

AUCD
SEX TALK FOR SELF-ADVOCATES WEBINAR
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>> Hello. Welcome to "Sex Talk for Self-Advocates."

My name is Anna Costalas and I'm the resource manager here at AUCD. We would to thank you for joining us today. Because of the number of participants, the lines will be muted throughout the webinar. You can ask questions at any point during the presentation on the chat box. You may send a chat to the whole audience or the presenters only. This entire webinar is being recorded, and will be available on AUCD's webinar library following this event. There will also be a short evaluation survey at the choose of the webinar. We invite you to provide feedback on the webinar, also to provide suggestions for future topics. I would now turn the mic over to Lind say Mullis, the share. Sorry about that. Lindsey.

>> Thank you. Thank you, everyone, for joining us today. It is the seventh Sex Talk for Self-Advocates. We are excited to be talking about marriage today. These questions are coming from self-advocates from across the nation wanting to know about the topic of marriage and the information provided. We're excited to have you all and get started. On the next slide we're talking about our -- introducing our esteemed panel that we have with our every time. First we have Max Barrows who is the director. He helps youth speak up for themselves and become leaders. He leads their technical assistance team and local and state self-advocate organizations. Max connects to people on all levels for true people with disabilities and the message that when you meet the individual with the disability, presume competence. He received the White House for change in 2015 and is an accomplished self-advocate in Vermont and the self-advocates becoming empowered from 2008 to 2016.

>> Thank you, Lindsey. My name is Lindsay Sauve. We are delighted to have Katherine McLaughlin with us today. Katherine is an expert on sexuality and developmental disabilities. She teaches sexuality education to people with DDID as well as trains them to be peer sexuality educators themselves. Katherine is the author of an "Agency and school sexuality and education for people with developmental disabilities" and developed two online courses one to train professionals and sexuality 101 and for parents. Talking to your kids and developmental disabilities and sexuality.

>> Also on the esteemed panel of educators, we have Erica Thomas. She facilitates the direct support professional academy. Erica delivers person-centered health education coaching sessions for people with disabilities and on an array of topics. She serves community providers that support people with disabilities. Erica advocates for support and assists people with navigating the health care system. She develops and implements the curriculum and education sessions including topics with the sexuality, intimacy, and current safety for people with disabilities and their support teams. When she's not advocates, she enjoys traveling the world and spending time with her adorable baby boy.

>> Setting the stage we'll be using person first language and acknowledging there are other ways to talk about disability language that we like to use person-first language and knowing that the participants are what are used in the questions. We want to be respectful for self-advocates that completed the survey. Sol of the things we talk about we'll be using medical terminology or today's presentation legal terms. If there's things that might not make sense or things that might sound different in different parts of the country, make sure to ask questions or follow up as we're providing the information in the best way that we can.

>> Marriage and sexuality are very personal topics. Sometimes things comes up for people. One of the things that you can do is to reach out and talk to somebody. We've put the number here for the crisis call center. If you do feel uncomfortable or if something that comes up in the webinar today reminds you of like a bad memory or something. That is upsetting and to just reach out and talk to somebody and do that by calling this number or reaching out to someone that you trust like a support provider or the staff or someone in your team.

>> If you have any questions, we'll be monitoring the questions in the chat. You can send those to everyone. You can select individual people to send questions to. If there's something privately that you wanted to send to Lindsey or myself, feel free to select our pictures on the side and send us a comment privacy. We'll be able to address those questions as well.

So as I mentioned before each of these questions are from our sex talks with advocates survey. We'll have others lead the discussion and we'll have the panelist that will be answering those -- these are things, or if these are topics of interest, check those out. These are topics by the wonderful educators and panelist.

>> There's a question from Leeann about whether the copy of the slides are going to be sent out after the presentation. And that's correct; right?

>> Yup. Auna mentioned the recording of the webinar will be on the AUCD web site attached with our sig. Yeah.

>> Awesome. Okay.

>> And Rhonda we'll get the links put in the chat here in just a second for you. As we get started with when we brought the topic together thinking about what we wanted to bring to you today, the statistics on marriage was one of the first things we talked about. What are the numbers? What are we thinking about when we talked about marriage? We looked at the indicators to assess the quality of outcomes for disability services provided to individuals specifically with intellectual disabilities along with their families. So the 2017, 2018 statistics on marriage for individuals that show that 94% of

individuals are saying they are single compared to only 2% that are married currently or married in the past or didn't know how to answer. That's a very big difference in numbers for people with intellectual disabilities being able to experience marriage. I also looked at the centers for disease center disability and health data system and marriage with anyone of a disability type with cognitive, physical, hearing, or daily task, 43.7% of individuals with disabilities reported being married or in a relationship compared to 58.3% of the population without a disability. And on the next slide you can see here it varies by state. Looking at marriage status of adults and different state by state where it could be for individuals with disabilities as low as 22% or as high as the 50%. How does it look different depending on where we live.

>> We asked some folks about whether it is legal for them to get married. We did some research and found that every state is different. For the most part it is legal in most states for people with disabilities to get married. We did find that some states have laws that are still, you know, in their constitution that say that people with IDs cannot get married. It is different state by state. Technically in most states people with disabilities are not prevented from getting married. We did also find that some states do have guardianship laws that give guardians some additional power, I guess, or additional right to say whether the person who their guardians for can or cannot get married. Again that's really going to just vary depending on the state that you live in. And what the laws are in your states and the rights are. We also had questions about social security benefits and whether getting married affects a person's benefit. Again this is going to be something that is really, you know, depend on an individual's disability. This is information that you got from the social security office web site. If you have web site disability benefits, your benefits don't change. If you have what's called SSI so supplemental security income, SSI, that's something called the marriage penalty unfortunately. If you marry, your benefit amount can change from what's called the individual's rate to a couple's rate. And one of the quotes from the web site here is benefits for married couple both of whom receive SSI and have no other income amount to 25% less than the total they would receive they were living together but not husband and wife. We just want to remind folks this is -- again this is going to be different depending on the person's individual situation. But it is possible that people who are on SSI could have their benefits affected. And this is something potentially to advocate about to contact your representative or the organizations to really kind of work on changing this penalty that people receive when they get married. Again we provided a resource and a link -- at the end of the resources page to the social security office web site so you can read some more information. We don't have time to go into the individual questions about this. But we really encourage you to contact folks who can provide some more information and support around this.

>> So people --

>> Sorry about that. So people -- go ahead. I don't want to interrupt.

Okay.

>> So people with disabilities unfortunately still get told when they can and cannot do. This definitely has an affect on their personal life. One of the areas of their personal life that it has an affect on is whether or not they can get married or want to marry. So what I have found is this. If someone tells you that you can't get married, it is important to know the following. That is number one know your rights. And learn about what the

laws say in your state. You can also talk with another advocate. We would say another self-advocate in the self-advocacy movement in that regard. Contact someone on the team that you trust. Also you can contact the state's advocate organization -- the list of those is in the resources page that's going to be a out toward the end of the slide show. One of the things that I mean when it comes to talking with another person on your team or someone else that you trust is, you know, some people have teams that were made up of like their family or even like, maybe, case manager or something. Examples of people in your life maybe on your team that can help you like your case managers, your service coordinator, or even like your personal agent. Overall it is just -- it is important to know the laws and how they protect your right. Because people will try and stop you from exercising your rights as a person. And really the bottom line is you as a person with a disability have the same rights as someone without a disability. So it is really beneficial and it is worth really going over the laws in your state and also taking action in the regard if you feel like your rights are being violated when it comes to being told you cannot pursue a marriage or can't get married.

>> Next slide please.

>> So we hear marriage equality. That's a big term. And it is used mainly when we talk about marriage equality for LGBTQ plus couples. Lesbian, gay, questioning, transgender, or queer as they say. What comes to mind -- I want to point this out. Marriage equality is bigger than just, you know, how we -- you know, how we hear it in terms of, like, just used to talk about, you know, marriage equality for people with different sexual orientations. Marriage equality is not just an issue for people who are LGBTQ plus. It is a big issue for everybody. Examples of marriage equality would be probably, you know, getting rid of the barrier -- well, not properly, but getting rid of the marriage penalty. Which is still a barrier that keeps people with disabilities from getting married. A lot of self-advocates have said, you know, like what have we done that is wrong to deserve to have our benefits when it comes to SSI get cut because we married the person that we love. Yeah. There's still work. That's an example of how there's still work to be done on marriage equality and just recognize that it is a big term that affects a lot of people. It goes a long way with a lot of people not just LGBTQ plus couples. So, you know, whatever we can do to make sure that people pursue their marriage and also just make sure that their marriage does not infringe on what they need in life to take care of themselves. And for people to, you know, just stop people from stopping people with disabilities from getting married. I think that's something that we need to really consider and take, you know, a stand on and take action toward. So I wanted to bring that up when it comes to the term marriage equality that's bigger than what we just hear of in the area where it is used.

>> Hello. I wanted to check in with you today. I want to make sure everyone is safe and healthy. Today I want to talk to you about monogamy, Polyamory, open relationship, and LGBTQ plus. A lot of what Max just talked about. Over here in the corner I would like to bring attention to the YouTube channel about people with disabilities and their relationships. They answer questions from their subscribers. Over here in the corner that's me and grubs and another one roll with control and charisma and the life of A & K. The resources will be available for you at the end. If you are interested in checking out those YouTube channels, if you haven't already

done so. I just want to put this out there too it doesn't matter what kind of relationship that you choose to have. The most important part of the relationship is you talk to your partner about your wants, needs, and desires. Let's keep that in mind as we move along. All right. Let's talk about monogamy. You are in a relationship with one person. You are sexually and emotionally intimate with one person. Partners choose to be in a monogamous relationship. If we look at the different types of relationships that I just read to you, no matter what relationship you choose to be in, it is your choice. It is being intimate with one person. When we talk about intimacy, it means whatever we look like for you and your partner and what you and your partner agree to do. It might be kissing and talking and holding hands. Whatever that looks like to you and your partner. So the next type is polyamory. It is not cheating, it is consensual. Practicing and being in open relationship with more than one person. Polyamory is a choice. We've heard of the term polygamy. That means one person is married to two people. It is not when just one person married to another person. It may be a person who is married to two people or more. So the only place in the United States where that's legal is in Utah. And different places around the world, polygamy is legal. Places in Africa, Egypt, Kenya, Morocco, and some others. Asia, Iran, Indonesia, Jordan, and other countries. Like we talked about with polyamory, it is the practice or desire for the relationship with more than one partner.

So the next type of relationship that we were asked about is called an open relationship. And that's a relationship where both partners agree that each may have a sexual relationship with other people. And both people are openly allowed and able to have other sexual and romantic partners. There's an agreement between the partners that having sex or emotional relationship with others is okay. And having an open relationship is a choice. So sometimes people may ask why would someone concern an open relationship? Maybe when your partner have a lot of love to give and you believe you can love more than one person at once. Maybe you want to explore your sexuality or different relationships or someone with a different gender. Maybe one partner wants more sex than the other partner or more sex and intimacy than the other partner. Maybe one partner isn't interested in having sex. Other people may have -- other partners may have fantasies, or maybe someone heard about it and they are curious about it. There are many different reasons why people choose to engage in open relationships. There's a conversation between both partners. They agree it is okay to have an open relationship. More about open relationships. They can be physical or romantic relationships with other people. And then it might be a situation where only one partner engages in the types of relationships. One partner can be in an open relationship, or both partners can be in an open relationship. It is a choice that's made and communicate is the key and making sure they are going over boundaries and the specifics in what the relationship is going to look like. All right. So the big question is do open relationships work? So just like any relationship both partners have to be honest with each other. So if certain boundary or whatever else is set. You have to be honest about what you are doing with other people and making sure it is staying within the rules that everyone has established. A partner may become jealous and being jealous is an emotion or feeling that may come up. Partners are going to be intimate with other people. You want to make sure you are checking in and talking through those feelings with your partners. We talked about setting

boundaries. Talking about what you and your partner can and cannot do. You want to make sure you are setting boundaries and sticking to them. If something comes up, you may want to have a conversation with your partner again to go over the boundaries again. Safety is on the list. Being safe may include STD and HIV testing, only be intimate in certain places, et cetera. You always want to make sure you are checking in again with your partner to make sure things are okay, jealousy, boundary, and communication is key. Then Max talked about LGBTQ relationships. And a healthy relationship is the healthy relationship regardless of your sexual orientation. If you choose to be in the LGBTQ relationship, that's up to you and your partner. LGBTQ can start off as friendship and go into marriage. Relationships are a choice. If you wanted to know more about LGBTQ plus relationships a shameless plug we did sex talk for self-advocates number 6 and details relationships in more detail than we have time to go into today. Communication is very important and necessary. That is going to counseling.

>> Hi, everybody. I'm Katherine. I'm going to take you through the next few slides. We'll be talking to some couples about their relationships. So I think first it is just there's a lot of myths out there about counseling in relationships. There was some questions that we got around premarital counseling. Counseling before you get married. But just there's a lot of myths out there about relationships and counseling. So here's some myths. In a good relationship all you need is love. And another myth -- so it is not true is in a good relationship partners don't fight or have any problems ever. In a good relationship, partners won't focus on problems, because it only makes them worse. And sometimes people think that seeking counseling when you are in a relationship is a sign of relationship. And couples should be able to solve their own problems on their own. These are all myths. All of these things are not true. I'm wondering if people can write a few things in the chat box around why do you think these aren't true. Just a couple of things.

I'm going to start talking. Let me throw those in there. Let me tell you some truths about counseling. No two relationships are the same. Relationships are complicated. Relationships take work. Yeah. Working through problems and help promote the growth. There's no one-size-fits-all. We need to help to navigate working through things. Absolutely. When we look at the next slide, you see that -- there. Thank you. There's nothing wrong with getting help when you are in a marriage or even before. You know, before you get married or during a marriage. And many couples need help in the relationships. So it is okay to get that help. It is really important to get that help. We also -- often times when people come together and get married and even just in a relationship, they have -- they expect certain things. And you might not even know you expect those things until you are in a relationship and so, for example, one partner might think they can clean the house. They expect the woman in the relationship to clean the house. Then they get into fights. And so really knowing about what you expect beforehand is really helpful. And since we grow up in two different families, we learned how to be different families. We know how relationships work, because you grew up differently. So the next slide. Then it is called premarital counseling. Counseling before you decide to get married. And many people say it prepares you for the big adventure. And also that many times it is connected to some kind of religion. Anyone can get premarital counseling before you get made. It is helpful that you know

how people think about the topics beforehand. You have the conversations about what you believe and what you feel and your values and things. And then during a relationship or marriage, you know, sometimes we get into fights. And disagree. And that really that's not a bad thing. That tells us this is something that we need to focus on and figure out. Solve this problem. And also you can go to counseling just because you want to have a healthier relationship. You don't have to be fighting all the time and feel like things are really bad. You can also go just to help you communicate better together. It can pull you together, and it can help you and your partner change anything that might be unhealthy. Maybe one partner doesn't communicate very well. They can learn ways to communicate better. And in the earlier we start doing this in relationships the less likely these problems are going to get bigger and unable to fix. And also less likely for people to feel resentment and angry at their partner about these issues as well. And there's been research done on marriage and one example is that you are supposed to have five positive interactions between the couple and -- to every one negative. If you are having lots and lots of negative interactions, fighting and disagreeing and, you know, being sarcastic or whatever that's not healthy for you. You want to make sure you have way more positive interactions. There's lots of -- the Internet today. That's the problem with the online ventures. You can see the picture. They had written about their relationship ahead of time while they prepared for this. You can see the picture on the left Sandy and Glen one thing you'll notice is they often wear the same color and the same sweatshirt and things. They were -- they participated in becoming a sexuality educator training in Michigan. So that's them with their curriculum and learning how to be educators for other people with developmental disabilities. When they are not kissing like they are in the picture -- they wanted to become sexuality educators. They wanted to help others reach their relationship goals and they want to share with the world that people with disabilities want healthy relationships. All right. And then a lot of couples today is Rae and Colette. She's a proud self-advocate. She was diagnosed as autistic in adulthood. She's a few more courses away from completing her masters in public health and epidemiology. Which is a timely choice in the year of the pandemic. Yes. And when she's not working, or studying Raesin enjoys spending time in nature and trying to make the perfect waffle. Colette is a facile day working with -- she holds an bachelors degree as well as a masters of science in conflict analysis and resolution. She's probably good at being in a relationship and figuring out conflicts and things; right? Yeah. Yeah. In her spare time she enjoys being in nature, writing, and keeping her lemon tree alive. Very nice. Thank you both for being here. And Erica, do you want to introduce Ricardo and Donna?

>> I have the pleasure of introducing you to Mr. Ricardo and Mrs. Donna Thornton. Ricardo is a nationally self-recognized advocate who lives in the nation's capitol. They both live in Washington, D.C.

They are passionate advocates that believe people should be able to make their own decisions and choices and people with disabilities can achieve almost anything with support. Ricardo speaks internationally on institutionalization, advocacy, and human rights. >> They have been married for 36 years. They have children and grandchildren. They were the TV subjects "For family normal."

If you are interested in the movie, it is in the resource --

>> Thank you for being with us here today.

>> I think we're going to start with the love start. I'll start with Sandy and Glen. They are upset they wouldn't be here. We're excited to share their story. Let me read what they had come up with for their love story. How did you meet? They first saw each other at special Olympics while both were competing in snow shoeing. They didn't get to know each other until later when they worked at the Amway Grand Hotel. Sandy worked in housekeeping and Glen as a steward. Glen sent his friend, a wing man, for sodas when he went on breaks. He started offered to walk her to the bus stop and stayed with her. Just for safety, of course. Sandy caught on to his tactics. From there, they began dating. This went on for five years. They didn't want to rush things. They were in a long dating relationship and were married July 13th, 1991. And they had a big reception with over 250 guests and Sandy was 27 and Glen was 37. And they've been married 29 years. As far as their marriage story, Sandy and Glen feel their marriage is so successful because they respect each other's feelings. They both have learned to like some things that the other likes. They appreciate each other's differences. They communicate so they do not fight. They feel if they fight, karma will come back at them. So they try to live life to the fullest. It is just more fun to be happy about things. They say I love you every day with a hug. And how they knew that they were the "One"? Sandy knew because he met the list of things she had in her mind. She wanted to be with someone who was kind, cared about taking care of her, appreciated who she was, and did not drink or smoke. Glen knew Sandy was the one when he first met Sandy. He had that twitter patted feeling in his stomach and heart. So that's Sandy and Glen. Colette and Raesin, will you unmute and tell us your love story and answer the questions for us?

>> Okay. We met in 2011 at a meditation group in DC. And we were friends for about a year before we started dating. We've known each other for nine years now.

>> Yup. And then we got engaged about two years in. And I think we knew pretty early that we wanted to, you know, spend the rest of our lives together. When we got married I was 29. Raesin was 40. We had three weddings. Because why not? Part of it was we got married right before marriage equality was legalized across the country for LGBTQ folks. It was legal in Virginia, but anyway there's some complicated we had to get married legally in D.C.

We couldn't afford a giant wedding with everyone that we loved. We had another ceremony in the park.

>> It was like 70 folks. And the cake was home made.

>> Okay. So let's see. She's reading off my outline. Let's see. I knew that she was the one pretty early on. We bought and went on a trip after we were -- together for six months. We bought this broom from the guy who was making brooms. I thought we were going to jump over this. We did three years later or two and a half years later. But it was just easy to hang out with Colette. It was just easy to be with her. She was just really sweet and just a beautiful soul. Everything felt right. It was also important that I felt emotionally safe with her. In previous relationships I felt that we weren't maybe emotionally compatible, even if everything else was cool. That was such an important thing to have in alignment. When we first hung out, I was having a lot of health issues with food sensitivity. We had a plan to go on a picnic. I said you can't eat a lot of stuff right now. What can you eat? We had the picnic of odd assortment of

food. She treated it like it was not a big deal. That was a first in my experience. It was just a beautiful thing.

>> Nice.

>> Awe. Colette, how did you know that Raesin was the one?

>> I think I knew early on too. I think part of it was just the easy that I hadn't experienced before. Like it was -- I felt like I trusted her very quickly. I felt safe with her. And I just felt her talking the whole time. We had an easy connection. It felt healthy. We were very honest very early on and sharing our baggage. You know, things from the past. One of the things she told me maybe the first date was that she couldn't make eye contact with people. Okay. That was sort of how it started. And I think having -- all of those things helped to contribute to developing that level of trust very early on. And I just knew that -- this was a person that I wanted to spend my life with. So that's -- yeah.

>> Great.

>> And the waffles helped.

>> Well, of course, yes. And the lemon tree. Yes.

>> Yes. Lemon waffles?

>> I have made lemon waffles with raspberries on top.

>> Oh. Nice. Great. Thank you both. Erica, do you want to --

>> Sure.

>> Read the next piece.

>> Donna and Ricardo, do you want to take yourself off mute? And tell us about your love story.

Can you -- did you -- can the host take him off mute? Or invite him? It says connecting the audio. Can you unmute yourself?

>> These are the times that we're living in. We have to connect virtually. He's trying to connect.

>> Yeah.

>> Another option is if the mic isn't working, he can call in. That's another option.

>> Ricardo, can you hear us?

>> I'll call you.

>> Yeah. You are going to call in.

Lindsey, do you have that number? Oh. Hold on. He's calling me.

>> Hey, Ricardo.

>> Hey. I'm not sure what's going on. It says connecting. It is a circle. I apologize for the audio. I'm still learning how to use this computer.

>> Okay. No problem.

>> My wife just walked off to the restroom. So she will be back.

>> Okay. Do you want to start us off and tell us how you and Mrs. Donna met?

>> Sure. We met at -- we e both were living in an institution. And we were always friends there. I met Donna at McDonald's and we both worked at McDonald's. I was always the one that couldn't wait to get out and get something better. She would work and she was the french fry girl. I like the french fry girl, because she's spicy. When she wasn't doing fresh fries, she would come back and come back to the institution. We used to work back and forth. Donna moved into the new option. She moved into

the apartment and I moved into a group home. We started to go out to the D.C. in rural and romance and going to the movies and lunch at dinner. Donna was just a steward. It was the romance. After that I had to always make sure I got back to my cottage. Back to my group home before Monday, because I don't want to miss my bus. I sometimes do miss my bus. But it is okay. Donna one day had to become to the warehouse. I try to be the handy man. One day she happened to say she liked what I was doing and she proposed to me. I thought they weren't going orgeat married until 65. By that time, I won't use the worries. We went on to take the next. We really had a lot of fun. We carried a lot. And we took the next one for the social worker. And then them we thought -- we have one now. The first thing they came out and said was marriage? Are you kidding? You are just getting out of an institution. No. No. No, not right now. They were against marriage. It was just something unheard of. And when Donna comes, she can tell you the rest on how she felt. But we had a hearing and there was so much negative talk about any of us with disabilities that we wanted to tell our story. I got a chance to work at the library and Donna got a chance to work at housekeeping in Walter Reed in D.C.

And we told our stories. We went to testify. We went back to come out to the wedding. We are going to get married. We had determination then. We got married. We had planned it and my provider who helped us coordinate it. We had many people with disabilities in the wedding. We invited the politicians and people think they didn't know come to the wedding and see a beautiful wedding. And many came. We didn't get the right people. We got a chance to get into the "Washington Post." From there our story was told. Just to bring you up to date. Hurry up, what are you doing, Honey. I laugh around with her a lot. We did get married. And then after the marriage we got a chance to meet Mike Wallace. I don't want to make it too long. I'll just make it short. The story with Mike Wallace was he wanted to find out why many of us with disabilities are having so many problems. Why are we having people beat us up, abuse us, and not give us the respect that we deserve. And we had to break that ice. That's what Mike did. They opened up the door for us. We did get in there. We had a beautiful marriage and a beautiful son. After the son there was problems in the relationship. We're going to talk about that later, right.

>> Yeah. We'll talk about that later.

>> Okay. Okay. But the marriage was wonderful after we -- and what we've been doing is educating others about the marriage. They want to get married, here's some stuff they could take towards marriage.

>> How long have you been married?

>> We've been married -- Donna -- are you in here yet? How long have we been married? It's been about -- I want to say 35 years -- somewhere around there. You know, after 30, you know, you just enjoy life. It just -- don't tell her that though. Please don't tell her.

>> Okay. We'll keep your secret safe.

>> Okay. Thank you, Erica.

>> Thank you. You have some more to come. Keep your phone out. Okay?

>> Okay.

>> Great. Great. I can't stop smiling listening to both couples talking. You exude such positive, happy feelings. We're going to talk more about the experience of being

married and some of the barriers even like Ricardo started to talk about some of the barriers. I'm going to read Sandy and Glen again. So we're going back to their picture. There they are again. So the question what did people say when they told them that they wanted to get married. Glen's father and stepbrother were against him gets married. However his mother was okay with the idea. Glen's aunts and cousins said congratulations and hugged them. And the barriers -- Sandy's family as well as Glen's aunt helped them plan the wedding and the reception. They helped them with some of the finances for it as well. It took about eight months to plan. And Sandy and Glen made the decision not to have children. They took precautions to prevent that. As far as how they make decisions as a couple, they research by getting information online and then talk to people in their circle of support. Their circle includes family members, friends, advocates, and their support coordinator. They think about pros and cons and make their decision together. Glen has a public guardian and Sandy gets support from the payee at the arc located in her county. The question of how do they save money and live together, they live in the condo that Sandy's mother helped them purchase. Glen's guardian handles his financing. They both contribute to their expenses. As I mentioned earlier, they are both retired now. And the question about SSI, and what they said is like everyone there are tax breaks that you lose when you get married. Their SSI amounts changed. But they save money by having one place to live rather than two. There's a lot of people that help them make financial decisions. So that's Sandy and Glen. Colette and Raisin, how about you? If you want to answer all of those or jump around a little bit. Tell us about where there any barriers and what was it like when you told people that you wanted to get married?

>> Yeah. People were for the most part excited for us. My mom was really excited. She had things to talk about with her friends. It was interesting that people got on board, I think because marriage equality was -- at least for LGBTQ folks was becoming legal in more and more states. It seemed like there was a massive shift from no, you don't belong here to when it the wedding and am I invited? The other thing that came up to her surprise was that people were asking us if we wanted to have children. You are against us getting married last year. Now you want to know if we're going to have -- create a family and how we're going to do that. Just kind of a surprise.

>> Yeah. And there were some people that made weird comments or not really anyone close to us but people that just didn't think that an LGBTQ marriage would be the same as a straight marriage. Somehow they were different. We had a few weird comments here and there. Mostly I think people were pretty supportive.

>> Uh-huh. Was there anything around disability as far as a barrier or reaction to the two of you getting married?

>> No. Because I found out I was autistic after we got married.

>> Got it. That wasn't sort of in the conversation then.

>> Yup.

>> Great. And then tell us about you as a couple. You know, how do you make decisions? Save money? Anything? You know, tell us about you as a couple.

>> Okay. Usually if it is a big decision, there's spreadsheets and data collection and figuring out the option and do the data analysis together about what's right. I'm not even kidding. If it is, you know, everyday decision, we usually discuss what do you

want to do? And then if one of us doesn't really feel strongly about it, we'll say do what you want.

>> Yes. That is a common phrase. Do what you want.

>> And it is fine. That seems to have worked for us.

>> Except for deciding on paint colors.

>> Oh, man.

>> We have yet to successfully work that out. But maybe Ricardo or others will have some advice for us.

>> That's a good point. That's true. The paint colors that we had years ago.

>> What do you see the difference? One of you like bright things? What's the difference there?

>> I like warm, and she likes cool.

>> Yes. Yes.

>> Yeah.

>> That's the gist.

>> That's the gist. Great. And then anything around money or -- I don't know if you've received benefits and was there anything around that and getting married.

>> I don't receive benefits. As far as money -- I'm all for the premarital counseling idea. We did do that. That was advised to us by a loved one who offered that. And then as far as money I heard from someone who -- whose first marriage didn't work out. He got it right on the second one. He and his wife have three accounts. His/his wife, and theirs together. My wife likes purses. If it is coming out of our money and she has 200 of them already, it's going to be an issue. If she pays for the purse and it is not our money, she can have 300 purses. That made a lot of sense. Money issues can strain or destroy a marriage. I didn't want that. It works for us. I buy lots of yarn. You know? I could probably have a separate room for yarn. It is working for us. And anything that's for us together or the home we must pay for it together.

>> Yup.

>> I don't think so.

>> You said you did premarital counseling. What was the benefit of that?

>> What was the benefit?

>> Yeah.

>> I think it was really helpful. I didn't really know what to expect beforehand. But we had an assessment through it. We got to just have more intentional conversations about finances, about whether we wanted children, some key big picture things that I think is good to kind of

>> Great. Thank you. Thank you, both. Erica?

>> All right. Ms. Donna and Ricardo, your experience of marriage. What did people say when you told them you wanted to get married?

>> Is it echoing?

>> Uh-huh.

Hold on. One second. Oh. It is working now.

Okay. I think we don't need to use the phone anymore.

Can you hear us? Did you hang up?

Technical difficulties. Give us a second.

>> We're the one that created all of the technology. It is kind of our fault that it is a pain.

I think Ricardo is going to try to call me.

>> Can y'all hear me now?

>> Can you hear us?

>> Yeah. Okay. So basically what are some of the challenges that we had? We wanted to get married. Was everybody helpful for us to get married?

>> Everybody was helpful?

>> When you fell in love with me, and we went to tell everybody, were they happy about that?

>> No.

>> Why weren't they happy?

>> Because they were not happy when we got -- when we told them. And I asked them, well, -- I asked them I said, well, don't you got what we don't have? And I asked them, I said ain't you? They said no. I said tell me this are you married? You have rings on your fingers. You got a car. You've got a house. You've got children. And they say yes. I said, well, you got everything that we want. And this is what we want. We want what you have. And that's -- you know, that's what we want. And I said -- and I said, well, if you have it, that's what we want. In life. And we got it. We told them this is what we want. We did ask our caseworkers. They said no. I said, okay. I said, well, you know what? We're going to see about this. We're going to do it anyway.

>> And.

You proposed to me.

>> And I proposed to him. I should have never proposed to him. I should have let him propose to me. Not me propose to him. I was so in love with that to propose to him.

>> We had a wonderful wedding though. We had a wonderful wedding. We had lots of people with disabilities that have never been part of the wedding and we had the provider who was my coach in special ed. Now the agency wanted to see me be successful and happy; right?

>> Yeah.

>> So how do you two make decisions as a couple?

>> We usually try to work together. We see something that we don't like. We have a disagreement.

>> Sometimes we -- sometimes we argue it out. Sometimes we don't.

>> Sometimes we sing it out.

>> We sing it out. We sing it out. Sometimes we pray it out. You know. Just things that you do.

>> You need to work at Walter Reed army medical center. There was times when she could come home and something happened on the job that would just get her so frustrated. As the man of the house, I had to learn how to listen and not be so fast to jump --

>> Don't jump the gun.

>> Let her get the express out. And really, really let me know how she felt. She didn't beat me up. She just expressed herself nice. I would have to sit and listen. At the end of the day, we were relieved. And we went back to being happy again.

>> Yeah. Yeah.

>> Right, Honey?

>> Yeah.

>> Just be yourself.

>> What about saving money? How do you save money?

>> I'm a spender. I love to spend money.

(Laughter)

>> I like to save money. I'm a budget -- I'm a budget person. You know? I like to budget money.

>> One thing is she likes to make sure -- we have a joint account that we have together. And we are saving that. She also has her personal account. Which the husband does not touch that.

>> No. No.

>> But the husband wants to know why. But it is okay. It is her money. She saves it. I respect that. And also in case of an emergency or something. She's really teaching me to be more of a saver and not so much of a spender. Right, Honey?

>> I'm not very strict, but I like to budget.

>> She likes to save and budget and I like to spend.

>> You have a saving and checking account. Not even your son.

>> Not even him. Not even my son. No.

>> No. But we pay our bills.

>> I do make sure our bills --

>> We share -- more like when he had his bills, we share -- we share. When he got bills, I more like help him with his bills. We take turns on bills.

>> Right. More like the bills and with his bills.

>> Donna was independent before I met her. She always took care. She doesn't mad. She managed money very well. It is the husband she got to work with.

>> Yes. It is not easy.

>> Oh. Oh, my gosh.

>> Can we scroll back to their picture? And we can see their wedding and their beautiful family?

>> Yeah.

>> Oh. You had a picture you see there. That's my son. Donna got pregnant. We were supposed to have a class like a la maze class. They talked to her. We did the exercises. This one particular day they decided they wanted her to come to the la maze classes.

>> It was a Monday.

>> I wasn't able to get there. I tell the story when I do page.

They said they wanted to get the baby today. So they wanted her to have the baby today. I told them they couldn't do it today, because I had a basketball game. Two rounds of the special Olympics. I wasn't able to get there. So I was told in a nice way that I should be there. My wife let me there she wanted me there. And the cameras were over there. Of course I came over will. I came over there. But it was an opportunity to see Donna and the baby. We were both in the delivery room. He was a 2 pound 11 ounce baby boy on arrival. The beautiful story is he came out breathing on his own. Donna asked them -- you tell your story.

>> I was put in the delivery room. I asked the doctor, I said will my baby love me? And the doctor said sure. Then I asked the doctor again I said are you sure that baby will love me? And he said sure, that baby will love you. You are going to one day hold that baby.

>> Just take a moment to pause when you hear that word. Will my baby love me? Can a child of disability overcome obstacles in my life, now I'm going to be a parent for the first time? And today to update you, you may see a picture there where my son loves her. She's now -- he went to school; right? He has his own --

>> He went to school now. Leah, Maria, and Daniel. He's the oldest. He had -- he has all of the questions and my little girl Leah Maria and 5 or 6 years old. They can't wait to go back to school. You know how that is. They can't wait to go back to school.

>> Then we have Ricky. Who we all talked about. He graduated from high school. And with all of that going on, we had support. We had a support system for him. Because we really needed some extra help getting over that hill that he was going through. One he got over that hill, he was fine.

>> Yeah.

>> And his wonderful wife.

>> His wonderful wife, Tia. Helped him along the way. Yeah.

>> Thank you for sharing that with us. And -- hmm? Y'all have a wonderful -- I'm a parent each time.

>> Thank you to all of the panelist for sharing their stories. Now we have Max one of the other educators does have a specific question for the panelist and then we have a couple of questions come into the chat. So I'm going to turn it over to Max and let him ask those questions. Then we'll get any of the rest of the questions that you have on the call today hopefully answered. Hopefully we'll finish out. Max?

>> That was mostly directed at Raesin and Colette. It can be for anybody. Any of the panelist. I'm just curious to know something like what is your advise to someone like me on the autism spectrum pursue a relationship without my autism being a barrier? I ask because I'm concerned that someone may find me a bit too quirky and strange which can be a turnoff due to the con going disconceptions of autism and disability. Plus I was going to add this. I don't feel -- I don't want to feel like I have to just date people with disabilities. Sad. But okay.

>> I think my response to that is go where the love is? You know, I feel like -- we didn't know that she was on the spectrum until a few years into our marriage. I had a lot of learning to do what it meant and what it looked like. Once I had a better understanding, those of some of my favorite qualities about her. You know? And it is not anything that I would change. It is part of who she is and part of why I love her. I think there were people out there that will appreciate and love you just as you are. You know? That's what I think.

>> I would also add that it is important to spend time with people where you can really be yourself. I know with autism people have things that we're supposed to do and ways we're supposed to act. I personally think that that's impossible to keep up. I mean when you are with somebody that you love, you should be able to really relax and be yourself. And not have to follow scripts of what to say or do or how to conduct yourself. I would just Colette said go where the love is. Go find people that you are

comfortable with. I have a number of autistic friends that we hang out with. She loves them, because she loves their honesty. They bring, you know, no filter to conversation sometimes. That's why I like them too. It is just -- there are penalty of people who like the no nonsense aspects of my personality. I would just say, you know, just find who you are comfortable with. If I had to do it all over again and I were dating, I wouldn't want to be with somebody who already -- who sees autism and is like I don't want to deal with that. I would choose to disclose. If they get with that, they are not worth my time. I don't know. I know it is not easy.

Don't give up. Does that answer your question, Max?

>> Yes, it does.

>> Max just wrote a comment in the chat box that her husband is on the spectrum. They've been together 14 years. So it is definitely encouraging as possible to find someone. Thank you, Hannah, for sharing that.

>> I would also like to add there were some things that we needed to figure out. How to argue in a way, because I'm very literal. If my wife was just telling me something like I'm hurt because of this in the beginning, I would give a 90 bullet point list of why that was not right. No. I do these -- I did this and did this and -- I feel like you are not listening to me. I would pair it back exactly everything that -- she said. And really what -- I had to learn what she was trying to tell me is I'm hurt in the moment right now. I need you to really understand that. And once we figured out how to communicate -- because she also had to recognize I'm very literal. If she's not precise with her language, I'm going to be responding to what she said and we might not even be talking about the same thing. So we learned -- we figured that out. That's another place where the -- can we figure that out before? I can't remember.

>> Yeah. Yeah. It was helpful so just kind of understand her brain thinks this way. My brain thinks this way. We have to figure out a common language. We can address each other.

>> The other questions that came in the chat earlier when we were talking about open relationships and asking about how do you establish the emotional connections beyond the control and regardless of what the rules were and when you set you have a boundary that maybe it is a sexual only part of the open relationship and emotions become attached. How do you help individuals with I/DD to understand that?

>> That's a tough question to answer. I don't know if there really is an answer to that question. The most that I can honestly say about that is -- maybe you can chime in too. Everything around the relationships is going to be based on communication and having those conversations with people. And I always look back at myself and when something was told to me I might not have gotten it the first go around or maybe the information should be presented to a person in a different way. We had a lot of advocates speaking to us today. Someone they could trust and someone who looks like me. You know, that might be helpful. And I agree I'm looking at the question now. It is not always going to be -- it is not always going to be four. You are always going to run into difficulties. But going back to the rules that were discussed going back to the boundaries and talking about things again. The basis is communication. It might take more than one time to come to the conclusion about something. Do you want to add anything or what are your thoughts?

>> What was the question again? I'm so sorry. I was in the chat.

>> Sure. What about emotional connections beyond a person's control regardless of what rules were agreed to in helping individuals with I/DD to understand that. It said everything is not going to be $2 + 2 = 4$. It is a lot to take in. That's a good question.

>> Emotional establishment, you said.

>> Yeah. Establishing emotional connections beyond a person's control.

>> Oh. I think it depends -- you are talking to someone who is not in a relationship. I think it depends on how things are worked out. I think as long as there's a way to, I guess, you know make sure that the -- you know, both of you are okay. It is not some sort of barrier to accepting yourselves or accepting each other. I think there's a way to make things work. And I don't expect people always to be the same even if you are -- like, if you are in a relationship. I think -- people are different. I think it is just one way of adopting to that. I think it is just accepting someone for who they are and making sure that things work out regardless. I think it is just a matter of -- making sure the both of you are okay in your relationship. Nobody gets hurt and nobody -- you know, it doesn't ruin -- hopefully it doesn't ruin the relationship. I think if that answered the question. That's all a guesstimation. But I just -- sorry.

>> I think when I asked the question about why were those myths and why were those things not true someone said relationships are complicated. I think they are. People are complicated. Putting two people together lots of things can happen. And I see that you wrote some more here too around this. But that it is a chose to be in an open relationship. But that sometimes you might be thinking, oh, it is just going to be physical. Then it ends up being emotional as well. I mean that happens -- we can't really control that. You know, that happens. We have to -- this whole thing we were talking before the webinar. It is your body, life, your mind, it is your choice. You get to decide what's right for you. If an open relationship because these things happen like emotional attachment maybe it didn't right for you. That's okay. So, you know -- letting people decide and people are going to get hurt. People are going to get their hearts broken. That's okay. Yeah. I mean -- it is hard. It is hard to watch. But someone might get hurt in the relationships. Then we can be there to help them reflect and think like what would you do different. Do you want to be in an open relationship again? You know, like every experience we learn.

>> I would say also too use it as a learning experience.

>> Yup. And thinking about what you want. And I think -- Sandy said she had a list of what she wanted in a relationship. You know, checked them off. Really knowing what you want too. It will help you make choices.

>> I know we're running short on time. Does anyone have any last-minute questions that they want to ask. Especially of the panelist that took the time to join us on the call today.

>> There was a request -- this should be real quick. Erica, could you just real quickly explain the difference between poll am reand polygamy?

>> Sure. The polygamy piece is more about marriage and how much people a person can be married to. If I was to marry one person, a monogamous relationship. Two people is polygamous relationship. Polygamy is only legal in Utah. With polyamory,

but being in the intimate relationship with someone. Did I clear it up? One is marriage and one is an intimate relationship without being married.

>> Poly means many.

>> And amory is love.

>> Having many loves.

>> Many loves.

>> Not necessarily many marriages.

>> Thank you again to everyone that took their time out to join us today to talk about marriage for the sex talks with advocating series. On the last slide you'll see that we have two more topics to finish out the series. It's been a great journey. The next one will be about children. And the resource list. The slides that we have and the links on the resource list, I'm going to face them in the chat right now. So we can have -- you guys can have the themes. Be on the lookout for the conversation about children sometime in late January 2021. We've got plenty of time to prepare for that. I know a lot of people have a lot of questions about people having children. Be on the lookout. As I'm putting this in the chat box, if you may be want to talk about the resources real, real quick, we'll pass it over.

>> Yes. Definitely. There were a number of resources that we mentioned without the presentation today. And these resources are listed here. They are profoundly normal movie that Erica mentioned is available on Amazon Prime. Some of the others are linked to resources around marriage equality and rights and then some of the YouTube videos that Erica also mentioned. It leads to those.

>> This is Auna from AUCD. I want to thank our panelist. Oh, my God. My heart exploded many times over. I'm going to share it with my wife. This webinar has been recorded. It will probably be available -- check the event page probably by tomorrow. The webinar, the transcript, and also the slides. We'll have those links for you. Thank you all for joining us. Please, please, please be safe. Take care. We'll see you again.

>> Thank you, everyone. Thank you.

>> Thanks, everybody. Take care.

>> Thank you.