed what is called FRAME – Faces Redefining the Art of Medical Education – in which you can go on and click on a different genetic condition and see pictures of that person living their life, not these black and white pictures with, you know, a bar across your eyes and this is this genetic syndrome that our medical students were learning about. So all of these I think impact our ability to be able to provide more foot soldiers to get more individuals willing to spend the time even if it's extra time, even if it's a little bit more difficult with our patients.

Rebecca Martin: Thank you very much. We are out of time, but this has been a great session. Thank you so much. Thank you to all the attendees. Thank you to Liz and Wendy, and thank you to the Division of Disability Services for providing us the opportunity to have this training today. We appreciate you all.

Liz Hayden: Thank you for the opportunity. Take care, everybody.

Rebecca Martin: Thank you.