Inclusive Services: Approaches to Improve Sexual and Reproductive Health Care for People with Disabilities
May 10, 2023

Nicole Nguyen:

Hi everyone. Good afternoon. Thank you for joining us today for our webinar on Inclusive Services: Approaches to Improve Sexual and Reproductive Health Care for People with Disabilities. My name is Nicole Nguyen, program manager of the Family planning program at the California Prevention Training Center. We hope you are all doing well and staying safe. The CAPTC, under contract with the California Department of Healthcare Services Office of Family Planning is sponsoring today's event. All right, next slide.

Nicole Nguyen:

So, before we get started with the webinar, let's just go over some really quick housekeeping slides. First, please make sure you can check your audio and select your desired setting to join through your computer audio or to call in through your phone. If your internet connection is a little bit shaky, we highly recommend that you call in through your phone for the best possible sound. Next slide.

Nicole Nguyen:

And then second, check please that you're able to see the viewer screen with the slides on the left and the go-to webinar control panel on your right. Next slide.

Nicole Nguyen:

And then you'll see this click control panel with this orange box with the white arrow. This is how you can hide or show your dashboard if you don't want to see it or if you accidentally click it, this is how you can make it appear again. Under that is the audio tab. This is where you can change your audio preference at any time. And then third, please submit all your comments and questions via the question box. Today's webinar will be from 12 o'clock to 1:45 and we'll include time at the end for the presenter to answer all your questions. So please send them in throughout the webinar and our speaker will address as many of them as possible.

Nicole Nguyen:

And this webinar is recorded and so responses to questions that are not answered, or we run out of time, we will collect them at the end and then we'll send it to the speakers to get the answers and then send it out to participant, along with the reporting and the slide deck. There is an evaluation at the end, so please make sure you fill it out because your feedback is extremely important to us and really help guide us in developing our future content. Next slide.

Nicole Nguyen:

And then, so before I introduce our speakers, I also want to acknowledge that we're working with University of Nevada, Reno School of Medicine to provide CMEs for this event. This webinar qualifies for a 1.5 CME credit and only available to those who watch the webinar live. Those who watch the recording afterward unfortunately will not be eligible for the CME credits. And we will get the link out to access your certificate along with the materials and the follow-up email after, with the recording, slides and the evaluation. Next slide.

Nicole Nguyen:

And then just for transparency’s sake, we want to disclose that presenters, planners, and anyone in the position to control the content of this activity indicated that neither they nor their partners have any financial relationships or commercial interests related to the content of this activity.

Nicole Nguyen:

All right, now to the fun stuff. I get to introduce our wonderful speakers. So first, we have Erica Monasterio. She's a clinical professor, Emerita, at the University of California San Francisco. She has over 35 years of clinical experience in primary care for youth and families at UCSF and San Francisco Department of Public Health. Working in collaborations with organizations at the local, state and national level, she provides training and technical assistance in the areas of sexual and reproductive health, trauma responsive care, healthy sexuality for people with disabilities, healthy relationships and relationship abuse, minor consent and confidentiality, and care of marginalized youth, focusing on young people in foster care and LGBTQ youth. So, thank you so much, Erica for joining us today. We're super excited.

Nicole Nguyen:

And then next for our second presenter, we're super thrilled to have Robin Wilson-Beattie join us. Robin is a speaker, writer and advocate for disability and sexuality and one of the first people to talk about disability, sexuality and marketing to adult product retailers and manufacturers. She combines years of personal experience with medically sound research to provide a unique experience on how life and identity impact one sexual expression. Her speaking engagements include multiple keynotes and panels, including the executive office of the Vice President of the United States in three consecutive years speaking at the Adult Video News convention in Las Vegas. Her work has not only helped thousands of disabled people, but also really inspired many others to become advocates for sexuality and disability education, an incredibly underserved area.

Nicole Nguyen:

And then lastly, before I hand the mic off to Erica and Robin, I also just want to note that while this webinar is sponsored by Office of Family Planning and the Family PACT Program. The information our speakers will be discussing today is more focused on the clinical considerations and inclusive approaches for providing sexual reproductive health for people with disabilities. We will not go into questions about the Family PACT policies or specific program benefits. If you have those questions, please continue to send them in and we will get them answered in the written Q&A afterwards. So, while we won't be able to answer those questions live today, you have questions about your specific Family PACT benefits, if your clients qualify for Family PACT, anything like that. Please continue to send those in and we'll get those answered afterwards. And then with that, thank you so much for joining us out today. So, Robin and Erica, please take it away.

Erica Monasterio:

Hi everybody, good afternoon. My name is Erica Monasterio. I am delighted to be able to partner with Family PACT and most particularly with Robin to present this information to you today.

Erica Monasterio:

So, I want to just start by framing the talk because when you talk about people with disabilities, you are talking about an incredibly broad range that is inclusive of many different diagnoses, many different conditions, varying levels of function within one individual, but also within the population. People bring different strengths and experience different challenges, depending on their disability and just who they are. And there is a huge range in terms of needs for support and facilitation.

Erica Monasterio:

So, as we talk, we talk in these generalizations, we talk about the population, don't miss the trees for the forest because it's the individual who you're working with at the moment that you're working with them. That should be first and foremost in your mind and the first consideration and the first source of information for you. But that said, we want to give you a general idea and some direction in terms of serving this very varied population. Next slide.

Erica Monasterio:

So, we are aiming to be inclusive, but I just want to remind you that it's a very challenging population to define, that an individual's diagnosis or their condition does not define their level of function. You have an enormous range of function within any given diagnosis or condition. And that, as I said before, the most important thing you can do start from a knowledge base, but individualized care so that what you're doing is appropriate and helpful and supportive to the individual who's sitting with you. Next slide.

Robin Wilson-Beattie:

So, we're talking about disability. Disability is a natural part of the human condition. And if you live long enough, as in the disability community would like to say, you're going to join the club. World Health Organization defines disability that it can result from the interaction between individuals with a health condition, with personal environmental factors such as attitudes, inaccessibility, limited social support. And it is something that can either be present at birth and we talk about those as developmental disabilities, your childhood developmental disabilities, conditions, disabilities like cerebral palsy or someone being born with down syndrome or some certain developmental disabilities. You can also acquire a disability. That can be related to an injury, for instance, having a spinal cord injury as a result of a car accident, or it can be a complication from a longstanding condition. An example of that would be something like diabetes and having to get a limb or get part of the body amputated.

Robin Wilson-Beattie:

Disabilities, they can be visible. Sometimes you can look at some someone and, "Oh, they have a disability." They're using a chair, whatever, so it's visible. Some disabilities are hidden. You have your learning disabilities, you have cognitive disabilities, you have chronic health conditions such as like IBS, Crohn's disease, diabetes, things that you don't necessarily see, but they are disabilities. Disabilities, they can be progressive and change in how they function over time. They can be static, or they can be intermittent.

Robin Wilson-Beattie:

There are models of disability. And in ways of thinking about disability, models are the lens by which we view disability and think about what causes it. So, you have various different models of disability. The one that you're probably most familiar with is the medical model, which is approaching disability from looking at it from a medical standpoint as in treatment, cure, diagnosis, all of those things about disability, seeing it as a medically diagnosed condition. However, that doesn't take into that. It doesn't take into account that their society can also impact and disable and cause disability. For instance, not having an accessible way for someone with a mobility impairment that needs a ramp to get into a building.

Robin Wilson-Beattie:

Also, social attitudes towards various disabilities and how they're treated and how they're included or excluded. And there's various different models of disability. You can go into the charitable slash what they call pity, where they're thinking that disability are conditions that have to be taken care of. And then you have religious and moral. But there are many. And then here is a hyperlink that will tell you about all the different models. And there are more. And there's a new model that came up, the holistic model, which kind of incorporates all of these things, all of these different models into a model.

Robin Wilson-Beattie:

So, when we're talking though about disability, you realize that people don't live single issue lives. We live lives that are impacted and intersect with all different kinds of issues. Someone with a disability can also be impacted by other parts of their identity. Race is one way. Gender, sexual orientation, your economic status, your education. And you can have a combination of these, you can have one of these. But you can be disabled and still have these other marginalized experiences that impact the way that you are allowed to navigate and participate in society. And that also spills over to unconscious bias in healthcare. For instance, we're talking about things like racism in medical care, looking at the mortality rates of black women who are having children or in childbirth and black women's maternity care. So that's one. That's an example of how your identity can intersect and impact your care.

Erica Monasterio:

So, we're going to look at a couple of just big picture issues. And the next couple of slides are all from an CDC infographic about disability in the US. And you can see that according to the CDC 26%, one in four, adults in the United States have some type of disability. That's equal to about 61 million adults in the US. Next.

Erica Monasterio:

And disability clearly impacts on function. And you can see here the different percentages for first you see the mobility disabilities, cognitive disabilities, disabilities that impact on one's ability to live independently. People who have hearing impairments, vision impairments or impairments in self-care. So as Robin mentioned, many people in the disability community, they say, "Well, you're not disabled yet because you just have to get old enough and you will encounter visual impairments, hearing impairments, sometimes impairments with being able to engage in self-care and possibly impairments in independent living and cognition." And then of course, mobility is something that as you age, you have less control. And many people have mobility disabilities as they age. So, you can see why this is such an enormous number. And as the elder population grows, the percentage of the population with disabilities will also grow. Next.

Erica Monasterio:

So, there's also significant impacts on health. So, by the data, adults who are living with a disability are more likely to have obesity, to smoke tobacco, to have heart disease, and to have diabetes. So, this does not kind of tease out what came first. Is the disability in response to these other conditions or are these conditions in response to the disability? But when you look at data with, of people with developmental disabilities, these things hold true. So, people who start out life with a disability tend to have more of these other impacts on their health as well. Next.

Erica Monasterio:

And then the impacts on access to care, which I think is something that we all need to be very concerned about because this is something that we can actually have an impact on. So, one in three adults with a disability, and these are just up from 18 to 44 years old. So, we're not talking about elders, we're just talking about the adult population. So, one in three do not have a usual healthcare provider. They don't have a primary care provider. And we know how that can really impair access and quality. One in three also have unmet healthcare needs because of the cost of meeting those needs. And one in four adults with disabilities have not had a routine checkup. So, they're often not getting the preventative care that they may need. They may have lots of interactions with the healthcare system related to their disability, but they're not getting regular preventative care. So, all of these things, you can see how the access to care is very tightly related to the health impacts of having a disability. Next slide.

Robin Wilson-Beattie:

And here we are going to, and this we're going to watch a video, A Tale of Two Visits. One moment.

Nurse:

Okay. So, her blood pressure looks like a little low, but it's fine. Can't really do a height and weight right now because we just can't. So, we'll just skip that for today. It looks like Mei. Has been using Depo and just here for another refill. Is that right?

Speaker 1:

I don't know. I'm just her ride, actually.

Mei:

My name's Mei, it's M-E-I. And you can weigh me actually, but whatever for today, that's fine.

Nurse:

Well, she'll be in just a bit. Dr. [inaudible 00:19:00] will be in to see you, so she'll talk to you about that. Okay?

Mei:

Okay.

Nurse:

Okay.

Mei:

Do you need me to move?

Nurse:

Yeah. I'll do it. It's okay. No, no, it's okay. I'm on it.

Mei:

Okay.

Nurse:

No problem. All right. Okay.

Speaker 1:

Oh, she's here.

Dr. Ernst:

Hi. These rooms are so small with a wheelchair in, let me just... Oh no, I got it. It's no big deal.
Hi, I'm Dr. Ernst. It's so nice to meet you. Hi. You must be Mei, it's so nice to meet you. How are you doing today?

Mei:

I'm good.

Dr. Ernst:

Good. So glad to meet you. So why are you here today?

Mei:

I'm really here because, so I've been on the Depo shot for so many years and I-

Dr. Ernst:

The Depo shot works great. I have a lot of patients with disabilities. Has it stopped your periods?

Mei:

Yes, but I was reading-

Dr. Ernst:

I always find with the patients with disabilities that it helps them stay cleaner down there because they don't have a period once a month. And the other thing is for women with disabilities, well it stops the seizures. So, I think it's a good idea for you to stay on that.

Mei:

I don't have seizures.

Dr. Ernst:

Okay.

Mei:

But also, isn't it bad for your bones? Because I'm not active anymore so I worry about my bones.

Dr. Ernst:

Well, I'm not too worried about that. I think it's a good idea to just stay on it to help control your period. Is there anything else you needed today, or do you want me to just put in a refill for that?

Mei:

One more thing. One more thing before you go. So, pap smear, I'm super nervous about it, but I think that it's time.

Dr. Ernst:

I don't think you need to be nervous because I really don't think you need it.

Mei:

I am sexually active.

Dr. Ernst:

You are?

Mei:

It's kind of weird to have her here.

Speaker 1:

Can I leave?

Dr. Ernst:

You know what, it's better if you stay. I might have some questions for you, or you might need to help us move her later. So, I would prefer if you just stayed for now.

Mei:

Just put your earphones on please. But shouldn't I have it done at some point? Because I really don't need cancer.

Dr. Ernst:

Maybe at some point, but it's really complicated. We could call a lift team to try to get you on the table.

Mei:

She's great with helping me. I'm pretty strong up here. She can-

Dr. Ernst:

And another thing is women who have a spinal cord injury can get this problem, autonomic dysreflexia, and it makes the pelvic exam kind of dangerous. So, I'm not sure we need to do that here today. It was so nice to meet you today and I'll see you again maybe in a year or two. Okay? Nice to meet you.

Mei:

Thanks.

Nurse:

So, we got your height and weight outside of the room. I'm just going to plug that into your chart really quick.

Mei:

Love the scale out there. It's really easy to roll on and off.

Nurse:

Great. Yeah. And then according to your chart here, it looks like you want to talk to Dr. Ernst about whether you're due for a pap smear.

Mei:

Well, I know I'm overdue and I've never had one, so I'm nervous about it today. So, if you just let her know I've never had one.

Nurse:

Yeah, absolutely. And we'll do our best to make you comfortable while we're here. Anything else I can do for you?

Mei:

That's it.

Nurse:

All right. So, Dr. Ernst will be in, in just a little bit. I'll go bring this to her and we'll get you set up.

Dr. Ernst:

Hi there.

Mei:

Hi.

Dr. Ernst:

I'm Dr. Ernst. It's really nice to meet you. You're Ms. Woo?

Mei:

You can call me Mei.

Dr. Ernst:

Perfect, Mei.

Mei:

My main concern is I've been on Depo-Provera for about 10 years now and I've been reading it's not good for your bones. That's really the first thing I want to ask you about. I love not having my periods, but is this good for me?

Dr. Ernst:

Yeah, I understand your concern. Yeah. There is some data that shows that Depo-Provera over the long term can decrease your bone density. And for women who have another risk factor for low bone density, someone who is non-weightbearing, I actually agree with you. I think that there are better options for you, for contraception. Before I tell you what else I'm thinking about for contraception, can you just tell me if you're thinking about getting pregnant and what's your timeline for that?

Mei:

You're the first person who's ever asked me that and I can tell you, yeah, when I was a kid, I dreamed of being a mom.

Dr. Ernst:

And so, I would say just because you have a spinal cord injury doesn't mean that you can't get pregnant. I totally understand that. So, the thing that I was thinking might be a good option for you is long-term contraception, like an IUD.

Mei:

But I just didn't think you could do that for me. I've never heard of someone with a spinal cord injury having an IUD.

Dr. Ernst:

Yeah, yeah. We've done it before and oftentimes we can do that right here in the office.

Mei:

Okay.

Dr. Ernst:

I think what we'll do today is I'm going to give you some written information about the IUD and today we'll try to do a pelvic exam. We'll do a pap smear; we'll do some screening for some infections. Okay. And we'll see how you tolerate that. Okay.

Dr. Ernst:

And then if you do okay, we can try to put the IUD in here in the office.

Mei:

Great.

Dr. Ernst:

Yeah. I wanted to ask you before we do the pelvic exam, if you need help or assistance transferring onto the table.

Mei:

I think I can do it with just a little minimal assist from the medical assistant. I have pretty strong upper arms, or my sister can come help me.

Dr. Ernst:

Perfect. Yeah, that sounds great. Since Minji is used to it, we can grab her and have her help. So, before we do the pelvic exam, I'm going to have you empty your bladder. I will go get Minji and she can help you move over and transfer onto the table.

Robin Wilson-Beattie:

So, from this video, you can see some of the issues that we're talking about, the family planning challenges that people with disabilities can face. One of the things, inaccessible healthcare facilities and equipment. That includes things like being able to weigh yourself, being able to be weighed from a chair or being able to have a scale that is equipped to weigh different kinds of chairs. And power chairs are much heavier in things than say a manual chair. And you have also the stereotypes and discrimination, particularly around the interest and ability of disabled people to have children, or to get pregnant. And so, you have these stories that people tell themselves about what people with disabilities are doing.

Robin Wilson-Beattie:

Also, so inaccessible family planning clinics, where they have not thought about disability, thinking about terms of communication or saying for instance, there have been cases where people have been sued because they aren't bringing in a sign language interpreter for someone who is deaf and needs to access communication that way.

Robin Wilson-Beattie:

It's just this programmatic inaccessibility, thinking about the examination tables being inaccessible for people to be able to transfer on and off. And also, transportation barriers to accessing the facilities, being able to, not everyone drives, and public transportation is not the same everywhere. Not everyone has that kind of access to public transportation, particularly because public transportation can offer as an accessible way to get transported to the doctor's office or a clinic. But the thing is, patients can't just readily get an Uber or another taxi unless they can find the accessible vehicle to transport.

Robin Wilson-Beattie:

And some of the family planning challenges for people with disabilities, your limited coverage of healthcare, providers who lack disability related training or sensitivity, or they fail to recognize a woman as a person with sexual and reproductive healthcare needs. Problematic interactions between hormonal methods of contraception and some disability related medications and difficulties using barrier methods due to limitations in manual dexterity, loss of sensation, contractures or spasticity.

Erica Monasterio:

So, I just want to say the little video clips that we looked at just basically did our talk for us. But what we will do is reinforce and give you the data and the source-

Erica Monasterio:

But what we will do is reinforce and give you the data and the sources for why the practices you saw that were so detrimental to the client are certainly unfortunately not uncommon. And how simple changes in how you approach the visit can have a huge impact on how included and welcomed the client feels and how much they're able to really access in terms of the services that you provide. So, looking just at sexual and reproductive health rather than general health, we have 12 to 18% of what are termed reproductive aged women. And I apologize for some of the language here, but we have used language that reproduces what the questions or categories were in the research. So sometimes it's maybe not the most up-to-date language, but it's what they actually looked at in the research. So, 12 to 18% of reproductive age women have a disability.

Erica Monasterio:

There are so many biases and Robin has been touching on these biases that people have about people with disabilities. And these really impact these biases that we carry, that we sort of have been imbibing since birth. Attitudes really inform how we approach our clients with disabilities, and they inform our attitudes about our clients' sexual activity and behaviors, our assumptions that we make about them, their ability to engage in consensual sex, including those who have cognitive or intellectual disabilities. That doesn't mean that they can't engage in any decision making. It means there's some limits to their decision making. Their ability to become parents, you could see in the video, the provider was like, "Oh, why would you even think about needing contraception? Why would you even think about having a child because you have a disability?" And also, Mae's response when the provider asked her that, "Oh my goodness, nobody's even ever broached that subject with me."

Erica Monasterio:

So compared to women without a disability, women with a disability are just as likely to desire a future pregnancy, to be sexually active. And actually, in adolescence, the sexual activity rates of youth with disabilities are actually higher than those of youth who are not currently disabled. And they're just as likely to experience a pregnancy. So, we really need to erase all those assumptions. Think again, you can't really erase assumptions without surfacing your biases, which means really taking a look at what are my attitudes When I see a person who I can readily identify as a person who has a disability, what assumptions do I make about them? Where do those assumptions come from and what can I do to put them away, move them aside, and really meet this person with an open mind and an open heart and the assumptions that they have the same needs as any other client. Next slide.

Robin Wilson-Beattie:

Oh, I forgot that I was going to share my own experience around getting sexual and reproductive health. My experience is rather intersectional. Back in 2004, I was having a surgery to remove an AVM inside of my spinal cord. So basically, I was having an aneurysm inside the spinal cord, and I found out a week before the planned surgery to remove the AVM that I was pregnant with my now 18-year-old. And from there, that is where I got to have firsthand experience with dealing with the ableism, which ableism is bigotry against people with disabilities. And I also dealt with racism as well. Some of it was around... Oh, I was strongly pressured to terminate that pregnancy because I was going to be disabled. And that along with because I was having a very major surgery and that they didn't know what the outcome would be, and they didn't know what the outcome would be on the kid or me. So that was part of it. But the other part of it was I got to see this when I was being admitted into a rehabilitation center because the result of the surgery was, yes, I got to lib, and I also acquired a spinal cord injury. I checked into the rehabilitation hospital from the hospital that I had had the surgery, and this was in the south and it was an older white male doctor who came in and he barely said hi. He looked and I'm sitting there with my husband. He looks at me up and down with kind of a disgusted look on his face and said, "If you knew you were going to be like that, why didn't you use birth control or something?" It's that sort of attitude towards women of color around our reproductive health rights, around our agency, all of that. So that was something that taught me about the disconnect that healthcare providers have about disability and wanting to have kids, wanting to be pregnant, and rather than it being like this controlled and not being able to have kids based on ableist beliefs. Then we could also go into eugenics, but that's another topic. So back to you, Erica.

Erica Monasterio:

Thanks, Robin, and thank you for sharing that story. I think that that's what really informs us is people's lived experience. So, blame and shame doesn't get us very far and it certainly doesn't motivate us to change. We have a really limited availability and limited training in terms of the world of providers. And again, this is where the data is, so you may not see your profession reflected. But you can see that the vast majority, 81% of medical students have no training in disability care. 75% of medical residencies have no experience in disability care. 44% of OB/GYN clinics report that they're unable to provide care for people with mobility disabilities. And think back to the percentages of people who would be defined as women of childbearing age, 18 to 44 who are dealing with mobility disabilities. And only 41% of physicians feel confident in their ability to provide for patients with disabilities. And this is, if the training isn't happening, we're not going to be ready to do the job. Next slide.

Erica Monasterio:

So, this leads to very significant health disparities. And you can see the data here, unmet needs, which certainly if I had a visit like the visit that they demonstrated for Mae, you wouldn't see me back in that clinic again. So how are you going to get your needs met? You have a general lower utilization of reproductive healthcare. We see higher rates of pregnancy complications. Some of these are related to the issues with the disability itself. But many are related to inability to access care, continue with care, and get supportive and appropriate care. And so, then you see adverse birth outcomes as well. There are higher rates of physical abuse and sexual assault among people with disabilities, and we will address that later in the talk.

Erica Monasterio:

Higher rates of STIs, much lower rates of screening for breast and cervical cancer as Mae demonstrated, much less likely to receive a pelvic exam at any kind of regular interval. As Robin mentioned with eugenics, higher rates of female sterilization and hysterectomy and higher rates of mortality from breast cancer. And then again, when you layer on issues in terms of intersectionality, you have subpopulations within that broad population of people with disabilities who are going to be even more impacted because of other aspects of their identities and the kind of access to quality care that they can receive. Next slide. So, we're going to go into a little bit of the nitty gritties here about providing sexual and reproductive healthcare for women with disabilities. Next slide.

Robin Wilson-Beattie:

Okay. So, some of the family planning challenges for women with disabilities is... We just talked about it, the limited coverage of healthcare. The fact that providers who lack that training or sensitivity fail to recognize our needs as a person with sexual and reproductive healthcare needs. And also, we saw with the interactions between the hormonal methods of contraception and some disability related medications. But also talking about the impact that some of the methods of birth control have in how they interact with your disability. For instance, like Mae mentioned in the film about not being non-weightbearing due to being seated in a chair. So, there's certain other kind for instance, but also hormonal birth control would be something that because she is seated, it could lead to a higher incident with blood and blood clots. So, the birth control pill would not be a great option for her.

Robin Wilson-Beattie:

She mentioned the fact because she was non-weightbearing, how the Depo-Provera shot has been shown to reduce bone density. And so, for people who non-weightbearing, people who have eating disorders, people with various different osteoporosis, osteogenesis imperfecta, those forms of birth control would not be recommended for them. And another thing though, when we're talking about communication and talking to your patients with disabilities, you need to focus on the abilities and not the disabilities. You need to respectfully, talk to the person, also know their names or ask them how to pronounce their names or that sort of thing. Do not shout, do not infantilize, do not talk to people like they're little kids. Explain what is going on. Take time, greet the person first before addressing the accompanying relative or support person.

Robin Wilson-Beattie:

Oftentimes, and as somebody who's disabled, I have experienced this. If I am seated in a chair and I'm with someone who is able-bodied, automatically, they'll start talking to the person with me. This has happened checking out at the supermarket, but it has also happened at a doctor's office. So that's one thing too, you greet the person first. Invite your new patients to bring any existing personal health records and films, anything that is related to their condition that can also help you treat them. Paid support staff may be unaware of vital elements in a person's medical history. Encourage them to make and keep notes and to bring those for subsequent consultations.

Erica Monasterio:

So, we rely a lot on a verbal interaction to take a history. In order to do this with a patient who might have a communicative disability, a communication disability, you need to first find out how your patient communicates best. They may want to write; they may use a communication board. They may sign to an accompanying person who can translate or interpret their signing to you through using ASL. So, there's lots of different ways of communicating. Just because someone is difficult to understand doesn't mean they don't understand you. And generally, if you just slow down and take time, pressure and anxiety, make dysarthria worse. And so, it makes someone who might be understandable, less understandable. So, you need to really assess their verbal capacity and know that there can be this imbalance between receptive and expressive language.

Erica Monasterio:

And you want to always check like with any client, you want to teach back. You want to make sure that you have communicated the information that you need to communicate and that your client has understood that information. If they can't tell you back what you think you told them, then you have not communicated well and you need to try again. If your patient has limited or absent verbal stills, do not assume that they are not competent to make decisions or engage in the healthcare visit. This is just a barrier in terms of communication. And as we have told you a number of times and the video demonstrated, and it's just so common. My daughter is a wheelchair user and 9 times out of 10 people will talk to me about her and she's like, "Hello, what about..." she's 25 years old. She's not shy, but it's very frustrating to her. Always talk to the client first, even if they don't have verbal capacity, you can communicate with them.

Erica Monasterio:

And get your history as much as possible from the patient. And then you can revert to the accompanying person if you need to. But know that paid staff often do not know that much about the medical history of the person that they're assisting. So that issue of bringing records, maintaining records, is really helpful. Next slide. And don't forget about confidentiality. As we saw in the video here was the patient's teenage sister sitting there being forced to listen to a confidential conversation. So, make sure you clarify with the patient when they want an accompanying person in the room and when they do not. Remember that there's lots of ways we communicate. So even if you have a non-verbal patient, you can use body language, gestures, facial expressions, signing, pictorial device materials, electronic devices, communication devices. There are lots of alternatives. You need to sometimes think outside the box.

Erica Monasterio:

And be prepared, so if you see a client once and you encounter these barriers, do some problem solving before you see them again and record in the chart what worked best for your communication with them so that the next person who sees them may start out at least in a somewhat better place than you might have started out with. And it's good at the front end before when the patient's making an appointment to train front office staff to ask, does the patient use any kind of communication device or system? Because I can't tell you how many times, at least with my adolescent patients, they use a communication device, but oops, they didn't bring it to their appointment, it stays at school. Their family has another way of communicating with them. So just emphasizing that they should bring their device. Robin, was there something you wanted to add?

Robin Wilson-Beattie:

Oh no, I'm just agreeing with you.

Erica Monasterio:

Okay. So, let's go to the next slide then. So, this will look very familiar to you. These are the PATH questions. And the reason that we chose to include this graphic is to remind you that your patient who is living with a disability is no different than any of your other patients. They deserve exactly the same approach. And one advantage of following the PATH questions is that it keeps you from starting off from your place of bias and assumption. It kind of forces you into asking a question that it might not occur to you to ask of someone with a disability. Do you think you might want to have or have more children at some point? So, I want to just remind you that best practice is best practice. And best practice for your...

As we might call temporarily able-bodied patients is best practice for your patients with disabilities. Next slide.

Erica Monasterio:

Okay, so the issue of competency and decision making is a very important issue. Competency is actually a legal term and capacity is more what we talk about in healthcare. Next slide. A capacity assessment should be made on the first visit. You should go through a process. The provider needs to go through a process of assessing the individual's capacity. So, you're going to present the relevant facts to make a decision like you would with any client. You're going to assess the patient's understanding of those facts like you would with any client. You're going to ask for the person's choice, shall I repeat myself? Like you would with any client. You're going to assess their appreciation and reasoning. So, this is where maybe a little bit different because you're seeing does it match up? Okay, does their understanding of the facts and their reasoning about their choice match up with their decision? So, you reassess the choice, paying attention to whether there's logical consistency of the choice based on the reasoning. So next slide.

Erica Monasterio:

And then in terms of assessing their decision-making ability, you're looking at their understanding. So that's their ability to state the meaning of the relevant information, the meaning of their diagnosis, risks and benefits, the indications, the options. And then a question you might ask, "Can you tell me in your own words what I just said about whatever it was we were talking back about?" So that's that teach back that hopefully you're doing with all your clients. Expressing a choice, your client's ability to express their decision. The question might be based on what we just discussed, "What would you choose?" So, this is when you're making for example, a treatment choice. Their appreciation of the decision, can they explain how the information you gave them applies to them? "Can you tell me what you see as your medical problem around diagnosis, around benefit and risk?"

Erica Monasterio:

"Regardless of what you choose, do you think that it is possible that the medication can benefit or harm you?" Okay, and those are two separate set. You don't never want to use double barrel questions unless with someone who may have some communication challenges. So it would be, "The medication can benefit you regardless of whether you want to take it or not. Can you talk to me about some of the benefits? And regardless of whether you want to take it or not, can you talk to me about some of the risks?" And then assessing the reasoning, you're looking at comparative reasoning. So how is decision X better than decision Y for you? And consequential reasoning, "How could decision X affect your daily activities, your ability to go to school, your ability to take care of your child," whatever it is that are your client's issues.

Erica Monasterio:

Next slide. So, this is informal in that it's not a form you're filling out, but it is a formal assessment where you're making sure you go through these steps. Now this is an example and I know you can't read it. And the point is just for you to know, and it's cited if you want to look for it, this is from Canada. And so, it has some things that we don't have here in terms of where you refer and etc. But this is a series of questions. It's a form you can fill out that is a capacity assessment. Next slide.

Erica Monasterio:

And then this is the... If they answer yes to all the questions, they're capable. If they answer no to any of the questions, you may need to look a little further. Try again, make sure that they understand. But if they still don't understand, they are not capable of making a decision. And then if you're unsure, you're going to need to call in collateral information. Talking with the family if you haven't done that again, considering seeking a second opinion and getting a formal capacity assessment. And that's where the

Canadian stuff comes in. The provincial regulatory college, we don't have that in the US. Next slide, but this is available to you. You can look at it and find it on the internet.

Robin Wilson-Beattie:

So, part of when we're talking about sexuality and sex education, particularly if we're talking about disability and sex education, one of the things that is important that should be included in comprehensive sex ed would be relationship skills. Talking about essential relationship skills. Where does capacity fit in? So that capacity, we're talking about the ability to say no, the ability to hear no. Knowledge that having unprotected sex can result in pregnancy or a sexually transmitted infection. And the ability to differentiate appropriate and inappropriate times and places to engage in intimate relations. And the ability to recognize people or situations that might be a threat. Talking about consent. But that is very important when we're talking about that. So that's kind of a key element in part of that education, but that's also related to being able to treat someone for sexual health needs. Erica?

Erica Monasterio:

I suddenly got this message that my computer was about to die. My apologies.

Robin Wilson-Beattie:

I would've taken...

Erica Monasterio:

Okay, so let's talk about the GYN exam itself, how you need to facilitate it, how you can avoid it, etc. And just an aside, this is still from a wonderful video that's available I think on Netflix called Margarita with a Straw, which is sort of a coming-of-age story of a young woman with a disability. Next slide. So, you need a longer appointment. We recommend a double slot if you're doing any kind of physical healthcare where the patient is going to need to transfer because that takes time. Pick your most accessible exam room, have the necessary equipment and practice with staff, practice asking for the patient's preferences as you saw in the video that can your sister help you with the transfer. Practice providing assistance. Don't assume that the accompanying individual can help. You need to be prepared to as a team to help with transfers and know your safe transfer techniques. And then flag the chart to note that this patient requires accommodation so that you don't start all over with every visit. Next slide.

Erica Monasterio:

Actually, this isn't just good people doing the right thing. This is the law; the ADA requires office adaptation if the patient cannot access the exam table. So, if you don't have a high low table or an accessible table, the office needs to provide that assistance. You cannot insist that the patient bring someone with them to provide that assistance. And you need to know how to do it, so that the transfer is done safely and also preserves the dignity of the patient. So, practicing as a team before you practice on a patient is a very good idea. Next slide.

Robin Wilson-Beattie:

So, one of the things you know about the thing is talking about access is a legal right. It's a legal civil right and healthcare providers must have an accessibility that meets the 2010 ADA standards for accessible design. And included in this pack is a link to talk about what those standards are. And also, because there are penalties for if a provider is not providing these things that are outlined in the law. And even though a lot of clinics have not, a lot...

Robin Wilson-Beattie:

A lot of clinics have not, around the country I will have to say it looks very different to how people adhere to the ADA standards. For instance, as somebody that needs to use an accessible examination table, the first time I ever saw one of those was when I came to California in 2016. Where I was from in the South, I didn't even know they existed for that. And even when I was in disability specific places like hospital to treat, that examination table still required me to transfer over. Whereas so see that's very important. But you can look at all of the things that are required. There are laws that are listed out. But there are also, like I said, people can be sued for not meeting those standards and for doing retaliatory things like, oh well you have too many needs, I'm firing you as a patient. You can't do that. That's illegal. So next slide.

Erica Monasterio:

Okay, so in terms of the pelvic exam itself, first thing you need to do is determine whether you really do need to do a pelvic exam and is it for preventative care or does it add to the diagnosis of the presenting problem? So, if it's for preventative care, there are times that you may want to delay, split the visit into a couple of visits, give your patient information. I sometimes would get up on the table myself and demonstrate for my patient positioning, et cetera, and then bring them back the next time. So, the prep time that you need versus if it's a presenting problem, you need to deal with it.

Erica Monasterio:

You want to assure that the patient feels safe, well supported, and that's both emotionally, psychologically supported but also physically supported, that they feel physically safe. My daughter hates to get on exam tables because they're narrow, and she just doesn't feel stable as she's afraid she's going to fall off. So, they need to feel confident that they're not going to fall. Because you cannot relax, it's not a relaxing experience. And if you're afraid you're going to fall it really does contribute to being very tense and sometimes the spasticity as well. And consider extra padding on the exam table. Using pillows and blankets liberally can really help as well. Next slide.

Robin Wilson-Beattie:

Okay.

Erica Monasterio:

Transferring. For those of us who are nurses, we got training in transferring way back when, but we may not have done it since. So really make sure your transfer skills are up to date. Be prepared to assist the patient with the transfer. Think about if you have, there are lots of reasons including age, body habitus, et cetera that make it hard for people to get up on a high table. So high low tables are a really worthwhile investment for anybody who has mobility issues. And try to avoid doing exams in the wheelchair. They're really substandard exams, including breast exams. You cannot do an adequate clinical breast exam with the patient sitting unless that's the patient's preference. And if that's their preference, one thing you want to do is reassure them that you actually can assist them with a transfer and that you can't really do as good a job of taking care of their health if you're trying to do it in the wheelchair. And you will have patients who do not want to transfer and as long as they understand the repercussions, that certainly is their right. Next slide.

Erica Monasterio:

There's lots of options in terms of transferring. Your patient will know what's the best approach for them for transferring. They often will bring equipment with them. For example, my daughter always brings a little folding step stool because she does stand pivot transfers with assistance. Patients may be bringing a transfer or a sliding board because they slide over from one surface to another. So, you really want to adapt your transfer strategy to the patient and know that the patient knows best. What's their best approach for transferring? Now if they've never transferred onto an exam table, you may need to lay out the options, but generally people have to get out. If you're using a wheelchair, you have to get out of your wheelchair to use the toilet perhaps to get into bed, perhaps to sit in another chair perhaps. So, people have their ways of doing it and they know how they do it. You're the one who's the learner here. Next slide.

Erica Monasterio:

So then in terms of positioning, just maintain an awareness that your client may have impaired balance or weakness, particularly on one side, so they may list to one side. They may have spasticity, which means that they can stretch out their muscles, but their muscles are tight and in contraction. They may have contractures which result from long-term spasticity where they cannot straighten out certain joints because those joints have become fixed in a flex position and you really need to pay attention to skin pressure, especially over the sacrum. You don't want to leave someone sitting for a long time with pressure. Next slide please. So, in terms of managing spasticity, slow, gentle positioning can really minimize spasticity and pressure and rushing can really maximize spasticity.

Erica Monasterio:

You may want to talk with your patient about how their experience has been and consider the use of diazepam, tizanidine or baclofen. Tizanidine and baclofen are very commonly used for spasticity among people with disabilities. Diazepam is somewhat sometimes used, it's more sedating but it's also super effective. So as the patient if they've ever tried anything and what has worked best in the past. Using a local anesthetic gel can be very helpful as well in terms of minimizing discomfort and unintended stimulation. And just because somebody has limited mobility doesn't mean that they have limited sensation. And just because they have limited sensation doesn't mean they have zero sensation. So again, let your patient be your guide. And then Robin is going to talk to us about that. Thinking about hot packs after the procedure as well. Just something that is relaxing. And giving people enough time. They are not going to leap off the exam table, jump into their wheelchair and zoom out the door. So don't pressure your patient about getting done and getting out.

Robin Wilson-Beattie:

And one thing I wanted to say about that, yes, and also patients too also know their bodies, so can know their bodies. A lot of times people with disabilities are like, I am the expert on my body because I live with this body, so I know how it's going to act. For the reason, like I mentioned, one of the things like when we were doing this presentation, I mentioned talking about having to get the lidocaine shot for any type of implanting a device or to do any kind of cervical examination procedures like to scrape for abnormal cells or whatever.

Robin Wilson-Beattie:

I had to advocate and bring in information showing why I would need to have that kind of numbing beforehand. Because my level of injury might state that I don't have much feeling below my neck, but the way that my disability presents, my body does not, it feels in some places, doesn't feel in others, but it over feels in places and one of those places is inside of my vagina. So, but having to have to advocate for that, that's something that was. But also, something that was awesome, the hot packs post procedure. That, once again California, that's where I got to encounter that and I was like, oh wow, this is something that is very useful, very helpful.

Erica Monasterio:

Okay, so any patient, you want your patient to empty their bladder first. Remember that a trip to the bathroom can take additional time, especially if it involves transfers and you might want to consider getting a urine specimen even if you're not sure if you need it. You don't want to have to try again later. So, if your patient is going to go to the bother of going to the bathroom, have them save you a urine specimen, you can use it or not as needed. Think about alternative positions to facilitate the exam and let the patient help you figure out the best position. And I'll show you some alternative positions in a minute. Consider using a Pederson speculum rather than a Grave speculum. They're narrower. Most women, for most women, it is adequate for women who have had many children.

Erica Monasterio:

It may not be because the Graves is wider and gives you better exposure, but in general a Pederson is great and a little more easy to accommodate and you can use the speculum with the handles down as you would conventionally, but you can also do it with the handles up depending on the position of the patient. You may need to do a blind pap smear if you can't get to the cervix. So that would involve sliding over your finger and into the cervical os to get your pap smear. You do get a decreased rate of endocervical cells, but you can by touch identify where is the os and still get a decent specimen. And always think about whether you really need a pelvic exam. Can you get the information you need today with some alternative screening or diagnostic approach such as urine or vaginal swabs for STIs? Next slide.

Erica Monasterio:

So, these are some of the positions that you might consider. Again, if your patient has had a pelvic in the past, they will be able to help you. You can see some of these positions are going to work, be better for people who have looser joints and limbs who, and some will not work for people who have tightness and spasticity. These pictures are from Table Manners, which is a wonderful resource that is in your resources here on the webinar. I would just advise you that the last edition was 2001. So, in terms of inclusive language, it is not at 2023 expectations of inclusive language but extremely valuable. Lots of pictures, lots of ideas really, and I've never found anything else like it. So, I continue to recommend it. Next slide.

Robin Wilson-Beattie:

Here's Dr. Anna Tirado. She is an OB-GYN in Connecticut and has an OB-GYN clinic that treats people with disabilities. And for her practice, she has some innovative accessible equipment. For instance, like we were talking about spasticity and positioning, her clinic has examination tables that account for those kinds of disabilities and for different positioning, but also, she has a lot of knowledge and things about communication and all sorts of things. I've included her because I think, and then a link to an article about her, so you can find out more information and take a look at the type of things that she's doing in her clinic because her clinic is centered around disability and treating reproductive and sex health for disabled people. And so, a great resource.

Erica Monasterio:

Okay, so let's quickly look at some contraceptive considerations. Next slide. People have a lot of concerns about combined hormonal contraceptive. So just remember that efficacy, contraceptive efficacy, in combination with some anti-seizure medications is impacted and that seizure disorders are common with numerous conditions causing developmental disabilities. You have to consider prolonged immobility or limited mobility and the thromboembolic risk for women with spinal cord injuries, with traumatic brain injuries with cerebral palsy and other conditions where immobility is, or limited mobility, is a big issue. Combined hormonal contraception can be useful in mood regulation if they are sick with behavioral issues for a client, particularly a client with an intellectual or cognitive disability and difficulty in communicating their needs, concerns and wants. They also may be useful to treat painful menses and other problems related to the menstrual cycle and management of the menstrual cycle as well as using continuous combined hormonal contraception to reduce the number of periods. Next slide.

Erica Monasterio:

Women with intellectual disabilities may face adherence challenges. So, all of those tools that help people remember, med boxes, alarms, phone reminders, et cetera, or they may need a third party that helps them to remember to take their daily medication. And again, as I mentioned, extended cycling may be an appropriate option for menstrual management. You can use the patch or the ring in a continuous fashion as well. Breakthrough bleeding is the most common side effect and what I would usually recommend to my patients is that if it works for them, if they have breakthrough bleeding before the next scheduled bleed, just go ahead and stop their pills, have their bleed and resume. Because once you start with breakthrough bleeding, it's kind of hard to catch up with it. It's better to just let the lining slough and start again. And you do see complete amenorrhea at one year in about half of patients and 26% will have only occasional spotting with continuous combined hormonal contraception. Next slide.

Erica Monasterio:

So just around drug interactions, we have this kind of idea, oh, you can't use birth control pills if somebody is on seizure medications. That's not actually the case. And you can see the list here of those that do decrease combined hormonal contraception efficacy and those that do not impact it at all. So, know what medication they're taking and engage with the person, the neurologist or whoever, maybe you as a primary care provider, is managing their seizure disorder because there may be an opportunity to change seizure drugs if they want to take oral contraception. Next slide. We do also have the question of VTE risk in persons with disabilities, and this is related to immobility. There's not much information actually on adult wheelchair patients. It suggests that there's a small increase in risk in adolescents, VTEs are rare.

Erica Monasterio:

We actually have more research on adolescents than adults in this area. And you can see here. So, you have to think about other risk factors such as obesity and a family history. And you want to think about which progestin you're going to use in a combined pill so that you're using one with a slightly lower rather than higher risk. And then you can see that the birth control combined, well estrogen is a category three drug in women with MS with prolonged immobility. And that's because they have a three time increase in their thromboembolic risk. Next slide. So, makes one think about maybe progestin only contraception being a better approach. But we do have to consider issues of bone density and weight gain for women who use Depo-Provera, particularly in adolescents. Progestin only IUDs are an appropriate option if that's for both contraception and menstrual management, if that's what your client wants.

Erica Monasterio:

But insertion can be challenging with some patients who need sedation for other procedures. Again, this I have found this more with patients of mine who have more profound disability, cognitive disability that makes it difficult for them to really participate or cooperate with an exam if they're, for example, getting sedation for dental care, will try and organize their dental care, their blood draw, their IUD insertion, their pap smear all with so that it's one anesthesia experience instead of multiple anesthesia experiences. And this isn't the bulk of your patients, but you will have some patients who need this kind of intervention. And just remember that the bleeding patterns with the implant, which are very unpredictable, can actually be problematic for women who can't independently manage their menstrual appliances and so may not be the best choice. Next slide.

Erica Monasterio:

And this is just the data on menstrual suppression. And you can see the percentages here with the progestin only pill having quite a bit of breakthrough bleeding and pretty low rates of amenorrhea. The implant also irregular bleeding and pretty low rates of amenorrhea. Depo with a considerably higher rate, but issues of weight gain and bone density. And then the progestin IUDs, which have a very higher rate of amenorrhea and are well accepted if the patient is interested in them and can manage the insertion. Next slide. So, let's move on quickly to healthy relationships and abuse prevention.

Robin Wilson-Beattie:

So, one of the things, the rates of sexual assault and abuse are much higher than the rates against people with disabilities are much higher than the rates of sexual abuse and violence against able bodied people. So, there's reasons for that risk though. There's more vulnerability with the dependency on others and communication difficulties. With mild developmental impairments, the victimization due to the need to fit in. Abuse occurs more frequently with family and caregivers. Only like 14% of people are abused by a stranger. The American Academy of Pediatrics data says that overall incidence is two to 10 times higher than for the general population without disabilities. 68 to 83% of women with developmental disabilities will be sexually assaulted.

Robin Wilson-Beattie:

What contributes to that vulnerability? These factors that influence these statistics are less able to defend themselves, not being able to maybe have the physicality to everybody's like, fight back, do this, kick. Well, that's not an option for everyone. Not everybody's bodies can defend themselves like that. Often not alert to potentially dangerous situations, particularly with maybe some cognitive and mental health. Not being able to see that you're in a dangerous situation, you don't know how to report the abuse, who do you go to? Where do you go or don't have a way to do that. Sometimes that vulnerability, that seeking that approval and affection and inclusion. Disabled people are often socially isolated in very various different ways with some intellectual disability, depending on the spectrum, they may be more vulnerable due to the desire to fit in with their peers.

Robin Wilson-Beattie:

They want to fit in, be that idea of what is considered "normal." May be exposed to a large number of caregivers for your intimate care. When you are dependent on someone for your intimate care like giving a bath, getting you dressed, cleaning you up, all of those kind of kind of things. Helping with the toileting and cleaning up and things from that, you know can also, that exposes you. And particularly being taught to be compliant to authority. Listening to the people who are in charge, always being put in that position of, you know, are reporting to someone or somebody else is responsible for how you get to live life.

Robin Wilson-Beattie:

And the words of disabled people who have been vulnerable, they have said, we are taught to trust grownups more than anyone else would be. Because when you have a disability, people are always telling you do as that person says, do as this person says and all of this other stuff. And these were quotes from the series of interviews by Joe Shapiro for NPR on sexual abuse and disability. It happens to people like us. And why is because we're easy targets to take advantage of. We think that the people that we're around, we can trust them. But you don't know that by looking at them. You can't judge a person by their looks. I was thinking maybe it was a relationship, a bad one. I was just in denial. I had to figure out, it's not my fault. I had to go through all the memories and name it and open up that box. You really don't want to open up Pandora's box.

Erica Monasterio:

So often people are not prepared to deal with these issues because in the family we don't want to go there, we don't want to talk about relationships, we don't want to talk about sex. I think this little visual says very well. The young person who's using a wheelchair says, "Mom, I would like to begin my sexual life somehow. Can we discuss this?" And mom says, "Eh, is this your biggest problem now? You really don't have enough issues? You're only 28, you still have plenty of time now." With her typically developing child, I don't think that that mom would use 28 as the cut point of when you start talking about having a sexual life. But this idea that this really isn't an important part of the lives of people with disabilities is very pervasive. And so, we don't really prepare them adequately and we don't prepare parents to prepare their children. Next slide.

Erica Monasterio:

For people with social and communicative impairments, this really impacts on their development of friendships and romantic relationships. They have less opportunity to learn about sexuality from their peers, their judgment to apply sexuality in a socially acceptable way or interpret the intentions of others may be impaired. And that can result in literal or incorrect interpretations of information relating to sexuality. They may not get sexual codes, may not be as clear and for people on the autism spectrum, this is something that they may struggle with as well. Next slide. What we advocate is universal healthy relationships.

Erica Monasterio:

Education, again, not just for your patients with disability, for all your patients. What's a healthy relationship? What are the characteristics of a healthy relationship? And what are the characteristics of unhealthy relationships? What is sexual coercion? What is consent? How do you get to consent? And what are the red flags when maybe someone's pushing you in directions you don't want to go? And really creating a safe environment to talk about relationships so that people can share information rather than pressing them to disclose what's not going well in their relationship. Just talking about the value of relationships, the quality of relationships, and being open to hear if your client has relationship issues. Next slide.

Robin Wilson-Beattie:

Now, the relationship challenges for people with developmental disabilities. Negotiating relationships, that's a learned skill. This is something that we are taught in society through socialization, from how we're being brought up. So that's a learned skill. But people with developmental disabilities, they have fewer opportunities to practice through friendships. ... practiced through friendships. People with disabilities, they have fewer social outlets and higher levels of adult supervision. People with developmental disabilities desire romantic relationships, but often they have no models among their peers. The sexual decision-making, it requires abstract thinking skills, but with some individuals with intellectual disabilities, they may not develop that kind of abstract thinking.

Erica Monasterio:

Can you still hear me?

Robin Wilson-Beattie:

Yes, I hear you.

Erica Monasterio:

Can you still hear me?

Robin Wilson-Beattie:

I can. Well, in the interest of time, though. One of the things that we could do is about teaching boundaries and consent, teaching people that they have the right to say no and that they have the right to say yes. Teaching the right to refuse because as we mentioned earlier that people with disabilities sometimes can be trained to be compliant, to listen to authority, to listen to people in assumed authority. Remembering that context is everything like your lessons. How does this information fit into their real life? You discuss social situations as an example. Also, it's not all about no.

Robin Wilson-Beattie:

A lot of times people come to sex education from a preventative standpoint, preventing pregnancy, preventing sexually transmitted infections, preventing pregnancy, preventing abuse, but we need to talk also about the fact that pleasure, autonomy, agency. Adults and youth with disabilities desire and seek relationships including romantic relationships. Speaking of pleasure, access to pleasure is the real accessibility issue. Full inclusion means access to pleasure. It means a reasonable chance for relationships. That is from Mitch, Dr. Mitch Tepper, who is a disability sexual and reproductive health educator, from his Sexuality and Disability: The Missing Discourse of Pleasure. Erica?

Erica Monasterio:

Yes. Thank you, Robin. My earbuds went out. On this last slide, we chose to include Sins Invalid because I would encourage all of you who are thinking about issues of disability and sexuality to just go to this website and take a look around because just experiencing the website is an education unto itself. I really encourage you. It will just open your mind to what are the possibilities and the needs, interests and desires of people with disabilities around the issue of sexuality. Next slide. We do have some resources here, but Robin also compiled a fantastic bibliography and resource list that is available to everybody who is on the webinar. Next slide. That is the end, so we do have a few minutes for questions.

Nicole Nguyen:

Yes. No, thank you so much, Robin and Erica. That was amazing. I think you stunned our audience too because we didn't have a lot of questions, but we have a couple questions. I sent them your way, so feel free to take a look at your question box. I know there are questions I directed toward Robin, and there's this question I directed toward Erica, but feel free to answer both. If you want to do that, go ahead. Would you like me to read out the questions or would you like to read yourself? Go for it.

Erica Monasterio:

I can start with the ones I can see because they seem we can get address them quickly. "Are we calling obesity a negative health outcome? How does that intersect with medical fatphobia?" Yes, I hear you. Again, as I mentioned, this is presenting the data as it was queried and formulated in research studies. Certainly, when you look at weight and disability, especially mobility disabilities, weight contributes to mobility disabilities and complicates mobility disabilities. In that sense, yes, it is a co-factor and we do see higher average weight among people with disabilities, and that can be impactful on their health. It's not necessarily impactful on their health.

Erica Monasterio:

There's also the issue, so I'll just share personally, my daughter is now 25. I help her with transfers. She's bigger than me. I'm not a very big person, so her weight can have a really big impact on who can help her physically with transfers, et cetera. That's something that really motivates her to try and maintain her weight at a point. We have a cut point where anything over 170 pounds, and I just can't do it. I'm not big enough to do it, so there are those considerations as well.

Nicole Nguyen:

Robin, you can stop sharing the screen, too.

Robin Wilson-Beattie:

Okay. I'm sitting here trying to figure out how to do it. Okay, sorry.

Nicole Nguyen:

No worries. There you go.

Erica Monasterio:

Did you want to add something there, Robin? About the issue of is obesity a health issue?

Robin Wilson-Beattie:

Mm-hmm.

Erica Monasterio:

Then the other question I have here is, "How long do you have to stop pills for a breakthrough bleeding?" So, I'll just have them stop. It depends on what formulation they're taking. Some formulations are four days off, some formulations are seven days off, but whatever that break is. Usually if it works for the patient, to take seven days off, let them slough the lining they have, and then restart. It will reduce the amount of breakthrough bleeding you see. I mean, sometimes they can make three months, sometimes four, sometimes six without breakthrough bleeding, but it just depends on the person.

Robin Wilson-Beattie:

Now one of the questions I see here is, "I work primarily with high school students. In the past, I have encountered student aids who have stopped me from explaining reproductive health information to students with intellectual disabilities saying that they don't have the capacity to understand that yet. How could I being the visitor at their high school go about in this situation?" That's something actually that's a question that teachers, particularly special education teachers, they encounter this attitude from parents about talking about sex and reproductive health, but there is a book that came out last year. I should have included it in the resource list, but it is written by educators who work with special education and are also sex educators. They talk about the issues and how to address that communication with parents. I can follow up, and I can provide that resource.

Robin Wilson-Beattie:

However, I'm wondering if there is a respectful way that you can point out to the aide that this person, that they do have autonomy and they do have agency and they have a right to learn about their bodies, and they have a right to learn about their sexuality and their reproductive health because the same way that they are learning other things about how to navigate life. Particularly we're talking about high school. We're not talking about babies. We're talking about high school. This is very important.

Robin Wilson-Beattie:

That is having a discussion maybe about that you were talking to this person and also that you can have an understanding of being able to assess if they have the capacity to learn information, but also in what form that you are relating that information, if that makes sense, because there's different ways to communicate about sexuality and terms, things. There are ways to put things in plain language, but yeah, encountering the ablest attitude that people that are working with disabled people, it is an issue. My recommendation is having that conversation about the fact this person has a right to learn and also why it's important because sexuality is part of who we are as a human being. As such, we all need to learn about our bodies in order to maintain, treat our sexual and reproductive health. It's not up to that aide to make those kinds of decisions about whether or not they can have the capacity to understand that. That's between the people.

Erica Monasterio:

Can I add?

Robin Wilson-Beattie:

Yes, please.

Erica Monasterio:

If you're looking for resources, there's an organization called Elevate Us, which has fantastic. They have online and in-person training for sexuality educators working with people with intellectual disabilities. They have training for self-advocates, and they have a curriculum that you can adopt and adapt for the population that you're working with. In that situation, I mean you want to make sure you're delivering information in a way that's accessible and that they can understand. You might remind that aide of the data that this young person is actually more likely to get pregnant than a non-disabled peer, more likely to get a sexually transmitted infection, more likely to be sexually active, so withholding information certainly isn't the best approach. There is a tendency to underestimate people's capacity as well. Particularly if there hasn't been a formal assessment, how do they really know what their capacity is?

Robin Wilson-Beattie:

Another resource I was thinking of once you mentioned Elevate Us, I'm like, "Yes, yes, yes." Cripping Up Sex with Eva. I am a firm also a believer in nothing about us without us. Eva, they are a nonverbal, a sexual reproductive health educator, and they also use a power chair. They do education around all aspects around, and they have webinars. Crippingupsexwitheva.com. They talk about things like this in dealing with the ableism around capacity to understand and going to the doctor, but all of those things related to that. That's another resource on some advice. Also, they have webinars and things like that and resources you can purchase on their website as well, so that was one question.

Robin Wilson-Beattie:

My other question I got was, "Can we discuss mask mandates or lack of them as a disability access issue?" Yes. "Risk of COVID, RSV, et cetera can be limiting factor for immunosuppressed or high-risk patients trying to access care things." Personally, yes, I feel like it should, but definitely in healthcare settings that it should be mandated that a patient should be able to ask their providers to please wear a mask. Actually, I feel like that should also be maybe an option that's on the intake saying, "I need my doctor, or I need my provider, I need the people to because of my disability. As a disability accommodation, I need you to wear a mask because acquiring COVID." Not to mention all the other viruses and things like that, all of those can impact those people who are immunocompromised and are high-risk. Yes, it is a disability access issue, and it is ableist to be like, "Oh. Well, we don't have to wear a mask, so it doesn't matter to me." Erica, do you have a better way of putting this?

Erica Monasterio:

I actually was thinking of it from the other direction, that there are also some people with disabilities who cannot tolerate wearing a mask. They may feel very claustrophobic. I mean, we all feel somewhat claustrophobic, but it may be intolerable to them. They may not be able to breathe adequately, so also being tolerant and inclusive of those that we need to mask around because they cannot mask themselves, as well as having masks available for those who enter an area where other people are not masked, but they need to protect themselves.

Erica Monasterio:

I think these are all considerations. We are now in the age of back to individual choice in terms of masking, but as healthcare providers we need to be very cognizant of these issues. Both that some patients may be immunocompromised and at greater risk. Their condition may make them at greater risk, but also that you may have patients who just cannot tolerate masking. They rip off their mask. They get very agitated if they're wearing a mask. Sometimes families or caregivers have found alternatives for them like a face shield, something like that, but we have to be able to mask around them when they cannot mask themselves. Do you have more questions, Robin?

Robin Wilson-Beattie:

No, those are ... Okay, wait. One more question. I thought I saw something pop up.

Nicole Nguyen:

Yes. I think we have two more questions. One is, "How can we shift societal attitudes toward people with disability and promote greater understanding and acceptance of their sexual and reproductive rights? What role can healthcare providers and policymaker play in this process?"

Robin Wilson-Beattie:

I really wish I could read that question because of how I process information.

Nicole Nguyen:

Actually here, let me send it to you.

Robin Wilson-Beattie:

Okay.

Erica Monasterio:

While you're reading it, Robin, I'll just speak for a minute. In terms of being advocates, be advocates for inclusion. Look around at where you're providing care. Start small. Look at where you're providing care, and is access truly access? For example, Robin and I were talking about how it's inevitable that that disabled-accessible bathroom gets filled with the biggest boxes, the chairs. We have no place to store things. This looks like a great spot. Well, if you go in there with a wheelchair, you can't use it, so just little things like that are a start. Thinking of inclusion first, advocating for universal design. A ramp to the front door does not mean it's accessible. Physical accessibility doesn't mean true accessibility if you don't have adequate staffing supports, time, and a headset that's inclusive and really putting your patient in the center. Now I'll pass it back to you.

Robin Wilson-Beattie:

Another thing that I was thinking about is as far as promoting understanding disability and acceptance, making sure that it is seen as something that is part of society in representation. I've noticed that when I go to a doctor's office, particularly if I am going to an OBGYN's office, I'm not seeing any of the brochures or literature, anything that shows disabled people getting reproductive healthcare. You can see the advertisements for birth control or whatever, and they're showing the little happy couple or whatever, but you don't see somebody, one of the people that's part of that happy couple in a wheelchair or using a cane or has a trach. We don't see, but we need to normalize seeing disability because the largest marginalized population on this earth. It's a part of the human condition, so the fact that we don't see it represented when we're looking at charts or models.

Erica Monasterio:

One of the things that I was mentioning when Erica and I were talking about these things, talking about intersectional things as well, when I go into a doctor's office, the models and things that they have depicting parts of the body like the drawing of a penis or inside of a breast, they are the color of the individual that they're portraying. Their part of the body is white. Think about all of those little peachy colored models of everything. Representation is very, very important because representation shows that you have a right to be here, that you are included, you are part of society. Part of that is showing, like I said, representing it, having examples, but also taking courses like this and having these kind of courses, cultural competency around disability in your practices. That also is one way you can also promote a greater understanding and acceptance of sexual and reproductive health.

Nicole Nguyen:

Wonderful. Then our very last question. I know we're a little bit over time, so if anyone needs to leave, please go ahead, but we'll definitely get your questions answered. One last question, "In low- and middle-income counties where state runs generally short of resources for health budgets, needs of differently abled are least prioritized. In what situation could we go to for particularly infrastructure support?"

Robin Wilson-Beattie:

One thing that I have been, because yes, people are like, "Yes, it's a financial burden." There are grants that are out there to help with acquiring inclusive equipment and acquiring medical equipment that is accessible for disability. For instance, the scales that we're talking about, or Erica mentioned there's a chair, an examination table.

Erica Monasterio:

And the weighing table.

Robin Wilson-Beattie:

Weigh you there in the examination table, but there are grants. There are programs. I mean, you might have to get creative as far as trying to find the funding, but the thing is you have to actually also make that a priority. Like I said, not just to be nice, but also, I mean, it can have financial implications for you if you don't get it done because you can be sued. That's some of the things that I can think of offhand, but more also communicating the fact that accessibility and inclusion should be a priority. That also takes education as well. I mean, there is funding. Like I said, there's grants. I've seen government grants, but also things from the Ford Foundation philanthropy I've seen where they've created programs and other grants like that. Actually, you know what? I can provide after this talk some more resources I can find about funding and stuff like that to help, especially with rural clinics and things like that.

Erica Monasterio:

The other thing is you tend to think about the big-ticket items. Exam table is a big investment. An electric exam table is a bigger investment, and a high-low table is. Yes, but first there has to be the will, and then you find the way. There's also a lot of things that help. You can find used transfer boards, having a transfer board in the clinic, extra pillows, extra blankets, the little foldable step stools. All of those are low-ticket items that really make a difference when you have them there and can utilize them to support your patients and transfers, et cetera. I think the main thing is thinking about it and planning for it, prioritizing. Then you find a way to do it. I know with the funding for the ACA with all the buildouts in Federally Qualified Health Centers, there was funding for increasing access, but I don't know if that funding is available anymore.

Robin Wilson-Beattie:

That, too.

Nicole Nguyen:

Okay, so I think that concludes our webinar. Oh, my gosh. Thank you, Robin and Erica. That was just probably one of my favorite webinars so far. This is such an amazing topic, so I want to thank you both for participating and speaking for us. This concludes our webinar. There will be a survey that comes up when this webinar ends. Then the link to the CME certificate, this recording, all the slides and all the resources that both Robin and Erica mentioned and any other documents we share will be available a few weeks after this webinar concludes. I want to say thank you again for our speakers for giving such a wonderful presentation. We hope you enjoyed it and found it really helpful. Then thank you for taking the time to join us today. We hope you stay safe and have a wonderful rest of your week. Thank you all so much. You're awesome.