

**The Lewin Group**  
**Supporting the Preventive Health Care Needs of Dually Eligible Women with Disability**  
**May 12, 2021**

Poorvi Soni: Hi, thank you so much. My name is Poorvi Soni, and I'm with the Lewin Group. Happy National Women's Health week, and welcome to the webinar, *Supporting the Preventive Healthcare Needs of Dually Eligible Women with Disability*.

Today's session, will include a presenter live discussion, followed by time for audience question and answer. This session will be recorded. A recording and a copy of today's slides, will be available at [resourcesforintegratedcare.com](http://resourcesforintegratedcare.com)

There are two ways to listen to today's presentation. Audio should automatically stream to your computer speakers. Make sure that your computer is connected to reliable internet and that the speakers are turned up.

If the computer audio option is not working for you, there is also a dial in option. To access this option at any time, click on the black Phone widget at the bottom of the screen. A phone number and access code will appear. Calling the number will allow you to listen to the presentation through your phone.

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For this interested in continuing education, you must complete the pre-test at the beginning of the webinar, as well as complete the post-test with a passing score by 11:59 PM, Eastern, tomorrow.

This webinar is supported through the Medicare and Medicaid coordination office, at the Center for Medicare and Medicaid Services. 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 learn more about current efforts and resources, please visit our website or follow us on Twitter for more details. Our Twitter handle is @Integrate\_Care. You can also find us on LinkedIn.

At this time, it is my pleasure to introduce our presenters for today. First, we have Dr. Monika Mitra, PhD, who is the Director of the Lurie Institute for Disability Policy, and the Nancy Lorraine Marx Associate Professor of Disability Policy at the Heller School for Social Policy and Management at Brandeis University.

Then, we have Dr. John Harris, MD, MSc, who is an Assistant Professor in the Department of Obstetrics, Gynecology & Reproductive Sciences, at the University of Pittsburgh as well as the Director of UPMC Magee-Women's Hospital Center for Women with Disabilities.

After Dr. Harris, we'll hear from Amy Shannon, who is a consumer at the UPMC, Magee-Women's Hospital Center for Women with Disabilities.

And finally, we will hear from Sarah Triano, who is the Senior Director of Policy and Innovation, of Complex Care at Centene Corporation.

Here, we have our learning objective. As we will go through attending this webinar, you will be able to recognize the challenges and barriers to accessing healthcare that women with disability face, including attitudinal biases, physical access barriers, communication challenges, stigma, and unmet social needs.

Identify how providers, care teams, and non-clinical staff, can employ integrated and person-centered approaches, to support women with disability in receiving care that meets their needs and preferences.

And describe how health plans and providers can support women with disability, by improving communication and physical accessibility.

And here, we have the outline for today's event. We will first ask you to complete two introductory polls, and then Dr. Mitra will share an overview of the issue. She will be followed by Dr. Harris, who will share clinical considerations for accessible and inclusive healthcare for women with disabilities, and then our consumer speaker will discuss her experiences as a woman with disability accessing preventive healthcare.

We will then hear from Sarah Triano, who will share her health plan perspective. And finally, we will end with an opportunity for you all to ask questions, and hear responses from our presenters.

To begin, let's do some polls to get an understanding of who is attending the webinar today.

First, we'd like to know, which of the following best describes your professional area? You may choose one of the options provided on your screen.

If you could move to the results. It seems like our audience is health plan, case managers, care coordinators, we also have health plan administration management, as well as providers, in the audience. Welcome.

And the next poll question. The next question is; in what setting do you work? Please choose one of the options provided.

And if we can move on to the results. A majority of our audience works in health plans, but we also have some community based organizations, and some consumer organizations, and long-term care facilities.

Okay. Well, thank you, every one, for sharing in the polls. And with that, I want to turn to our first speaker, Dr. Mitra.

Monika Mitra: Hi, Poorvi, thanks for the introduction. Hello, everyone, and welcome. As Poorvi mentioned, I'm Monika Mitra, and I'm the Director of the Lurie Institute for Disability Policy, at Brandeis University,

Next slide, please. I'm going to be in the next 10 minutes or so, providing you with an overview of what we know about people who are dually eligible, and really focusing on women who are dually eligible.

And right off the bat, I'm going to tell you that, in terms of research, in terms of data, specifically when it comes to dually eligible women, the research is pretty slim. So what I'm going to end up doing is just talking about sort of what we know from the data, and also filling in the gaps by discussing and by documenting what we know about women with disabilities in general.

So first, I'm going to give you an understanding of the population, like who are people who are dually eligible, then I'm going to go into specifics about chronic conditions for women who are dually eligible, preventive care, preventive health care access, pre-conception care, as well as prenatal care. And for each of that, I'm going to discuss some of the barriers that women who are dually eligible, face, in accessing these types of care.

And in the end, I'm going to summarize and give you an idea of next steps, and really, what are the data gaps.

So what we do know is that, as of 2018, 12.2 million people were enrolled in Medicare and Medicaid, and 60% of dually eligible women -- dually eligible individuals, are women, and this is based on the available data that we have.

But we also know is that, people who are dually eligible, faced high rates of chronic conditions, including diabetes, heart disease, and hypertension. About 60% of dually eligible people experience multiple chronic conditions, and more than 40% have one or more mental health diagnoses. And across all ages, what we've seen is that the proportion of dually eligible women, among those with multiple chronic conditions, was higher, than that of men.

Next slide, please. So just in terms of the general population, what we know is that, disability and age, there's a strong correlation. So the older you are, the more likely you are to have a disability.

When it comes to dually eligible individuals who have a disability, so 64% have reported not being able to access needed care. And this includes preventive health services. So 64% of those who are not being able to access care are women. And dually eligible women, so on one hand, they're more likely to have problems in accessing care, including preventive care, and on the other side of the dually eligible women, who have a disability, are more likely to be hospitalized and have a greater number of days, inpatient days, compared to non-dually eligible -- compared to their peers who are not dually eligible.

Among the general population are disabled women, and what we've seen, their screening rate for breast and cervical cancer, among women with disabilities, are consistently below national standards. And there is some variation depending on the type of disability.

So for example, in a study that was conducted a few years ago, what we found was, women with physical disabilities who develop breast and cervical cancers die from them, at an earlier age, compared to non-disabled women.

Next slide please. So what are the barriers to preventive screening? And I know that the speakers after me are going to discuss this in greater detail, but people with disabilities face significant barriers to accessing care, and to accessing preventive care. There have been reports and the research that they have conducted, there's a great difficulty of getting an appointment, and there are long wait times.

Transportation issues, the lack of transportation, the lack of accessible transportation, the lack of accessible public transportation is a significant barrier for people with disabilities, whether accessing preventive care, accessing job opportunities, or social participation, every aspect of their lives.

So in addition to transportation which we've also seen, is that even when they actually get to their providers, there is a lack of accessible equipment, and there is a lack of accessible facilities.

But even today, which is what, 31 years after the Americans with Disabilities Act, people with disabilities and women with disabilities are facing inaccessible healthcare environment every day.

Women with disability, for example, often face challenges, getting into the required position or on to an accessible exam table. In my research, what we've seen consistently is women with disability have reported just not been weighed. And we've even spoken to women with congenital disabilities, who have never in their lives or even know of an accessible weighing scale.

There are also additional barriers, for example, communication barriers. So there is a limited available of appropriate and accessible communication tools, there's a lack of American Sign Language interpreters.

And often, beyond these barriers, what we've seen is, women speak about the attitude of the providers, and the support staff that they had encountered. Sometimes, the attitude is really due to just the lack of provider experience and in providing care to women with disabilities, particularly when it comes to actually even having the knowledge.

So this was a study that's conducted in Massachusetts a few years ago. What we found is that, rad techs, for example, often didn't have the appropriate experience and knowledge in positioning women with physical disabilities.

Next slide, please. And all of this of course, is related to the lack of adequate provider and staff treatment, and a lack of adequate training, both in terms of interacting with people with disabilities, but also to understand the diverse needs of women with disabilities.

So in a recent study by Lisa Iezzoni, and her colleagues, what they found was, among the physicians that they surveyed, 41% reported feeling very confident about their ability to provide the same quality of care to individuals with disabilities, compared to those without disabilities.

And as I mentioned before, what we found is that, women with disabilities often report that healthcare providers interact with them in a pejorative, and condescending and often in a patronizing manner.

Next slide, please. So in this slide, what you're seeing is that women with different disabilities are less likely to receive mammograms, the recommended mammograms compared to non-disabled women. So what we've seen is 73% of women without disabilities -- report between the ages of 50 and 70 -- report receiving a mammogram in the past year, compared to 67% of women with any disability. And when it comes to women with cognitive disabilities, they are the least likely to receive a mammogram.

Next slide, please. And again, we see similar disparities in terms of the receipt of Pap tests for cervical cancer screening. And often, what we've, in research that was conducted by Dr. Parish, is what we've seen a lot of providers just assume that women with disability are non-sexual, and so there's a less of a likelihood of Pap tests.

Next slide, please. In the research that I've conducted with these -- women with and without disabilities, while they report similar pregnancy intentions, and their desire for children, that they often received disparate treatment, compared to women seeking contraceptive care. They're also less likely to use moderately -- effective measures of contraception, but they are more likely to be sterilized, and sterilized and also sterilized at younger ages.

Next slide, please. And so on one hand, what we are seeing is that, women with disabilities, there is a disparity in terms of their pre-conception of care. But when they get

pregnant and when they are seeking pre-natal and perinatal care, what we're seeing is that, women with disabilities are more vulnerable to multiple risk factors, they're also more vulnerable to pregnancy complications, they face a higher rate of adverse birth outcomes including pre-term birth, including babies who are smaller babies, so pre-term births considered small for gestational age.

And they are more likely to experience pejorative attitudes from their healthcare practitioners, both at pre-conception care, and throughout their prenatal care.

Next slide, please. So I just want to summarize my presentation by just saying, again, we are (inaudible) is that there is really a need for data and a need for greater understanding about the needs and the experiences of dually eligible women in terms of their -- seeking preventive care. We know that people with disabilities and women with disabilities, particularly women who are dually eligible, they are more likely to have higher levels of poverty, of poor mental health, overall health, elevated levels of stress, and trauma, and poor experiences with their healthcare practitioners.

So what we really need to do is also understand how these factors and their social determinants have helped impact their access to preventive care. And I do want to end by pointing out that what we know very little about is the intersection between disability and other marginalized identities, this includes women, for example, who are -- racial and ethnic minority women with disabilities, and we understand what are their experiences, what are their (inaudible) and what are the access barriers that they face when it comes to accessing preventive care.

And now, I'm going to turn the talk over to Dr. John Harris. Thank you.

John Harris: Good afternoon. My name is John Harris, and I am the Director of the UPMC Magee-Women's Hospital Center for Women with Disabilities. So let me tell you a little bit about that clinic, about what we offer, and about the experiences that will be generalizable to many different populations and settings. Next slide, please.

First, I want to tell you about our center. It's been in existence for the last 20 years, and we're very proud of that history of access for our patients. It was started by Dr. Sandra Welner, who was a physician who developed a mobility disability as an adult, and so, I guess from both sides, both the challenges of providing medical care, as well as the challenges that the healthcare system had, and being able to receive the healthcare, because she needed to receive it herself. And she was instrumental in starting our clinic here in Pittsburgh 20 years ago.

Sadly, she died right after it was opened, and in a house fire, which is a known occupational hazard for people with mobility disabilities. It's been carried on by other providers, including Dr. Corey, who I took over for. And currently, we're a team that's made up of myself, Julie McKechnie who's a nurse midwife, so that we have both a physician as well allied practice provider, as well as Dr. Peter Bulova who's an internal medicine physician who comes and sees our patients cooperatively. And then we have an experienced and enthusiastic nurse coordinator that really provides some care

management for these patients, because they do have complicated situations frequently that need a lot of communication. Next slide, please.

Just to tell you a little bit of our clinic. These sort of clinics that specialize in these services, are unusual, and ours is one of the larger ones, but it won't seem large under the descriptions of kind of normal general OB/GYN clinics. So we see about 400 or more women each year, we see mostly women with cognitive or mobility disabilities, we see a few people with sensory disabilities, but we are much more focused on intellectual and physical disabilities, and about 61% of the women that we serve are dually eligible. That makes sense both in terms of the high rate of disability, as well as that many of our patients are independent or they no longer have other family members that are able to provide care.

The services that we generally offer are going to be preventive well-woman care, we also provide problem visits for acute and chronic conditions related to reproductive health and GYN care, and we provide medical and surgical consultations related to OB/GYN needs. Next slide, please.

I want to start with thinking about how to improve accessibility for patients that are going to any clinic, this does not need to be a specialist clinic. But it really should be true of all clinics that they're receiving women's healthcare services. First, the location itself needs to be accessible. So what does that mean? There need to be handicap parking spaces that are available, and you know, reasonable to access. Sometimes, these spaces are in positions that are actually surprisingly inaccessible, and so it's one of those things where if we can think about that as a healthcare system or healthcare providers, that that's vital to think about how to optimize those. We want to make sure that there are wheelchair-accessible van drop offs. Many of our patients do use publicly available accessibility vans, services, and so the drop off there is important.

You know, one of the things that we're sensitive to for our dually eligible population is the cost of receiving care, so that would be the last thing that we want to be of concern. So we provide -- so we're here in a city setting where the parking would be relatively expensive even inside the hospital building where I'm at, and so we provide a voucher so that we can make these --the parking completely free for our patients, which is one of the few clinics that offers that.

In large buildings and hospitals, you know, frequently, people come with caregivers, they may not be familiar with the hospital and mobility and getting places can be more complex, and so making sure that people don't get lost or turned in the wrong direction is important. So our front desk is exactly where our clinic is. And they all try to help our patients whenever they realize where they're going.

Next, you want to think about the clinic itself. And so we've established that it needs to be accessible to get to that clinic, but when people get to the clinic, what does it mean to provide the best possible accessibility?

So first is that, routinely, the front desk, the waiting area, may not have a desk that's low enough so that people who use wheelchairs for mobility, are able to see the front desk staff face to face. And so in part to provide that kind of accessibility, we want to make sure there's waiting there's waiting spaces accessible for people with wheelchairs, and that's just filled with existing chairs. And we have the ability to have a rather large waiting area that provides space for people with intellectual disability that may do a little bit better if they have a little bit more space to be allowed to move around and the caregivers can feel a little less self-conscious if people are a little bit more vocal or a little -- have just different behaviors than other people. Next slide, please.

So we've now moved into the clinic room. So this is one of the most frequently concerning areas for people with physical and intellectual disabilities, because we simply don't have a lot of clinics do not have the services necessary. So first is that, is there a wheelchair-accessible scale? This is a service that we offer that, as Dr. Mitra mentioned, is something that's very unusual, but to have a scale that you can weigh a wheelchair with the person in it, and without, so that you can get that person's weight, is incredibly helpful.

It's helpful for anyone at any time, and it's very important for people with mobility disabilities because changes in weight can change center of gravity, they can change accessibility, they can change independence, so we want to do our best to improve and maintain independence as much as possible.

Is there a space in the room for a wheelchair or a stretcher, and be available to transfer to an exam table? Is the exam table low enough that a transfer is possible from a wheelchair? For people that need more lifting assistance, we also want to make sure that our staff is stationed, so the ability to have a hooyer lift, which would lift the patient out who is a -- full assist lift; someone that would take two or more people to move, helps prevent workplace injuries, keeps our patients safe, and you want to make sure people are trained to use those hooyer lifts when necessary.

For GYN exams, it can be challenging for people that do not have independent control of their lower extremities, and so using what we would consider surgical style leg rests that offer full support, is something that we were able to offer within our specialized clinic and with the unusual other settings, but really vital to be able to provide personalized care.

And are there tools available to help make our patients with intellectual disability in autism, feel comfortable if there's something like sensory and activity toys, communication system, devices, are all going to be of importance. And then finally, making sure that the room and the bathroom is large enough to allow for both accessibility and to be able to these. Next slide, please.

And then we want to think about the people that are providing this care. So we want our staff to be prepared and trained. This is an important area, and this is something that every clinic, regardless of whether they have all the equipment, can do a great job in. But first, it's important before these patients come, if at all possible, to know what are the

transfer requirements and equipment needed. This is the way that for places that do not have this constantly accessible, you can help gather this equipment and make it possible.

We want to make sure that scheduling and other appointments are officially scheduled so our patients often have mammograms, before and after their visits so that they only come for their women's health visit once a year with their physician.

Are we staffed adequately for this care? You know, one of the challenges of providing this care is that we do have different staffing requirements than normal women's health clinics, and so we routinely have two staff members in a single room for an exam, which helps us be able to transfer and take great care of people. And that's something that's been set up in this clinic that's not true everywhere, but it's definitely necessary at times.

It's great to have staff that are comfortable with people with intellectual disability and autism spectrum disorder, so that they can make people feel comfortable, and to make sure that people have adequate training, especially with things like the Hoyer lift.

And I think it's important that our staff understand the history and the science behind what is known about the disparities for people with disabilities so we can do our best to provide good care, avoid stigma and bias, and so we definitely do orientation and frequent staff education to kind of stay up to date with the most recent research. Next slide, please.

So in terms of communication with patients, and this would be true at any level, including for care managers, and things like that, that it's important to get to know the specific needs and past experiences of each person. So people are not a single diagnosis, but everyone has a different experience, it's important to ask basic questions, I think humbly as open-ended questions that you don't assume to know what each person's needs and experiences are. So making sure that you're ready for those things involved, just asking those questions, and allowing plenty of time for that discussion to take place, and for the right amount of communication to go ahead. Next slide, please.

Alright, so now, I'm going to talk for a few minutes about specific health considerations, for difference common conditions that may cause a disability and how to best care for them in the setting of women's health. I'm going to start with spinal cord injuries. Spinal cord injuries are an area where I would say that the basic understanding of the complications of spinal cord injuries, may be poorly understood by a general women's health provider audience. And so training for these patients is important to do the best we can.

So there's a condition called autonomic dysreflexia, which is vital to understand for pelvic exams and evaluation of reproductive healthcare. Autonomic dysreflexia is a condition that happens after a spinal cord injury where there's a potential for medical emergency whenever there's a neurologic stimulus below the level of the injury, so that stimulus may be something like pelvic exam, it can also be something like full bladder or a pressure injury, a variety of different things that would cause pain at that level for other

people, causes a dis-regulated neurologic response at least the high blood pressure, a low heart rate, and at worse, can cause stroke, seizure or cardiac arrest.

Pelvic exams can trigger this, and so it's important to ask patients whether they've experienced in the past. Once again, patients are experts in their own body and will frequently be able to help educate staff and providers if they ask, I think if they have the - the providers have the right attitude towards realizing that the patient is as expert in their own.

The treatment would include for calling for help, often calling, sending them to the emerging room, removal of that stimulus, whatever maybe have caused it, placing the person in a sitting position, and removing tight fitting garments and treating blood pressure and heart rate. Next slide, please.

Things to think about for women with cerebral palsy, it's just to remind our audience that there's a group of conditions that involve the permanent, non-progressive muscular spasm, to spasticity. Cerebral palsy may be associated with intellectual disability, but it's not synonymous with it, and it's frequently -- it's confusing to people sometimes, people will use the term cerebral palsy as a synonym for intellectual disability and that it would be unfortunately incorrect, because there are many people with cerebral palsy that do not have intellectual disability.

However, they will frequently need personalized positioning for physical exams due to the limited body movements due to spasticity in lower extremities, and this makes pelvic exams very challenging. So we do our best to provide that personalized positioning for those patients.

And finally, in the case of all these conditions, there is limited evidence-based guidelines for common GYN concerns, including contraception, and managing periods, which can be very important in this population, and in general, people that are not ambulatory, we recommend for generally, avoiding estrogen containing medications due to the risk of embolism and DVT. Next slide, please.

Now, considering thinking about health considerations for women with Down syndrome, you know, very large population of women that do receive great healthcare, it's good to understand the basic physiology for different conditions, so women with Down syndrome will have normal periods, and normal start to their periods, but should tend to go into menopause at a much earlier age. Because of that, they have risks for bone density issues as they age. And it's important to have adequate education to provide autonomy and personal knowledge of people's bodies, and so we do sexual education and appropriate autonomy explanation for patients so that they have the proper understanding for their cognitive level. We provide routine screening for sexually transmitted infections, whether the patient or family reports any sexual activity, because unfortunately, sexual abuse is more common in women with disabilities. And there's an increased risk of infertility, but unlike men, where infertility is universal, there is a possibility of pregnancy, and so offering contraception is important for women that may be sexually active. Next slide, please.

Our next consideration is for women with autism spectrum disorder, and intellectual disability. Two separate conditions, but may have similar issues in terms of making people feel comfortable within a very uncomfortable exam situation. So it may be possible because people do not understand the nature and the reasoning behind these exams that people are more likely to be very guarded about these exams, and very cautious, and so, we do our best to make people feel comfortable, give people time to get to know us, and ideally, have a consistent provider so that people know who we are, and that we're not strangers to them.

Common medical issues in this population may be seizure disorders, or the presence of mood changes around periods, and those are the things we can help manage, and understand the interaction between say, seizure disorders and periods. Unfortunately, there's a high risk of sexual assault and abuse in this population, so once again, screening for that, and screening for infections is important, understanding the menopausal transition and how that can change behaviors and how people feel, such that they can't report it themselves, but maybe caregivers that notice the difference that's important. And managing periods, and contraception that are safe, and offer few interactions with medications and other conditions, is vital. Next slide, please.

So now, just to talk about general person-centered skills, for providing care, and for interacting with patients in the women's health sphere. First, when completing a complete OBYN history, it's important to cover many of the same areas that we would cover with anyone, so we would cover reproductive history and plans, sexual activity and dysfunction, expectations and concerns about pregnancy, past pelvic exam and history and experience and the effects of pelvic discomfort on spasticity, history of autonomy dysreflexia on women we're treating. Next slide, please.

When performing an exam, clinicians should offer assistance when necessary for transferring to an exam table, certainly, many people are independent, but we want to make sure that people feel safe, and put on transfer, and then sitting on the exam table. We do not perform exams in the wheelchair, that is certainly -- expedient in certain options, but in general, we try to provide people the exact same care and the same access to the right exams, as everyone else that we go to the extra process of transferring people, even with a relatively minor exam, like abdominals. And then as I said before, the use of specialized leg support is really vital for people that may need assistance with supporting their legs during an exam.

Additionally, when performing an exam, you want to notice, when positioning, to watch out for causing balance issues, causing issues with spasticity, causing issues with skin pressure, especially over the back of the hips where people can have pressure injuries, pressure ulcers, the presence of contractures, that may make it so that the cause of the pelvic exam position is difficult to kind of get to. And so we can use alternative positions, that's more comfortable for people.

To manage anxiety, which would be present for many people, when receiving women's healthcare, but especially for people that may not understand as well, for someone with intellectual disability, we will explain the process of that at an appropriate level, and seek

to gain trust. And so I always encourage other providers to really be especially humble in this population to ask people about what they understand and what they don't understand about the patient's condition, to take extra time to explain themselves, to encourage patients to give a lot of feedback, so that they can gain a sense of control throughout the visit. This could be a traumatizing visit for anyone, and even more so for people that have either less autonomy or may have less ability to control all their appendages on their own.

Anxiety medications may be helpful in certain circumstances, for people with intellectual disability, though I would tell you that the quality of the team is much more important to make people comfortable, than medications. Next slide, please.

And then, when a pelvic exam is indicated, it's important to communicate actions clearly, to protect the -- and especially gentle exam, to make people as comfortable as possible, including using medication with topical lidocaine, for people with spinal cord injury, emptying the bladder can be helpful, finding a position that's comfortable and using other proper instrument, and having the access to many different size instruments for pelvic exam is important. Next slide, please.

So I'm going to pass it off to Amy Shannon, consumer of healthcare, and an amazing person. So thank you so much.

Amy Shannon: Thank you, Dr. Harris. My name is Amy Shannon, I'm 44 years old, and I live in Southwestern Pennsylvania. And in 1989, I had a diving accident that resulted in a spinal cord injury and quadriplegia. As Dr. Harris said, spinal cord injuries can be very complicated, because the body does not function normally. For example, I don't have any sensation from my armpits down, but that does not mean that the nerves are dead, it doesn't mean that there's a blockage from the nerves from my feet, being able to send a message to my brain, to let me know that there is some kind of discomfort or pain.

So I've had a problem because I had surgery and the surgeons have said you don't need general anesthesia because you don't have any feeling, so let's just put on sedation. And the first time this happened, I was with the doctor, I was young, and I thought the doctor knew best, and so I was sedated for a hemorrhoidectomy.

And then part way through the surgery, my body went to autonomic dysreflexia, I was spasming severely, my blood pressure went up, and the doctor seemed like he panicked a little bit, so they brought me out of sedation and told me what was happening, and asked if they could keep me overnight for a procedure that was supposed to be outpatient, which I agreed, because I was like half sedated and didn't really know what was going. But afterwards, I realized that it was autonomic dysreflexia. And so ever since then, I usually try to talk to an anesthesiologist and make sure that they understand that I don't have any feelings but I still need general anesthesia, because we don't want to have autonomic dysreflexia or some reaction like that, during surgery.

Another thing that happened to me was that, I supposed to go to see my physiatrist, and they must have called to change the appointment, because they wanted me to get a pelvic exam, and the gynecologist wasn't available at the time that my appointment was

scheduled, but I never got the message about the time change. So when I showed up, they were like, they weren't expecting me and they say, oh, you were supposed to come this other this other day to get a pelvic exam. And I was like, what? I didn't know anything about that. And it was very traumatic because I felt like I didn't have a choice over having something done to my body.

They had said that they preferred to do this because I think it was probably in the early '90s and there wasn't a lot of options for women with spinal cord injury to find accessible gynecologists. So they just figured that they would schedule it and take care of that for me, but instead of them taking care of it for me, I waited until this year, at 44 years of age, to finally go to the Center for Women with Disabilities, and get a gynecological screening.

Another big issue I find is that, I would prefer to have my own attendant with me, in the room, to assist me with getting dressed, or undressed, maybe even assist with the transfer because there's a lot of things they know about how my body works and it's more comfortable, especially if I'm somewhere that I never met the people and I don't know what kind of training they have. A lot of people, a lot of staff doesn't have the proper training, especially with transfers. So most of my experience going to the doctors, they never actually transfer me out of my wheelchair, into the bed to do any kind of exam.

A lot of times when they do, they want to just go under my arms and under my knees, which doesn't support the heaviest part of my body, so my butt is hanging down and that's very unsafe because it could cause my shoulder to be dislocated.

Transportation issues, are something that are always a barrier to going anywhere for someone with a disability. And I've been very lucky to be able to have a personal wheelchair-accessible van, so that I can get to wherever I need to go. And then the problem when I get there sometimes, is, there's not enough parking, because there's always a shortage of handicap parking. It's not always safe to park somewhere, and then walk through the parking lot, because if someone's wheelchair is very low, they might not be seen by a driver in the rear view mirror, and they could be hit. I don't have that problem because I use a power chair. But manual chairs, that could be a bigger problem.

And then shared ride services, it's called Access here, but a lot of people with wheelchairs need to take shared ride services to get places. And the shared ride services are -- their main focus is to get as many people rides, as often as possible, and have many people get to their destination, in one day, is possible. So they take you off, and then they go pick up other people, and they like drop some other people off before, but they're not really looking at time and how much time that it takes or a lot of times when I've used it, I would be somewhere like an hour early and you're just sitting around waiting with nothing to do. So that's very frustrating because even if the provider will take you earlier, then you're probably going to be waiting for like an hour afterwards until the van comes back when it's scheduled to pick you up.

Accessibility is difficult. Like I said, when I've gone to doctor's appointments before, they don't transfer me out of my wheelchair but a lot of times when I'm in the office in the exam room, it's not even big enough for me to figure out where I can go and turn around. And a lot of times chairs need to be moved or I'm kind of like, that's halfway between the door and the exam table. I just never feel like rooms are big enough. And that makes it difficult to transfer if I can't get close enough to the exam table. Also, when you're looking at locations, parking spaces need to be flat. It's a lot easier to get in and out of the building if it's flat and not like on a big slope or kind of a steep hill.

And so my experience with Magee was very different because it is a big hospital with a lot of parking, although the parking is all full. So my mom and I did go and park somewhere else and then I had to walk through the parking lot to get to the building. And then when my mom and I were leaving, she figured she would go get the van and come pick me up because that would be easier, there were doors that were easily opened so that I could get in and out of the building. The elevator was accessible. And mostly, going to the Center for Women with Disabilities was -- the staff is so welcoming. The room was bigger. I saw a Hoyer lift in the room right away. The bed raised and lowered. And I just knew that I was in the right place to get the right kind of care.

But not all people with disabilities are good at advocating for themselves or even know how to advocate for themselves because a lot of times we're not even talked to as people. I went to a doctor recently and my mom was with me. And I saw a CRNP and she actually spoke to my mom about me in the third person for the majority of the appointment instead of talking to me. And I was the one who called and made the appointment. You know, I just needed my mom to drive me there, open the door and then I wasn't sure if they were going to need to take an EKG. So I wanted her to be there just in case. But, you know, that was really difficult. And I didn't know what to say and I asked a friend later, like how do I advocate for myself in the future because it was so uncomfortable? And I should have said something from the very beginning, but I hadn't gone to this CRNP before and I'm used to the other CRNPs that I've been to, you know, talking directly to me, and this was kind of a surprise and caught me off guard.

So I would say listening and asking questions, and talking to the person who has the appointment directly is very important. And then I will pass along to Sarah.

Sarah Triano: All right. Thanks so much Amy. I want to start first by just thanking Gretchen, Toby, the Medicare-Medicaid Coordination Office and Poorvi, Jennifer, the whole RAC and Lewin team for inviting me to participate on a panel and speak on a topic that is very near and dear to me both professionally and personally as a woman with a disability myself. In addition to a mental health disability, I was born with a hereditary and incurable immune system disorder and had an immunologist tell me when I was 16 that I should take birth control so I wouldn't quote, contaminate the gene pool.

So although I'm not dually eligible and have tremendous privilege as a cis-gender woman with a hidden disability, access to preventive care, healthcare for women with disabilities is something I definitely identify with and have lots of very strong opinions on. Today, I want to tell you just a little bit about the work we've been doing at Centene in this space

and then end by sharing some specific challenges and next steps for Centene, but also for CMS states advocates and other health plans that I believe could significantly increase access to preventive healthcare for women with disabilities.

Next slide please. Centene is the nation's largest Medicaid managed care and long-term services and supports organization serving over 1 million dually eligible individuals across 35 states. Next slide please. But before I tell you about one of our specific programs, the Provider Accessibility Initiative, I'd like to share just a quick story. In a prior life, I was the executive director of a Center for Independent Living in California. And my board chair was a fantastic advocate named Cynthia Waddell.

In 2012, Cynthia was diagnosed with a brain tumor. And she asked me to go with her to her first MRI. And I'll never forget the look on the MRI tech faces when we walked in and they realized, oh, she's deaf. And they had absolutely no clue how to do an MRI on someone who is deaf. I mean think about it, you're in there, there's that really loud noise. They're saying to you, hold your breath, now breathe, you know. How do you do that with somebody who's deaf? And unfortunately, by the time they finally figured it out months later, Cynthia's brain tumor was inoperable and she had passed away.

But I mean I'm not telling you anything you probably don't already know either through personal experience like Amy's or through a friend or family member who uses a wheelchair and can't remember the last time they were weighed at a doctor's office or who needed materials in accessible formats at the doctor's office and never got them. Or went for years without dental care because the dental offices had no idea how to effectively serve someone with an intellectual or developmental disability.

So as a woman with a disability myself, I'm very, very proud to work for a company that finds that situation unacceptable, and decided in 2017 to take a leadership role and addressing it, not because there's some requirement that says we have to, but because it's the right thing to do. Plain and simple. But also because Centene, we have a National Disability Advisory Council and dually eligible beneficiaries across the country in our member advisory committees told us that we should.

So in partnership with the National Council on Independent Living, NCIL, and NCIL's rock star network or Centers for Independent Living for the last three-and-a-half years, we've been actively working to increase the percentage of our providers across the nation that meet minimum Federal and State disability access standards so that our members with disabilities and their companions with disabilities, say a parent of a child who has a disability, have equal access to quality healthcare and services that are physically and programmatically accessible.

So how are we doing that? First and foremost, we set an expectation in 2017 that if you want to do business with Centene, you better be or quickly become accessible to people with disabilities. So we routinely ask all 1,091,000 of our providers with brick-and-mortar locations across the country to ask a standard set of questions about their disability access that are the same in every state. But we don't just take their word for it that they're accessible, right? Because a lot of them don't even know what accessibility really means.

So local Center for Independent Living staff have trained our health plan staff on how to conduct onsite accessibility site reviews of the providers' offices to verify their level of accessibility.

But, you know, it's not enough to just verify that a doctor's office is inaccessible and then put that in our provider directory. That doesn't help our member who needs an accessible mammogram. You know, one of the reasons that most providers give for not making their offices accessible to people with disabilities is cost. And when I was field director, I used to think that was just kind of a poor excuse, but after working in a Medicaid managed Care Company for many years now, I've seen firsthand that for many smaller mom and pop Medicaid providers, it's a very real barrier. Some of them are struggling financially just to keep their doors open.

And as the largest Medicaid and one of the largest dual serving health plans in the country, you know, we believe we have a responsibility and an obligation to help those providers remove that financial barrier to disability compliance so that our members with disabilities have equal access to the same healthcare and services as everyone else. So in 2017, we created a National Barrier Removal Fund that providers can apply to for money to remove disability access barriers at their office, whether they be physical barriers or programmatic. To date, over \$1.3 million have gone out to 152 provider offices in nine states to remove disability access barriers along with countless hours of technical assistance from NCIL, the local CILs, and our health plans.

Next slide please. And among those grants have been several specifically targeted to women with disabilities. So we helped install a digital enunciator that announces to floors and the elevator at the Institute for Women's Health in Texas. We did a complete women's restroom remodel at an internal medicine office in Florida. And we provided 91 accessible OB/GYN tables in all nine states where we've implemented this initiative so far.

Next slide please. And I'll never forget -- again, one of the first calls I got after we launched the initiative from a nurse at a women's clinic when her office received the accessible exam table, she was so happy because up until that point they have been doing what Dr. Harris mentioned, giving pelvic exams and pap smears to women in wheelchairs while they were sitting in their wheelchairs. Yeah, ouch. I mean, think -- I think that might have some impact on how many women actually schedule an appointment for a pelvic or Pap smear, yeah.

Next slide please. So one of the grants was also made to a residential addiction treatment facility in Illinois that was temporarily housing the women and men in the same wing of a building because the women's ward was not accessible and the state had to shut it down. We added a ramp and the women's ward was successfully reopened. And we were thrilled when a mental health office in Indiana asked for funding to install a fully-accessible diaper changing station in their women's bathroom.

So we know intuitively that these grants we're providing are improving the health outcomes of dually eligible women with disabilities, but unfortunately all attempts to

prove that by securing funding from the National Institute on Disability, Independent Living and Rehabilitation Research with three different university centers on disability have been unsuccessful so far.

Next slide please. So in addition to the provider accessibility, several other things our long-term services and supports and Medicare-Medicaid plans across the country are doing to increase access to preventive care for dually eligible women with disabilities include, they make extra payments to OB/GYN providers for practice visits, so that women with intellectual, developmental or other types of disabilities too can visit the office before their actual appointment, meet the staff, see and touch the tools that will be used on them in their exams to really reduce their anxiety and fear.

We also have partnerships with local centers for independent living and DD providers to proactively distribute HPV immunization information to women with physical and developmental disabilities. We require that all staff go through biannual trauma informed care training, which not entirely, but does disproportionately impact women. And every month, our quality improvement teams identify women with gaps in breast and cervical cancer screenings and then proactively work with our care management teams to contact those women and help them address any barriers that they might have to getting those important screenings that Amy was talking about, like actually scheduling the appointment, scheduling accessible transportation, getting an ASL interpreter.

You know, since the pandemic started, we've seen an increase in the number of women with disabilities that have flat out refused to schedule preventive screenings because the threat of going to a doctor's office and contracting the COVID virus is actually greater to them than the threat of getting breast or cervical cancer. So, to address that, our plan in California, Health Net, has done things like paid for home provider visits and screenings and in-home test kits.

But the fear of having someone unknown even come into their home is still very real. And as my experience when I was 16 demonstrates and as Dr. Mitra pointed out, there is a strong societal assumption that women with disabilities can't have children. And if we can, we shouldn't. But Superior Health Plan in Texas is directly confronting that stereotype by proactively offering care coordination assistance with perinatal, postpartum family planning for dually eligible women in our Medicare and Medicaid plan.

Next slide please. If I had to pick the greatest barrier for health plans today in serving dually eligible women with disabilities, I would say its data or lack thereof. In fact, in 2017, the United Nations Special Rapporteur on the rights of persons with disabilities released a report on the sexual and reproductive rights of women and girls with disabilities and cited the lack of data and information on women and girls with disabilities as the main barrier to implementation of gender-responsive and disability-inclusive strategies worldwide.

So let me give just one example of this problem. So when health plans get eligibility data from state Medicaid agencies through what's called the 834 file, it always lists certain demographic information for our members, like name, address, date of birth, age, sex. If

it includes language or race, and that's a big if, 9 times out of 10, it's inaccurate and it never includes disability, because the majority of State Medicaid eligibility applications don't ask Medicaid applicants if they have a disability. So the only way health plans really know the disability status of our members is number one, if we ask them, which we do but that takes time, a long time particularly if the contact information in the 834 was inaccurate, which it usually is.

So if we want to identify our members with disabilities quickly, we have to get at it through waiver eligibility, rate cells or claims. But even those methods are imperfect because you can have a member who is say, for example, deaf, who won't show up in any of those sources unless you try to piece together certain diagnostic codes. And even then, there isn't like a specific diagnosis code for deaf or blind. We have to take medically-based diagnostic codes like macular degeneration and retinitis pigmentosa and piece them together to get to the members who are blind.

I mean even with developmental disability, you can track the population in the IDD waivers, but what about people with developmental disabilities who don't receive waiver services and who have claims that are like for an ear infection or stomach flu? So on this slide, I've listed the percentage of dually eligible women in Centene's Medicare-Medicaid plans with women representing the highest percentage than men in all six states. And I also have here two graphs showing the COVID mortality rate among all six of our MMPs combined, stratified by sex, setting and age with dually eligible women and men over 65 in nursing facilities having the highest COVID mortality rate.

But if I want to get more granular than that and get a breakdown of how many of those women over 65 in nursing facilities have a physical, cognitive, developmental or sensory disability, I can't do it or at least not easily and without great expense. It's unbelievable. I mean if you ask the same question in an educational or employment context, there's no problem, tell me the number of kids that have developmental disabilities, boom, you got it. Ask it in healthcare, forget it.

Next slide please. So what do health plans need to better meet the preventive healthcare needs of dually eligible women with disabilities? We need data. We need state Medicaid agencies to ask about disability on their eligibility application using something like the American community survey disability question. And then we need them to share that with us. Number two, and I'm going a little out of order here, we need NIDILRR to fund evaluations of efforts like provider accessibility initiatives so we can prove that providing greater access to preventive healthcare for dually eligible women with disabilities have an impact, not only on the beneficiary health but also on larger systems, outcomes and cost.

Number three, we need more women with disabilities in the health professions. While we can certainly educate providers like mine who told me I would contaminate the gene pool, I'd much rather invest our nation's time and resources into helping women with disabilities become doctors who can then change the medical model from the inside out. And last but certainly not least, number four, yes, we are seeing COVID-specific, racial and gender disparities in testing, hospitalization, mortality, vaccination. But all of these

things are really just a microcosm of the systemic racism and sexism evident throughout our health systems, particularly for dually eligible women with disabilities.

And nowhere is that more apparent than in the widespread practice that Dr. Mitra mentioned of sterilizing women of color with developmental disabilities. Now, forced sterilization of women of color in ICE facilities and prisons have been in the news lately, right? But what most people don't know is that women with developmental disabilities have been and continue to be sterilized by their guardians at a rate three times that of the general population, all under the guise of preventive healthcare, to prevent them basically from menstruating, getting pregnant and yes, contaminating the gene pool.

And in their March 8 letter to President Biden calling on him to establish an Office of Sexual and Reproductive Health within the Domestic Policy Council, the National Birth Equity Collaborative stated that the greatest effect of our broken system is persistent inequity which denies people of color, people in rural communities, people with disabilities and people of low income without autonomy to determine their reproductive futures and therefore, the array of health and economic decisions key to their lives.

So to end, I'm not asking for much, right? Just reproductive justice for developmentally disabled women of color, healthcare jobs for women with disabilities, NIDILRR funding and data. That's it. I'm not very hard to please. Centene is just scratching the surface with some of the things we're doing to improve access to preventive healthcare for dually eligible women with disabilities. But thank you for letting me share some of those things with you. And I look forward to hearing your ideas on how we can advance them even further together. And now, I think I'll turn it back to Poorvi. Thanks.

Poorvi Soni: Wonderful. Thank you so much, Sarah, Amy, Dr. Harris and Dr. Mitra for your really informative and great presentation. Now, we have time for questions from the audience. Thank you to everyone who's already submitted questions. If you have any additional questions for our speakers, please submit them using the Q&A feature on the lower half of the presentation screen. You can type your comment at the bottom of the Q&A box and press Submit to send.

So our first question involves COVID-19. What are some examples of unique and innovative approaches to ensure that preventive and welfare is carried for this population during the public health emergency? Dr. Harris, I'll turn the question to you first.

John Harris: Absolutely. Well, I will tell you that certainly the whole healthcare system, we started it at an extreme level of caution about COVID-19 when we had real little information. I know that in April and May, our clinic shut down just because we thought that the last thing we wanted to do is expose anyone. A lot of our patients live in group residential settings. We don't want to expose people to the COVID-19. But over time, the evidence has shown that with proper protective equipment and precautions, that receiving even preventive healthcare services is safe in healthcare settings. And so we tried to reassure our own patients that providing -- that there's a good history here of being able to provide safe care.

And that while any of these particular services may be able to be delayed for some weeks or months in circumstances, we don't want people to be -- to forget about them or to not get them at all, and so we try to encourage people to come in and receive the care that they would normally get, whether it's a pandemic or not.

Poorvi Soni: Great. Thank you so much, Dr. Harris. Sarah, do you have any unique and innovative approaches during COVID-19?

Sarah Triano: Yeah, I can share just a couple of them. One was health plans are required to create care plans for our members and in those care plans, we have to share what the backup -- emergency backup is, in case if they have a personal attendant or a DSP who can't come. But what we found in COVID was that a lot of those attendants couldn't go to help the member because they either had COVID themselves, they were isolating and had children and then their backup in some instances, was usually a family member, got COVID and couldn't go serve them and specifically for people who self-direct their care, this was a huge issue because there was nobody -- there wasn't a plan C to the plan B.

And so we actually set up a 1-800 line that our members could call who were in this situation if they needed an emergency direct care worker and we would dispatch somebody within 30 minutes to 60 minutes in rural areas. So that was kind of one I think unique preventive measure that we tried to take during COVID.

Poorvi Soni: Thanks, Sarah. Dr. Mitra, I'll turn the question to you.

Monika Mitra: Sure. I'm going to go with telehealth. I think telehealth has been a real boon and particularly when we're thinking of for example behavioral health. But I also want to caution that the -- it is one strategy and if made permanent -- if the expansion to telehealth is made permanent, I think we have to ensure that it is acceptable and we also have to ensure that we take into account additional determinants of health and people's access to broadband and people's access to smartphones and in short, it's not just -- it's one of multiple strategies.

Poorvi Soni: Great. Thank you, Dr. Mitra. And Amy, do you have anything to share about your experience to accessing healthcare during COVID-19?

Amy Shannon: I agree with Dr. Mitra about the telehealth because I was able to continue seeing -- or talking to my psychiatrist and getting meds and I was able to do telehealth with my psychiatrist and my PCP as well so that I was able to continue getting the care I needed but didn't have to go into the office or anywhere that I didn't feel safe. So I hope that continues to -- it's been a great resource.

Poorvi Soni: Wonderful. Thank you. Following up on the issue of telehealth, Dr. Harris, how can providers effectively use telehealth to help address some of the transportation or appointment access barriers to preventive care that dually eligible women with disability face?

John Harris: The ideal circumstance would be that the care team does establish communication and ask some detailed questions about accessibility needs and

expectations before the patient comes in. I'm thankful to have a great team and my nurse coordinator essentially screens everyone that comes through to make sure that she understands their needs and that we're not going to have a constraint with two people needing certain pieces of equipment at the same time and things like that. So being able to communicate whether that's by telephone or by telehealth visit with the care team beforehand is critical and it really does help the appointment start off at the -- on the right step and we are able to be prepared.

Poorvi Soni: Thank you, Dr. Harris. Sarah, do you have any other strategies or considerations currently for telehealth?

Sarah Triano: Yeah. One of the things that we did because states were coming out at the very beginning of the pandemic with these hospital triage guidelines that basically said if a person with a disability or an older adult comes in for COVID, don't treat them. And so we established a partnership with the National Council on Independent Living and we've developed a series of tip sheets that we sent out to the over a million providers that we have across the country and one of those, they're basically saying that's illegal, don't do that and here's the rights of our members with disabilities but we also developed a tip sheet specifically around how to provide accessible telehealth for people with all different kinds of disabilities, highlighting things that most people take for granted like take off your mask when you're doing a telehealth appointment with somebody who is deaf.

Sometimes people don't think about that or they might just have it on instinctively. So that was one of the ways that we helped to really promote more effective use of telehealth to address some of these barriers.

Poorvi Soni: Thank you. Dr. Mitra, do you have anything else to add around telehealth?

Monika Mitra: I think one, I just want to be cautionary in terms of let's not swap one set of barriers for another. So obviously telehealth is really important because it's overcome the transportation issue. And I think Amy for example our client and we've done a lot of work and looking at barriers, for example the mammography. And one barrier is transportation but also as Amy mentioned, accessible parking spots. Often they're not designated and often they're not -- there are other people parking on it, not available. So yes, telehealth is great but let's again be cautionary and make sure that it's one tool in the toolbox and that they're ensuring that it's accessible and that we take into account people's access to technology.

Poorvi Soni: Great. Thank you, Dr. Mitra. In your early presentations, you mentioned some of these increased challenges and barriers that someone from racial and ethnic minorities sees when accessing preventive healthcare. So do you have any examples of best practices and changes to address these inequities? Dr. Mitra, I can start with you.

Monika Mitra: Sure. So I think I'm going to second what Sarah mentioned related to data. So we know that women with disabilities and women with different disabilities, particularly intellectual and developmental disabilities face significant challenges in terms of their access and also disparate outcomes in terms of their access to sexual and

reproductive healthcare, maternal healthcare and we also know that there are really profound disparities for women of color, particularly black women in the United States and these disparities are growing.

Very little is known really about the intersection and very little is known about how women who are -- black and brown women with disabilities about their interactions with the healthcare system about their outcomes and this is really, really important because what you want to know is that these disparities, are they compounded?

So whether being black or brown and having a disability, does it compound the disparities as opposed to being a member of either one of those marginalized groups? And so we really need to examine this intersection, we really need to understand it and develop a strategy so that we can eliminate these disparities.

Poorvi Soni: Great. Thank you, Dr. Mitra. Dr. Harris, same question for you.

John Harris: It is a very challenging circumstance to address multiple areas where there are disparities present and when the disparities intersect, one of the challenges is simply having enough information about the particular circumstances there to be able to correctly address them. So I try to approach my understanding of the disparities around race in the US the same way that I approach the disparities around disability care as one - - with humility and where I try to address my questions and concerns clearly and to patients.

And so I have -- one of the important resources for women with disability around pregnancy and parenting social networks and I do have some concerns that if the social networks don't properly represent minority populations, that that would be a barrier to making these groups of women that have stories and experiences around walking through pregnancy and parenting with a disability as being challenging.

And so I try to talk with my patients personally, I know I definitely want to have my patients be able to give feedback about how we can do better and we are trying to also address these issues by talking about disability care with community organizations that focus on the need for better care for in my -- what I'm thinking about is a particular community organization that cares for black women and pregnancy and parenting and so trying to reach out and try to offer a little bit of experience about pregnancy and also learning how we can better provide care by listening. So it's a real challenge and it definitely takes a lot of humility as a provider.

Poorvi Soni: Great. Thank you, Dr. Harris. Sarah, any questions from you?

Sarah Triano: Yeah, I think first and foremost, at least the way, approach we take at Centene is nothing about us without us, so we actually have executive diversity and health disparity council that is made up of experts from different communities of color who advise us on -- they look at the data that we do have and advise us on methods that we should take.

I will highlight there are a couple of specific things we were doing some work around, access to doulas for women of color in particular and then also there's groups like a nonprofit organization out of California called Reach that are doing some really great work around maternal health remote monitoring and they get blood pressure monitors out to particularly African-American women who are pregnant to really monitor their health during COVID when they're not wanting to go into a doctor's office, can't blame them. And so there are -- I would highlight that as a best practice that I have seen in this space.

Poorvi Soni: Thank you so much, Sarah. Our next question is around communication. Are there examples of communication strategies or messaging that have been particularly successful with women with disabilities? Amy, I'll direct that question to you first. Have you had any -- do you have any examples to share of best practice communication strategies?

Amy Shannon: I've been thinking about this a lot and I don't have any examples but I do think that this is very important because through thinking about it, I realized that a lot of my thinking, I have some limiting beliefs about things. When I see a flyer, a lot of times it's almost like I assume well, that doesn't apply to me but it doesn't say something about being wheelchair-accessible or inclusive or anything, then considering so many things are inaccessible or even if they are accessible, it's not a healthcare thing but my friend talked about trying to vote and she had to go this really long, convoluted way to get into the building and then it was through the basement and all this stuff.

And so I just assume that that's how things will always be, so unless I know that it is something that is accessible or -- with an organization that is aware of the accessibility issues, then a lot of times I'm already like well, that's not an option for me. So I just think that when you're communicating with people with disabilities, there's a lot of things that you have to combat as far as what I'm thinking and expectations because of that and -- but I'm not really sure how to tell people how to do that.

Poorvi Soni: That's a really important point. Thank you, Amy. Dr. Harris, do you have any examples of effective communication strategies?

John Harris: I think that, just to repeat myself, I always, when I'm educating other providers, I always want to remind them that, especially for people with physical disabilities, that they are an absolute expert in their care, they have seen many, many doctors and providers over many years. They can see straight through you and you cannot pretend in any way with a patient what amount of experience and understanding of the healthcare system, so humility and asking questions and listening go a long way.

We thankfully do have longer appointments at our center and so that's sort of built into our ability to provide care but frequently as we're saying, women's health clinics that our visit volume is pretty high and they would not -- the ability to have that extra time, it can be very challenging to the whole flow. So listening to patients, understanding what they have to share and then starting to apply our own priorities and the same goals that we have for the visit is really I think vital to communicating and having a successful therapeutic relationship.

Poorvi Soni: Great. Thank you, Dr. Harris. On that note about educating physicians and healthcare staff, are there other best practices that you recommend to educate individuals who may not understand what a disability is and how to provide to dually eligible women with disabilities? Dr. Harris, I don't know if you have anything else to add there.

John Harris: The resources that have been put together for this event are really incredible, I would say just first class in terms of the resources that have been collected and so I do want to just highlight the hard work of the team that put together those resources and just point out that there are a multitude of resources from many different places that would I think apply to your particular situation there, more provider focused ones, more plan focused ones, there's a lot of things out there and they are available and in this case are just well organized, so we -- I'm really thankful for that opportunity to use those resources.

Poorvi Soni: Great. Thank you, Dr. Harris. Dr. Mitra, do you have any best practices you recommend for educating individuals about disability and how to provide care to dually eligible women with disability?

Monika Mitra: I'm going to go to what Sarah mentioned and it's really nothing about us without us, so I think that we have to in terms of ensuring best practices is ask people, ask women with disabilities and women of color with disabilities, what is the best way of providing care. And I think also related to that, in almost all the research that I've done, providers, staff and healthcare facilities have all requested and suggested the need for training, the need for a better understanding so that they can do their work better. And I think that we often figure out as a society and how do we ensure that practitioners and providers at all levels, at all, are trained. And both in terms of beyond clinical training is interacting, ensuring that places are accessible because if we all do our own part in this, then it'll be beyond brands, it'll improve our attitudes towards people with disabilities, it'll ensure that we are fully accessible and inclusive.

Poorvi Soni: Great. Thank you, Dr. Mitra. And we have time for one last question, what strategies would you recommend for helping someone who is trying was traumatized in earlier years trust a healthcare provider to perform healthcare screenings? And Dr. Harris, I'll turn it to you.

John Harris: I think for providers that I do not expect to perform an exam often in that first visit, especially with someone that has had a traumatic experience, and I want them to get to know me and to get to know our team and understand what their experience is and move from there. So I think that sometimes thankfully most circumstances, that's appropriate.

Obviously if it was more acute, then you need to do what's correct but I think understanding that an introductory visit will be very appropriate and necessary for many visits after an experience when someone's traumatized and obviously we try to meet everyone's experience, we're thankful to have providers of different genders, different styles and everything else so that we try to meet people where they're at but we need to

understand where they're at and they need to feel safe to feel like they're not going to be asked to do something they're not comfortable yet.

Poorvi Soni: Thank you, Dr. Harris. Dr. Mitra, is there anything you would add?

Monika Mitra: This is a really important question and I think that we need to -- there are a lot of people with disabilities and a greater proportion of people without disabilities but were faced different traumatic events, they're also more likely to have experienced different types of violence, so I think for providers to understand this and to then provide care in an appropriate way is really, really important. And in terms of the best way to provide the care, I'm going to go with what Dr. Harris mentioned but I think this awareness of the potential for someone coming into the office who might've experienced a traumatic event is really, really important.

Poorvi Soni: Great. Thank you, Dr. Mitra. And thank you so much to all of our speakers for your presentations and answering our audience questions.

Thank you so much to our audience for joining us today. At this time, if you have any additional questions or comments, please email [RIC@lewin.com](mailto:RIC@lewin.com).

The slides for today's presentation, a recording and a transcript will be available on the Resources for Integrated Care website shortly, as well as the resource guide that Dr. Harris mentioned.

Follow us on Twitter at [@Integrate\\_Care](https://twitter.com/Integrate_Care) to learn more about upcoming webinars and new products. If you're applying for NASW credits or CNE contact hours, please complete the post-test by 11:59 PM Eastern Time tomorrow in order to receive credit.

Please complete a brief evaluation of this webinar so that we can continue to deliver high quality presentations. The survey will appear on your screen following the conclusion of the session.

Again, thank you so much to our speakers and thank you all for attending.

This will conclude the webinar.