

You First Podcast Episode 44: Disabled Marriage and Parenting - Part 2

Keith Casebonne: You're listening to "You First -- The Disability Rights Florida" podcast. On this episode, you'll hear our continued conversation with guests, Heather Watkins and Dom Evans about marriage and equality, disabled relationships in the media, and disabled parenting.

[background music]

Maddie Crowley: Hey, everyone. Welcome back to part two of our conversation with Heather and Dom. We're so happy with the feedback and response from part one of the episode. We're so excited to share part two.

Keith: Indeed. To learn more about our guests, please listen to the last episode. If you haven't listened to it, go listen to that first then come back. Without further ado, here's part two of our conversation with Dom and Heather.

Heather Watkins: Dom, you and I were just talking about that Oscar-winning movie.

Dom Evans: "The Whale." That's another one. I haven't seen it. You did, I think, right? It's scary. Those kinds of representations where you're looking at people. To us, it just feels so reductive. It's like, "That's when you think?"

He has so many layers of identity in that movie. He is disabled, he is gay. Ashton pointed -- Ashton is my partner -- she pointed out something interesting to me. She said, "I'm so upset that they made Brendan Fraser's character gay because he's a straight guy that had to literally just say he's gay."

You don't see any flashbacks. You don't see any...He's just gay [inaudible 1:39]. He had to do nothing, absolutely nothing. This will embolden other filmmakers to just slap a label on a movie and say, "This character, it's like the..." I hate to bring it up, J.K. Rowling thing, but Dumbledore is gay after the fact. What representation did that give gay people?

After the fact, representation is not helpful at all. As a fat, disabled person, the first time I was ever fat-shamed, I was in fifth grade. I was recently looking at those photos. I asked my partner, I said, "Am I fat in those photos?" We have the question was I fat being a "little girl" who was a physically disabled little girl. I got all the misogyny and the fat shaming.

I started gaining weight in fifth grade because of medication I was on. I had always been very tiny. Going from being tiny to being what you would consider just average size was suddenly, I'm fat.

There was a whole bunch of fat-shaming. I wanted to just write this post, like, "You should know what it's like," because people would [inaudible 3:02] at me. We had SeaWorld in Cleveland nearby. You were literally called The Whale when I was growing up if you were fat.

To have a film and have it celebrated and be called The Whale, what message is that giving the fat kids of today who are already being tormented at school? For me, it was also familial. My

mom was always saying, "We got to make you beautiful." She would stand me in front of the mirror and say, "We got to make you beautiful," which it said to me I'm not beautiful.

Then I would see everything I would see. I was chubby and sad. You personify those things so much. You feel those. You embody those things and then it becomes a part of your self-worth. I am in my 40s and I still have issues about my body. I don't like showing my body. I don't like how I look.

Even today, I get fat-shamed and called names. I used to stream on Twitch. I had someone come in and call me wobbler. That's another whale reference. The Whale is not helping anyone.

I wanted to go back and address something with stigma real quick. There is a pretty well-known couple. One of them is disabled. They are involved in YouTube and whatnot. They're constantly having to battle rumors that they're not a real couple. That she's using him. That she doesn't really love him.

I think that goes back to that idea, Heather, where you say if we're disabled and we're not shown, people don't believe our reality. It's taken to the extreme where I've had to try and prove I'm in a relationship to even...I remember going to camp.

Another girl [inaudible 5:08] who was disabled, she had her own internalized ableism because she had a disability where if you looked at her, you could not tell she was disabled.

At the time, I was a teenager. I was dating someone. She's like, "You're dating someone?" I was like, "Yes." She was like, "That's a lie. No one would date you." Even in our own community, we have people saying, "You're liars. No one would want you."

If you get the message, "No one would want you," if you're not in a relationship and you're disabled, then what are you feeling there is what I got to wonder? What messages are we telling single disabled people who maybe are struggling with ableism?

Either other people who are saying, "We won't date you because you're disabled," that external ableism, or internalized ableism, where you're saying, "Well, I don't deserve to date." A lot of us are internalizing these messages too on top of them being there and other people giving the message, where it's creating harm to us internally.

Maddie: I know we've been talking a little bit about the political context of some of these conversations as well.

As y'all were talking about The Whale, it is disheartening that is happening at the same time as, y'all are probably aware of this, the pediatric leadership board coming out with new rules and regulations about helping kids who are considered obese or overweight to get on medications and get involved in surgeries and things as early as age two.

It speaks to this whole narrative that these people are the individual problems, not this systemic look at things that we're taking in this conversation.

That these individuals have to be changed therefore they can be admirable so that they're worthy of marriage, of love, and relationships to be parents one day, instead of them just being fine the way they are, and growing into the bodies that they have, however, that looks like.

I think it's an interesting relevant update in policy that is disheartening for young, potentially disabled folks if they end up acquiring disability, but fatness isn't inherently a disability. It's not inherently disabling. It's medical neglect and things like that that's disabling.

It's interesting as y'all are talking about The Whale and Brendan Fraser getting best actor or whatever he won at the awards. Meanwhile, there's attack on fat children or "obese" children that is happening at the very same time. Yet this able-bodied, cis, "thin" man regularly is now getting lauded and applauded.

All of this praise at the Oscar, of all places, the most surreal award ceremony each year, the same time that's happening as this new change in medical policy. The medicalization of children, fat folks, and disabled folks who are at higher risk of being abused by the system or falling into these systems that we're talking about.

Heather: Also, during the same broadcast, during the Oscars, they talked about drugs like Ozempic, where it's for diabetics, but it's being used, and from what I can see, abused for the purposes of losing weight. I think I've seen some reports where diabetics were having a hard time getting the medication because we have a boatload of people using it for weight loss reduction.

Dom, you remember when we were seeing there was a drug for lupus during the height of the pandemic that people were using and lupus patients were having a tough time getting it? It was on backorder or something.

You see all of these instances where non-disabled folks will use things and create another barrier for disabled persons. It's frustrating because people don't see how...It's like their needs trump the needs of [laughs] so many other disabled persons in so many ways.

They just don't have this understanding of how all of our needs need to be supported. Other areas where the online grocery or the delivery service that we needed to feed our families. So many disabled persons were using service as well. We were getting our groceries delivered.

That got sent back by weeks because of the surge in demand from non-disabled folks using those services during the lockdowns. I'm thinking of different areas. People don't really have a better understanding.

Dom: Something interesting to note about all the praise that Brendan Fraser got is an actual disabled person was involved in an Oscar-winning film this year. Does anybody know about them? Because I do. James Martin, who has Down syndrome. He was in "An Irish Goodbye," which won the Oscar for Best Short.

There was just an article about how they did not name him. It said, "Oscar-winning film features actor with Down syndrome." It was crossed out and it said, "No. Actor that wins Oscar features actor James Martin," because it should say his name.

Heather: That's the thing. They are always downplaying, right?

Dom: Yeah. [inaudible 11:08] fault, we don't get mentioned. If you want to play us, you will get lauded. I say we shouldn't blame this on non-disabled actors because they don't always know, but it sure is hard when they keep doing it over and over because Hollywood lauds them for the same thing that we do that we get criticized for just for existing.

Heather: It's scary too because disability and being disabled is seen as being synonymous with negativity when as you know, it's more comprehensive than that. I like to start, when I'm talking to people about disability in general, just even the dis prefix.

How it's not only not an un but it has a Latin and a Greek derivative that means duo and two, hence another way of doing and being in the world. For me, when I learned that, I was like, "Oh." It just meant so much easier for me to use that as an identity marker and not see it as an indictment.

I think we have to start with the basics. It's old hat for us when we're talking about it, but people who have always seen disability and being disabled as not the thing to be or seeing it as a burden. That's something that sticks with a lot of disabled folks, just that piece that you might be a burden to your family.

We're striving extra hard to be "independent" when a lot of us live interdependent and rely on one another for the success of how our families work. We don't talk enough about that, I think. We're always striving to do things on our own when none of us do anything on our own. We work in this harmonic fashion in getting things done.

While we tell both stories, we don't really get to see those kinds of storytelling being done, which is important because it relates back to how we are seen in general out and about in the community as party goers and people contributing to policy.

When and how it contributes to quality of life decision-making in areas of housing, healthcare, education, employment? How it impacts our socializing, our dining, the way we shop, the way we vote, the way we parent.

I definitely would not be the mindful parent if I did not have a disability, have the experience of having a disability because it made me more intentional about all of my choices.

You are hyper-aware that your safety, for instance. I have to be safe. Then I have to make sure this little one is safe because if I don't, they're going to assume, "Oh, I'm incompetent due to my disability." That's always really scary.

That adds a layer of anxiety and watchful eyes on you in different settings, whether it's in a clinical setting, whether it's in a legal setting, whether you're at your child's school, or whether you're in your own family.

A lot of that stigma and bias comes from the family too, where they're questioning your choices. "You're sure you want to do that? You're sure you want to become a parent? Can you handle this?" It can get really scary and frustrating if you're not well-supported in that way.

Keith: That's a perfect segue for the next direction we wanted to take things in the episode. Going from how the various institutional interpersonal barriers of marriage equality, stigmas

related to that can connect to the topic of disabled parenting or discrimination against parents with disabilities. Let's talk a little bit more about what that looks like.

Heather: I'm glad you segued into parenting. My girlfriend is the biological parent of our son. She had him when we started dating, but I helped raise him. He considers me his dad. I consider me his parent. I did so much.

I helped raise him throughout most of his life, but because I was not his biological parent, even my family refused to acknowledge my parental role. That was one of the ways as a disabled person. He was not welcome at family events, so I didn't go to family events because I was like, "This is my family. You can either accept them or I guess you're not a part of my life."

That was the decision most of my family made, was that they were not a part of my life. I eventually got to see my grandfather who was never like this. It was just he was in his 80s and later 90s, and couldn't travel, and neither could I because I didn't have an accessible vehicle at the time. We didn't see each other for a long time.

When I saw him, he was the only one who was very much like, "Wow, your son's so respectful and kind." He diffused all the lies that he'd been told because he'd been told that I'd been taken away by my partner from my family. That I was incapable of making decisions.

That she had made the decision for me to not appear in family things when it was very much, "No, you're not respecting us. You're not respecting our family."

For me, it came down to a lot of lies I couldn't correct because of accessibility barriers. My entire relationship, my entire parenthood was denied to me because my relationship wasn't "typical," how I had my child was not "typical."

I think there's a lot of disabled people in these non-typical living situations. It's not always easy for us to have children. I physically lost the ability to have children when I had my hysterectomy. I was not given the opportunity to save my eggs because I was told, "Why would you want to? They're diseased. There's something wrong."

I have regrets. I did want to have a child. I did want my partner to be able to have a child with me that way. We were denied that because of my disability. I also think that my son was also excluded. Because of my disability and because I'm trans, we homeschooled him due to his own disabilities.

I design the curriculum myself. I was very active in homeschooling him. I created lesson plans. I created worksheets. I with him one on one. I was very active. To be told that's not good enough, you're not a parent, that can be very demoralizing. We didn't have a support system.

He didn't get to be involved in groups because nobody wanted the kid with a trans-disabled person around them. He faced the stigma of having me as a parent too. The thing is, he didn't care. He loved me. He didn't want people to deny. He would tell everyone, "That is my dad. That is my parent. You're wrong." That helped because at the end of the day, it was all about him.

One of the things I do wonder is did being disabled make me a better parent in terms of I come from a broken abusive home. I was spanked a lot. I had undiagnosed ADHD. I was considered a

problem. I was considered a troublemaker. I was manhandled a lot. I had to teach myself not to scream as a first response. I did. I broke that cycle.

I'm wondering because I physically couldn't grab him, because I physically couldn't spank him, would I have been like that because that's what my life was like? I'm grateful I'm disabled because I wasn't. My first instinct wasn't to grab him, because I couldn't.

I had to break the baser instincts from my abusive upbringing. Being disabled made that easier for me, I think. That's where my disability is a great thing. It made me such a better parent because of that.

[music]

Narrator: Dating with a disability can be hard. I know that because I struggled for years to date somebody with a disability. Having cerebral palsy, I encountered many people not even considering me as a potential partner.

When they did, there were judgements and attitudes. But successful dating and finding a healthy, joyful relationship, it's entirely possible. I finally figured out how to do this. I have been with my husband for over 15 years now.

The key is simply keep trying. Continue to go for what you want, despite the heartbreak and rejection. Believe in your potential as a dating and relationship partner. I know that sounds very simple. It's not.

That's why I created Dating Made Easier, the monthly membership that will teach you how to get the results you want, feel more comfortable and confident dating, and give you consistent support with monthly workshops, brainstorming, and networking. Go to radiantabilities.com/datingresources and join today.

[music]

Heather: I definitely think, as I said, having a disability impacted my parenting style. I often think about the kind of connection I wanted to have with my daughter, who's an adult now. She's almost 30, and I can't believe that. Time just flies. I'm parenting a queer kid. She's out, so I have permission to say that. That added another layer of experience for me.

Just being a parent in general is tough. Being a disabled parent, knowing that you always have those eyes on you about your ability to do so in a way that doesn't impact your kid negatively. I was always mindful of that. Whether she got hurt in my presence.

Would I be able to safely take her places, pick her up, put her down, bathe her, and care for all of her needs while having my own self-care needs? Those always things that I was considering coming up. I was always afraid of going out. I joke about this now, about putting the death grip on her little wrist so that she wouldn't run away from me.

God forbid she falls down or gets hit by a car, then me having a disability and not being able to run after her would have just crushed, as it would any parent. Again, that layer of having a physical disability was tough and crushing in a way.

I think because I didn't have that supportive network that was composed of other disabled parents, which would have been key because you can balance a little bit better in terms of resources, tips, and information-sharing, including frustrations because that's important.

You need to have a supportive network where you can just vent about your experience and have other people find commonality and community in that ability to relate to one another in that way.

I had support because I had our father, my mother, and extended family, but it just didn't match at that time other disabled parents like the way it does now with the groups I'm involved, in particular, the one I mentioned earlier, being on the advisory board of the National Research Center for Parents with Disabilities.

That has just been so helpful in many ways, but not only just for me, but sharing my experience, hearing other people's experiences, and then putting forth resources that prospective parents can even look to and say, "You know what, if I want to become a parent someday, I can do it," because you can hear, see videos, and have other forms of media that a variety of disabled persons are putting out.

I think that is so helpful in that way because I didn't have that. It goes back, again, to representation and seeing those kinds of forms on TV.

I know that we talked a lot about negative media portrayals, but I love the portrayals of a show like "Queen Sugar" by Ava DuVernay. They had one character on their named Aunt Vi who was a disabled person who had a chronic illness. I think it was lupus. Yes, that's right because...

Maddie: Yeah, it was lupus.

Heather: Ava DuVernay has...

Dom: Ava has it, yeah.

Heather: Yes, has lupus. Aunt Vi was a matriarch, a business owner, a love interest. She was just spirited...

[crosstalk]

Dom: She has the best love interest. She had a man that was devoted to her. Everybody needs to get themselves a Hollywood.

Heather: Exactly. When you have portrayals that are informed by writers who are informed, then these storylines will be so comprehensive and meaningful. I just poured over that show every week, like, "Yes, this is what we're looking for."

Then you have other shows like Lolo from "Sex Lives of College Girls." She has muscular dystrophy in real life. I can't remember her last name. Do you know who I'm talking about?

Maddie: Yeah, Lauren Spencer.

Heather: Yes, Lauren Spencer. Dom, have you seen that show?

Dom: I have not, although a friend of mine from college is actually on that show. It is on my list. Renika Williams is my friend. We went to school together. She has been in some of the film stuff that we were doing in film school. It's on my list to watch. The other good one, "The L Word Generation Q," has Jillian Mercado.

Heather: That's right.

Dom: We actually awarded her best representation of our study because her evolution, she started out as a supporting character. She's an international lawyer. She's doing stuff along the border, border law, and stuff like that. You see her going on a series of dates. She ends up dating the trans character.

In this next season, there was implications in one of the trailers. Now I haven't watched it yet, but it's my show to watch for this study.

See, I believe she's pursuing having a baby or something like that, so I'm very excited. What The L Word has done with her character has been fantastic. Another show, "New Amsterdam" featured a deaf doctor, played by Sandra Mae Frank. She literally was the love interest of the protagonist. She had her own interpreters.

She did her own surgeries. I also, I want to see the Ashton, that's Ashton's show. I don't know if it's this one, I think it's New Amsterdam. That there's a little person who's also a smaller supporting character. It's one of the medical dramas, but he gets to be like a nurse or something like that.

I was thinking about how there's a wheelchair-using nurse. I want to say, is her name like Andrea? I want to say her name's Andrea, but...

Heather: Yeah, Dalzell.

Dom: During the pandemic, she was doing all kinds of great educational things about being a wheelchair-using nurse. Seeing disabled people in these hospital settings is a very huge step forward. Sadly, what we're not seeing is kids getting represented.

That was the hallmark of our study was, where are all the children have babies? We found one baby that was disabled out of 1,342 characters.

Heather: This is us.

Dom: It was either that or what's it? "Call the Midwife." It might have been.

Heather: Call the Midwife is good for representation. This is us had a blind baby.

Dom: We might have counted him as a toddler, therefore a child. We do everything based on years and whatnot. Oh no. I remember what the story was because Ashton wrote about it. It was a child with SMA and they...Wait, no. Maybe I'm mixing up my stories. I'm sorry. I watched so much television that if I don't have a reference material...

There was a story about a child where the child was supposed to have SMA or they thought it was going to have SMA, and it didn't or something about that. It was all about how they weren't going to take the child because they thought it had SMA. They had a surrogate or something. Now I have SMA by the way. That's my disability.

The parents decide they don't want the child. The surrogate is all upset about the child and is going to keep the child, but then they find out, no, it's not true, the child doesn't have the disability, so the parents want the child again.

That's the message we basically get about my disability on television is that, if you have my disability, your parents shouldn't want you, but if you don't have the disability then...That sends all kinds of horrible messaging, having disabled children anyway.

Maddie: I wanted to touch on something that Heather was bringing up with. You said the show was Queen Sugar?

Heather: Yes.

Maddie: This really great, is representation become a big theme of this conversation, which is cool and I love it. I'm jumping down in our plan discussion.

Talk a little bit about people who are non-disabled, sometimes look at a person with a disability and go disabled. That person is disabled, [laughs] and that is it. It takes over any perception and wholeness of the individual.

I'm thinking this character from Queen Sugar, some of these other folks you've mentioned that are in relationships, pursuing relationships, maybe they already are in some married or partnership of some kind. Thinking about those things, but also thinking of your own, both of your own lived experiences as people who have been in relationships and now are in more maybe committed relationships.

What makes that great spouse or partner? Or when you are dating someone, we can continue that debunking folks some of those things. Like you mentioned that you said her name was Aunt Bye. How she was a matriarch and a businesswoman and she had the love interests, like the best love interest of the show.

Obviously, these are all very deserving things of disabled folks, but for non-disabled folks, that doesn't even cross their mind. If we could talk to that authenticity for a moment, that would be a great way to bring this conversation, which hasn't all been negative, but to recentering it and talking about these experiences that we want to see more of in film.

That we have in our own personal disabled communities that we see as valid and important and authentic, but to non-disabled people may not be perceived in that way.

Heather: That goes back to that idea of expanding the lens. For me, having a physical disability and being a parent and a caregiver and also a foster parent for my nephew who came into the household as an older teenager with an intellectual disability through the DCF Kinship Placement Department of Children and Families Placement.

These all contributed to me as a person and a parent and a disabled person. They were also interwoven as a Black disabled person who a lot of us we have lived in these multi-generational households, and again, interdependent. There were this tapestry that was happening in all of these details that I like to say contribute to the grand mosaic of who I am.

If I didn't have a disability in thinking about how particular and specific I had to be in my daily life in regards to choices I was making, because I knew that I needed to connect with my daughter in a more emotional building capacity, then physical, because I knew I wasn't that parent that would be out and about in the field and running and jumping.

I was like, I need to create an emotionally intelligent child. We'd be sitting in conversation all the time, very age-appropriate discussions about life, about energy and vibrations, and what her responsibility is in the world and how...I wouldn't dictate that. She would have to be open to thinking about what she wanted to do and be in the world.

In that way, I was creating a blueprint of how to be, but I didn't want to create a mini-me. I wanted her to feel empowered to listen to her own intuition and whatever was pipelined down to her from the creator or the great beyond or whatever you want to call your higher source. I wanted her to feel comfortable in that.

I don't think that might have happened if I didn't have the experience of having a disability. I might have been probably pretty vapid running around out there, being non-disabled and not caring about the little things. Those little details of daily life, what's important to me, and having more of a limited view of the world.

Disability gave me that gift of thinking a little bit further, a little bit more beyond. Thinking about things like when I'm tackling an issue or how a fracture has fissures.

You want to think about all of the ways that a choice might impact something else. Seeing how throwing out that pebble over the pond has ripple effects. I would just be in a meditative state thinking about different kinds of ways.

That might touch on things in the business community. As an artist, as a creative, and how they intersect but how, like what Dom was saying, how they overlap and how life is lived not within a vacuum. We impact one another. I don't get tired of saying that because I want people to understand that what you do affects other people. It will happen in unintended ways.

You want to stop these people from living over here, it's not going to stay static. Eventually, it's going to hurt you. I don't know why you're making those kinds of decisions. If you really understood how each of us can get free, your freedom touches upon that as well.

If we had a more nuanced understanding of disability, in general, that shows complexity, that shows range instead of just one particular kind of disability or how negative and burdensome that is, and do away with these myths and these stigmas, and had a more well-rounded understanding of disability in general, we might get somewhere. I'm hoping.

That's why it's so important to have these kinds of media representations. I'm a Mass Comm major, by the way, through Emerson College. I love having these conversations with Dom about

different ways that media has thrown up the latest backwards as representation of what it means to live with a disability or disabilities in all of their overlapping identities and how they show up in the world.

Like, "Really? They thought of us? Oh, wow." That's because you're uninformed. If you've hired disabled people from the writer room to the directors, to the crew, to post-production, all of this stuff.

Then we would get these representations where people would have this normalized idea of what disability is and wouldn't be so fearful and wouldn't think...The first thing I think would be burden and wouldn't think of disabled persons as undesirable.

It also needs to have a wide range of disabled persons, not just the wheelchair, the white wheelchair user. It needs to have people who have all kinds of chronic illnesses and non-apparent disabilities. It needs to show people of different colors and ethnicities, sexual identity, non-binary persons, trans-persons.

We need to see that range. They need to not have one identity. It needs to be complex because people live complex lives and they have different things that come up, and different things that affect them in different ways.

Sure you know one autistic person. Well, you know one autistic person, that doesn't apply for every autistic person that comes along, or one person with muscular dystrophy who uses a cane, who might also be an amputee, who might also be Muslim. The on leaves different factors provide more relatability.

Also as a disabled person working in advocacy, I love that I get to learn every single day because I get to learn about different kinds of disabled persons in all their many glorious facets. That's important to me as a person and as a person who is developing more of an enhanced way to relate to people and to become a better advocate.

Dom: What makes me a greater partner or a parent? Does it make me a greater partner? I don't know. I don't know if being disabled makes me better. I'm a work in progress. I really feel for my partner because when she got me, I was a mess. I was raised in an abusive household. I had a lot of internalized hatred. I was coming out as trans.

She had a lot to work with, but we made it work, and we're stronger because of it. I think that being disabled has made us think a lot about our relationship and things we do. We're a lot more intentional about what we do and whatnot. I think that being a disabled parent, it's one of those things you roll once with the punches.

I remember that I used to take him to the grocery store, and he's autistic. As Heather said, we got to be careful in public. I remember thinking, "OK, what do I have to do if he has a meltdown?"

There was one day, and kids are kids, and he was being a butthead and I was like, "Look, we got to go home." He was like, "No, I want to play." You know how they have those game systems that they would let kids try out games on. He did not want to leave.

The other parents are literally dragging their kids out by their hair and people are paying attention. If I grab him, one, he's going to have a meltdown. Then he's throwing himself on the floor. That's going to bring attention to us. They're going to be like, "What is this person in a wheelchair dealing with this kid alone?"

That was very the kinds of things we had to worry about. If he had a meltdown, we just instantly left the store if we were able to because it was safer to just go home than to have people question. As it was, I've always been very younger-looking facially. My girlfriend was a young parent. She's a couple years older than me.

We were not very old parents. I was 21. We had a young child. People were always like, "Oh, that's your little brother," because they couldn't fathom that I could even have a kid. It was safer to even pretend that because if they would think that I was his parent, then that could be a risk.

Even denying that this is your family becomes a part of this narrative. You can't be married, you can't be a parent, so what are you? Also, how does that affect your child by identity? I have to be very careful to where that didn't spill over into him.

He really never knew the brunt of what we went through. We protected him. That's what you do as a parent, you protect your child from all of this. That's what it really was for me, was my experience as being a child or being a partner and parent is I don't know if I'm a great parent or partner.

I'm there. I'm present. I'm there if my child needs me no matter what. I think my strength is in being able to adapt in ways that he's needed as a disabled person himself, and also being able to impart a sense of disabled pride and disabled self-love to him that he might not have gotten if he had not been exposed to disability or a disabled parent at such a young age.

Whereas I see so many other young disabled people still, they're struggling with their identity, they're struggling with who they are. What would I want to see to better represent in the media? I would love to see more sexuality represented, more sensuality.

Heather mentioned kink. Things like that. Where's our disabled, very better, well-written, actually BDSM "Fifty Shades of Grey" for disabled people? We deserve everything. It would have to be better because the non-disabled people can have the messy, not good representation. Give us the good stuff.

Give us the juicy stuff because I think that's the thing too, is you feel like, "I can't be sexual. I can't be sensual. I can't be pretty. I can't be attractive." You internalize that because you don't see disabled sensuality. You don't see disabled sexuality.

There's this idea that we're involuntarily celibate or asexual. I want to see intentional disabled asexuality, not forced asexuality. That's where I wish the representation of disability for families and relationships would go.

Keith: If we could just get your perspectives on what your hope for the future of people with disabilities are in this area regarding marriage and parenting. Maybe what steps can others do to help make equality in marriage and parenting happen?

Heather: I think that the steps that we can take are continuing conversations like this, talking to policymakers, maybe talking to the independent living centers, talking to other advocacy groups.

Informing them and also reading more articles and blogs, doing storytelling, and capturing what their lives look like being in partnerships and being parents, I think, are some of the simple, easy ways of getting that information out across the media landscape.

I think that is so important to get that messaging out to begin to open people's eyes and stay their awareness regarding disability representation told from our point of views.

Having all of these conversations and being on different projects composed of majority disabled persons and parents has been so helpful for me as a person, and also as a peer researcher coming up on an upcoming study regarding the pregnancy experiences and outcomes of Black women and Latinas who have physical disabilities.

I'm excited about that because we don't have a lot of that research. There are so many different complexities of parenthood, including the pregnancy experience and maternal health of Black women specifically that have been negative.

We need that kind of exploration that contributes more to research, planning, and family planning. We want to get to that point one day where planning for the future is not so fraught with [inaudible 47:13] . We can easily pick and choose not only in partnership but family planning and having more peace of mind.

Knowing that policy will back us in a way that is not discriminatory based upon disability alone, but will support our quality of life and our choices so that we can explore all of those possibilities and have more bodily autonomy and agency. That's how I'll summarize that. I'll toss it over to Dom to take it home. [laughs]

Dom: Thank you so much, Heather. Thanks for having us on this amazing discussion. I know it went to representation. I'm not disappointed. That was definitely not my intention, but I'm grateful that Heather's taken us there because I could talk about representation forever.

I think that where we need to go from here, the first place we need to go is we need a legislative solution. Social Security is not going to change. Starting with the Social Security, Medicare, Medicaid programs, addressing those, the government programs, we need a legislative solution.

We need the legislators to say that disabled people deserve marriage as a right because there is a codified support already. Justice Kennedy wrote a great support for marriage equality when LGBT marriage was passed. We can use that.

He basically said marriage is an inalienable right afforded to everyone. If you are a human, you deserve the right to marry. We can use that as a basis. Now, disabled people need to be intersectional. They need to be supporting. They need to look at all the anti-LGBT legislation right now. Marriage equality is on the issue.

Tennessee just passed legislation saying they can discriminate against interracial marriage and LGBT marriage. Interracial marriage helped codify LGBT marriage. LGBT marriage can help codify disabled marriage because it is an inalienable right.

We need to use this. Disabled people must support marriage equality rights issues if they want marriage equality to go through for us. I say this as a leader of the movement for disabled marriage equality.

By the way, if anybody wants to get involved, we do have an organization we've been trying to get off the ground called Disabled Union. We need help. We need support with that. If anybody is interested in this fight, they can reach out to me through my Twitter. I'll make sure you have those links and everything.

You need to be contacting your Congress people now, informing them about the issue, teaching them about it. This is a thing they're going to have to be told about over and over again because we know these people. They don't do just things for us. We must bug them until they do it.

We need to get them on the page where they see it's an inalienable right. We have the verbiage. If we reverse what Justice Kennedy said, we're all due. I don't see disabled people supporting LGBT issues. They don't, but this is going to impact you.

They have that poem. First, they came for this part, this community, then they came for this community. That's so true with legislation. This is to where the legislation will influence each other. We can piggyback off of other legislation because the language is already there. That's my thing.

The first thing is legislative. We must have Congress saying we're entitled to the right to get married because then we can go to Social Security and say, "Your requirements are unconstitutional." We need to be able to say that.

Then we have legal precedence for...I hate the word forcing Social Security, but that's what it is. We're going to have to force them to let us to get married. The thing that we need to fight for Social Security with is that we need Social Security to say that our partner or spouse has nothing to do with how we get care or services [inaudible 55:11] .

Depending on how much you're making, even what you're making as a disabled person should not have any bearing on whether you get things like food, health care, or things like that. It also should be recognized legislatively or at least governmentally that it requires more to be disabled in this world. It requires more money, it requires more resources.

I think that's what I want to see legislatively. As for the media, include us. I have multiple television scripts ready to go. Lots of disability rap, lots of marginalized rap. It's not intentional, as in, "Oh, we're just doing it to be diverse." It's, "This just happens to be the story of the people who just happen to be Black or disabled, or Black and disabled."

Gosh, my research sure says that the majority of representation is White, cis, and male. We want more diversity and disabled representation. Tell more love stories, tell more parent stories. That's where it's got to be. Legislatively, in the media, those are where we got to go. Then we can start seeing change.

Maddie: That was a wonderful way to wrap this all up. Thank you both so much for being on the podcast.

Heather: Thank you. Thank you for having us.

Maddie: This was such an awesome conversation. I'm sure that all of our listeners, readers, and viewers are going to love it. Thank you both for being on the show.

Keith: Thank you both.

Heather: Thank you for having us.

Maddie: Thank you, Heather and Dom, for being our guests on this two-part episode. I'm so glad we could share the space with you and learn so much from both of you.

Keith: Definitely. We'll be back with an episode all about digital accessibility on how to make things like social media, documents, websites, and more accessible. Until then, please help us be found by more folks by sharing this episode with a friend or by giving us a like, review, or rating wherever you're listening.

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