

You First Episode 38: The Intersection of Disability and Reproductive Rights

Maddie Crowley: You're listening to "You First," the Disability Rights Florida podcast. On this special episode, we discuss the intersection of disability and reproductive justice in response to the overturning of Roe v. Wade.

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Maddie: Hi, there. I'm Maddie, co-host of the You First podcast, and welcome to our latest episode all about the intersection of disability and reproductive justice.

Keith Casebonne: Hey, I'm Keith, the other co-host of the podcast. Since the overturning of Roe v. Wade, we've seen huge repercussions for people's safety, health, access to medical care, and more.

Maddie: Huge changes, yeah. We know that the overruling impacts people differently depending on who you are. If you have marginalized identities, you experience more barriers to healthcare and, therefore, more barriers to accessing abortion and other reproductive-related healthcare.

Keith Casebonne: To dive deep into how the overturning affects one marginalized community, the disability community, we invited four disabled activists on the show to discuss how this ruling affects them, the disability community as a whole, and other marginalized groups, especially in ways you may not have ever considered.

Maddie: That's right. It's important to bring an intersectional lens to these conversations in order to fully grasp what the repercussions look like after a ruling like this. I talked with Morénike Giwa Onaiwu, Rebecca Cokley, Keith Jones, and Heather Watkins about what this ruling means to and for the disability community.

Keith Casebonne: Please note that this conversation discusses heavy themes and references systems of oppressions such as racism and ableism, infanticide, abortion, and forced sterilization. Listen or read the transcript at your pace and always feel free to pause and make time to take breaks.

Maddie: Yes, the conversation is heavy, so please take care of yourself. With that, let's move on to the episode.

Hello, everyone. Thanks so much for being here. Before we get started, I'd like to have each of you introduce yourselves to the extent that you wish, whether that's your identities, education, work, what you do in your free time, anything that makes you who you are, please share it with our listeners.

Keith Jones: Thank you. I guess I'll jump in headfirst. My name is Keith Jones. Pronouns are he/him. I am the President, CEO of SoulTouchin' Experiences LLC, and I've been a disability rights activist for entirely too long. Thank you for having me on the show.

Maddie: Thanks so much for being here.

Morénike Giwa Onaiwu: Hi, everyone. I'm Morénike Giwa Onaiwu, pronouns are she/her/hers and they/them/theirs. Let's see, I do a lot of things. [laughs] Freelance, essentially but the majority of it is related to disability justice work and so forth.

I am a parent. I live in the Southwest. I will soon have a doctorate. It seems like it's taken all of my life.

I am an INFJ, a vegetarian, and before J.K. Rowling lost her mind, I would say that I was a Ravenclaw. Now I have to find some kind of other way to describe myself.

Maddie: [laughs] Thanks so much for being here, Morénike. I am also an INFJ and a Ravenclaw, so it's nice to have fellow-shared identities on this podcast.

Heather Watkins: I'll go next. My name is Heather Watkins. I am a Boston-based disability rights activist. I am a mother, a blogger, writer, caregiver, and a community builder. I serve on a handful of disability-related boards and projects.

I am also a chocolate lover and a professional daydreamer. My pronouns are she/her/hers. I am a Black disabled woman, born with a form of muscular dystrophy, who uses mobility aids, such as canes, on occasion a manual wheelchair. I also have a bedside companion called a ventilator to help assist with compromised respiratory muscles.

Happy to be here today and join in this conversation to share perspective.

Maddie: Wonderful. Thank you so much for being here, Heather.

Rebecca Cokley: Hi, my name is Rebecca Cokley. My pronouns are she/her. I'm calling in from unceded Lenape territory here in New Jersey.

I am a mom of three, a second-generation disability activist. My mom ran a disabled student center at a community college. My dad ran a center for independent living. Myself and my parents and two of my three kids all have achondroplasia, which is the most common form of dwarfism.

Like Morénike, I was totally a "Harry Potter" fan. I even have a constant vigilance tattoo in protest of the previous administration on my wrist, and I've been contemplating what I do with it now. I am a Slytherin and a Sagittarius.

Maddie: Awesome. Thank you all so much for being here. It's truly an honor to be able to share space with you all. I've looked up to y'all for a really long time, so it's an honor to be able to talk with you about such an important topic.

Before we can jump into our discussion today, it's really important to lay the foundation and touch on why this conversation is not only an important issue for folks who can get pregnant, but especially for people with disabilities with and without the capacity for pregnancy.

The overturning of Roe wasn't just about access to abortion, it's about access to privacy as well. Can some of y'all speak to a bit of this history and background regarding the intersection of disability and abortion, sterilization, medical ableism, sanism, institutionalization, anything related to that history?

Morénike: Well, that's a very loaded question.

Maddie: Yes, it is.

[laughter]

Morénike: Hopefully, we can all chime in and share. It depends on how far we can go back, but I think in terms of, when we look at various intersectionalities and we look at disability, race, gender, there has always been this element of control with regard to our bodies. That's bodily autonomy in general, but in particular related to reproductive rights.

In terms of, who could [inaudible 6:35] ? Who could raise their child, versus whose child was going to be taken away against your will? Would you be able to carry it and did you have the proper nutrition, and means, and healthcare to carry a child to term and/or to raise the child? Did you have control over whether you conceived a child or not? Things of that nature.

Then there is the aspect of...Here we can go back as Buck...Is it Buck v. Bill? I never remember. I'm not saying it right. There is different cases where we can look at people who were forcibly sterilized because they were deemed as incapable of being able to care for a child.

In some cases, very young children whose parents were tricked into signing the reproductive rights away. It's just really awful. This was done quite a bit. We had the No Más Bebés campaign and a number of other issues that happened.

Then even we could look into modern day with a lot of the guardianship agreements in terms of not having the autonomy to be able to have choices about their sexual lives and their ability to parent. Then there is stuff like custody rights, but I know there is a lot that people could share, so I'll stop now.

Rebecca: This is Rebecca. I was going to jump in on what Morénike was saying. As somebody with dwarfism, within our community, we talk about the pride that folks have being able to trace the lineage of their dwarfism back multiple generations. Was talking recently to a good friend of mine who was talking about how he had found out...

Well, A, people with dwarfism and people with disabilities were being bought and sold across carnivals and circuses. We all know that, but he found out that his great-grandmother was forcibly bred. She had something like 15 pregnancies. If the child was born without a disability, they killed it. If the child was born with a disability, they sold it.

It's part of the history of our community that we don't often talk a lot about, but as Morénike was indicating, just that whole conversation around bodily autonomy is one that it never went away for folks with disabilities.

I had my daughter in 2013 and was laying on the operating room table when the anesthesiologist said to my OB/GYN, "Well, while you're down there, why don't you go ahead and tie her tubes? People like her don't need to have more kids."

Maddie: Wow.

Rebecca: We continue to watch this, particularly in the prison system. Most recently we saw, I think it was the State of Tennessee, offered a year off of people's sentences if they chose to be sterilized. Let's be real, they were specifically talking about African American inmates.

You really can't have this conversation and do it its due diligence without taking into account the nexus of race, and class, and gender, and disability.

Maddie: Right. Thank you for that.

Keith Jones: This is Keith. The interesting aspect, as a man with a disability and talking about reproductive rights, we have to talk about the asexual aspect of the way they perceive people with disability [inaudible 9:41] community. First [inaudible 9:43] is sexual beings with any kind of emotion and/or desires. Secondly, how dare we want to perpetuate more people like you in this society?

The history, particularly for those of us who are from the diaspora, you were born in Mississippi going back to my great-grandparents.

If I had come along, then I would have been tied to a stake and used as alligator bait. That's the history of disabled slaves not being useful in the field and then being moved forward to here. We're in 2022, and we were talking about the pandemic about, again, the devaluation of people's lives solely based upon their human condition.

Even to get to the question of do we have the right to reproduce, the question before we even get to that is are we even human in these contexts of these discussions? Which is ironic, because the people who claim to make the decision about our humanity are moving in a very inhumane way.

I think those are the kind of challenges and issues we have discussing how do we get reproductive rights if you don't even see me as a human? You can have that cognitive dissonance between my ability to be seen as a man or a woman, never mind whether or not my physical autonomy is the way that I see my gender.

If I'm transgender, how can I do that? If you're saying sterilization is the best option for you. This goes to education. This goes to the school-to-prison pipeline. This is under the point that this is tragic healthcare. They never ask me about my healthcare, male health.

Never mind the fact there's the stereotype about men never going to the doctor. If I go to the doctor, they don't even see me as a real patient. Those are the kind of things, I think, in those kind of discussions, particularly in the medical field, the social field, and even within the

disability community, with the internal ableism, the racism, and the classism, we have yet to even come to the conclusion that we are all worthy of even making that choice.

Heather: This is Heather. I was just thinking about that, about seeing the devaluation of disabled folks and bodies, and withholding the information regarding reproductive healthcare and not seeing us as sexual beings. People involved with any kinds of sexual activity -- pleasure, beauty, kink -- any of those things that revolve around choice.

Let's consider even the structural access. If you can even get into a doctor's office where medically accessible equipment is, where you can have a mobility aid that can do a complete revolution in the office. Do you have enough room for that?

Are you encountering medical personnel who are culturally aware and sensitive and can provide that responsive kind of care? All of those things, because they don't consider you someone who would even conceive of trying to conceive.

You're not even given all of the information that your non-disabled counterparts and peers would be getting. That's the initial setback. I'm just thinking about all of that as each person was speaking in regards to access.

Maddie: Definitely. I'm hearing themes of how people with disabilities and their access to necessary healthcare, autonomy in their own decision-making is really impacted and entirely controlled by folks that don't hold those same identities as them.

Like you mentioned, that history, and those oppressive forces on folks with disabilities are still present today. These things that you're talking about as having happened in the past are what non-disabled folks or people that aren't familiar with disability-related issues, topics, and conversations, they don't necessarily realize that these things that are supposedly archaic to them are real and happening still today.

On the day that Roe v. Wade was overruled, it reopened the conversation about what autonomy is to everybody and what it means to have autonomy of our body and choices. That autonomy at the end of the day isn't awarded to disabled folks in the same way as their non-disabled peers, even while abortion and pregnancy-related healthcare was more protected.

Can you speak a bit to what that might look like in present day, now that Roe has been overturned, and how that could further impact the disability community? I know some of y'all touched on your experiences before Roe, but now that Roe has been overturned, what does that look like to you? How are you engaging in understanding what that looks like?

Morénike: I was just going to say that there's an article that came out not long ago -- I think it was a couple of weeks ago -- that actually highlighted how some of this has occurred, has happened. I'm here in Texas, which unfortunately started this horrific landmine toward what we're dealing with now nationally.

There was a story about a husband and the wife. The wife was disabled. They were expecting their first child, and they opted to bypass the screenings, because they said they didn't care if their child has a disability or not. They were just really happy that their little girl was on the way.

Then it turned out that her water broke really early, she was compromised, and this happened very early in the pregnancy. I think she was 24 weeks, or 16 weeks. It was very early, to where the pregnancy was not viable. They tried to see, even if they had her on bed rest, if their child would be able to survive.

They made the heartbreaking decision that they were going to have to end the pregnancy for the health of the mother and the child. In the state of Texas, because a heartbeat had been detected, that wasn't allowed. Even though they had proof of illness, infection, as long as they could hear a heartbeat, they would allow any...

Regardless of what her obstetrician said and everything else, the hospital refused to let anything happen. She was discharged, had to go home, and her infection had to worsen to the point where it was just this horrific smell, and to where they finally admitted her, and then forcibly were allowed to, had an ethics committee meet to allow her to terminate her little girl.

It was just traumatizing and heartbreaking for this family, and it was just heartless. I just think about this, and how this could be -- not could be, will be -- people's daily reality.

Keith Jones: This is Keith. I think one of the things, when you talk about that, Morénike, and going back to what Heather and Rebecca had said earlier, as a father with three daughters, when the decision came down, to flat about it, I'm Black in America.

I was like, "I don't why y'all getting mad now. They've been at this for 50 years. They've been trying to do this for 50 years. They never wanted this to happen." From the social construct, I was upset, because I'm the father of daughters.

We are irrational when it comes to protecting our children, so I just was like, "I don't know if I have enough bail money if somebody's wanting [inaudible 17:26] to think something crazy."

Heather: I've got you, Keith. I got you. I'll put some in.

Keith Jones: OK, I got you, I got you. It also was in this body autonomy discussion, particularly when it comes to the Roe v. Wade decision and decision-making. There is no discussion of males in the process. There's no discussion. How do you carry that psychological burden of, "OK, now, on this side of the equation, as a man, I don't have the control?"

If she wakes up tomorrow and says, "I don't want this baby," my emotions are whatever, but I do not have that control. How do you live with that kind of trauma or that kind of mental baggage? For me, the duplicity was, as a parent, seeing this and saying, "How can I give my daughters the free and fair access to anything in this country?" Particularly, because they're Black girls.

It wasn't like you were behind the 8-ball before. Now, you're not even on the pool table. For me, I guess now it's that -- I'm trying not to be too pessimistic, but -- it was this great White woman awakening, like, "Lord, Jesus, they're coming after us now." I guess that kind of weight is what I'm hoping we can push past that, but I don't know.

Maddie: Morénike brings up a really important side effect that's happening. The intersection of race, disability, and gender, and how these conversations are not inclusive at all. It's very White women-centric. The folks that are being covered in the news as far as protestors and speakers,

and folks that are going to be impacted the way that the bills and laws are not comprehensive to the full effect that these...

Folks in large-band communities are going to be impacted by this. Morénike was talking about the fact that now, in a post-Roe world, without abortion and proper medical care protections for things like miscarriages or ectopic pregnancies, we're already seeing complications of difficult pregnancies putting people's lives at risk.

How does this medical ableism and Roe intersect? How does a pre-Roe turning and now post-Roe world collide, and how do we still advocate for accessible and equitable healthcare for folks?

Rebecca: This is Rebecca. In the dwarfism community, when both parents have the same kind of dwarfism, it ends in a terminal pregnancy a quarter of the time. I'm the only one that made it in our family. My parents had two babies before me that had double-dominant diagnoses and one after me.

It is just a fact of our culture that it's something that we often talk about. I think the lens on this, that folks aren't often thinking about when they're like, "Oh, you can just go to another state," is, A, because of [inaudible 20:34], people with disabilities that are on Medicaid cannot use their Medicaid dollars to be able to access this.

B, we know that, for the average household with a person with a disability, we're talking about a minimum of \$17,000 of additional annual expenses for that individual that are not covered by insurance. If you're having to travel out of state, do you have accessible transportation if you need it? Do you have somebody to come with you? What does that mean? What does that look like?

Even if you do, as we saw in the case of the woman who reached out to Planned Parenthood in New York who was a wheelchair user, she was still denied an abortion, because they literally said, "We don't know what to do with you." The existing infrastructure wasn't accessible to begin with.

I give a lot of love to Laurie Bertram Roberts, who runs the Mississippi Reproductive Freedom Fund, who is a queer, Black, fat, fem, disabled chick, momma, who has been talking about this specifically in the reproductive space for decades.

Both her and Renee Bracey Sherman have been talking about the impact on women with disabilities and have largely been ignored when bringing this into the conversation. I think it is one of those things where people don't like to showcase us on this issue, meaning people with disabilities, because we make it too real for them. We don't have the luxury of not having this conversation.

Morénike: Yes. They also don't like to showcase us, because we are their excuse that they use to try to say why they would have reproductive justice in the first place, like, "Who wants a kid like us?"

Heather: This is Heather. I was just thinking about certain examples in terms of ectopic pregnancy. I had an ectopic pregnancy, and I didn't know that. So many of us are followed by high-risk, in the category of high-risk pregnancies. It was confirmed that I was pregnant, but after having a transvaginal ultrasound, it wasn't detected, and I was sent home.

I had concerns. I'm talking about it, and I'm still being sent home. I'm thinking about all of the disabled BIPOC folks who have extra concerns, but they're hushed away, because that believability factor, or the pain management, or drug seeking from certain other questions that people have regarding their bodies at that time.

Long story short, after I was sent home, and I was told to come back the following week, my pregnancy ruptured in my fallopian tube, and I was rushed to the emergency room and into emergency surgery. I lost my left fallopian tube, and I could have lost my life.

I think about that was before the overturning, and I'm in Massachusetts, where the governor has vowed that abortion law would be safe and legal. I think so many other states, obviously now, don't have that option.

Again, then we're talking about the believability factor and forcing people to endure an ectopic pregnancy, which will cost you your life, because you cannot survive an ectopic pregnancy without that removal, as I understand it. It's so infuriating and frustrating.

Maddie: Yeah, I'm hearing the frustration in y'all's voice, and just the deep-rooted distrust and lack of care from the folks that are in charge of the decisions and have the power to make these things more accessible and better for anybody who can get pregnant or people who would be impacted by someone getting pregnant.

It just seems that every step of the way, from advocates to doctors who have marginalized identities, whether that's a racial background, a disability, or the people themselves, how they're just shared, who is valued, whose voice and what community is believed, legitimized, taken seriously, I think, is a really important thing for folks to keep close in their minds when we continue having this conversation.

I want to go back to something that Morénike brought up, which is this escape clause when it comes to abortion. It's like an abortion loophole, for lack of better words. When people are talking about abortion, and then suddenly we start debating disability and what quality of life means for someone once they're born, we recognize that this is ableism.

This is ableism in action, and people without disabilities think people with disabilities have less quality of life. This idea causes people who could potentially give birth to someone who is screened to have a disability or likely to have one to terminate that pregnancy, just based on that.

How does this impact the disability community in both big and small ways, and how does this gap in conversation about abortion still exist to consider abortion more aptly or more seriously when a child is potentially going to be disabled?

Keith Jones: This is Keith. That goes to, again, what everybody has said. It's who's valued. You talk about the art, and I think Morénike talked about it at the beginning. How far back are we going to go? We don't even have to go that far back, considering the Ugly Law.

I was six when the Ugly Laws came off the books. I'll be 53 in about a month and a half. It's one of those things, when you talk about from the perspective of who's valued, we have to remember that the value in the society is based upon how much can you do with your hands? How much work can you do?

If you talk about agricultural work, you talk about migrant work, you talk about labor, particularly, again, using that thing that I said in the beginning, if you weren't valued as labor, you are not valued. How are we still skipping over this discussion?

We are still having this discussion, because people still look at us and go, "Oh, my god, you're such an inspiration. I don't know what I would do if I woke up like you." I'm like, "I'm glad you didn't wake up like me, because you suck." It's the discussion of this is the morality thing, because people fall back on their religion.

They fall back on their culture. They'll fall back on their training. The conversation will change once we start valuing humanity regardless of how we show up.

Maddie: Keith, I want to build on what you said, because it really informed a lot of my grant-making when I came to Ford. When coming to a foundation in the middle of the pandemic, I don't know about y'all...Actually, I can assume that I know where y'all land on this, but I know I was sick to death of watching non-disabled people, non-disabled doctors on TV talking about the pandemic.

Rebecca: When I came to Ford, one of the things I wanted to fund -- and we actually just launched it yesterday -- is Docs with Disabilities, a national membership organization for healthcare professionals with disabilities. It was because of conversations that I had with my OB-GYN, who still holds it down for me so much, and is still in DC.

I don't care. I'm in Jersey. I'll hop the train to go see her, because you all know. You have a good doc, she's my medical friend for everything. I've given her name and number out to everyone in the disability community, so getting an appointment's hard now.

In conversations with her, it really struck me, and even in talking to other friends of mine, particularly doctors who came through COVID, and have now either frankly PTSD because of the COVID experience, or are now self-identifying, and then seeing the leadership of folks like Andrea Dolezal, Justin Bullock, Dr. Feranmi Okanlami, Javier Lopez, and so many others, and being like, "No, these are voices that matter."

Part of how we shift this conversation is an infiltration agenda. How do we help support doctors and nurses and genetic counselors with disabilities? When I had a sonogram with my youngest -- who I lovingly refer to him as boringly average, because he's non-disabled -- the sonographer was like, "Oh, everything is measuring normal."

I was like, "But his arms and legs are so long." They were like, "No, that's on-point." I was like, "Am I looking at a spider? What am I going to do? What kind of life can this child have?" I'm like, "His brother grew up around presidents." I'm like, "What kind of job can a kid like this have?"

I was like, "Is he just going to be around to be a duster? Can I have him go work retail and hang up clothes?" My OB is on the floor dying. He's like, "Becca, stop it, you're killing me." The sonographer was like, "Oh, my god. Oh, you're kidding."

I was like, "Yeah, I'm totally kidding, but what am I going to do with this kid? He's going to eat me out of house and home [inaudible 29:45] ." I was like, "The superior dwarf baby is more cost effective than your average babies." Thinking about how do we change the conversation and how do we infiltrate where it's happening?

I've been actually really pleased to see the growing... We saw disability organizations for first time really issue statements on the [inaudible 30:08] . Honestly, I'm also going to acknowledge that, do you know why it happened? Because we have women in leadership.

Little People of America, my organization, decided we are going to have a town hall where we are going to listen to everyone's complex feelings about the issue, because it's run by men. I do think that there is, how do we challenge the structures within our communities, and how do we build new power structures to facilitate how we have these conversations?

Heather: I was just thinking about what Rebecca was saying, challenging people, but then we have people in leadership like the VP, who was just talking the other day and giving pronouns and visual descriptions. You have people in Congress making fun of that.

I'm thinking of the tweets I've seen talking about, "Why is she giving visual descriptions and using pronouns?" That was on July 26th, the Americans with Disabilities, they [inaudible 31:10] talking about reproductive rights, and specifically Roe v. Wade overturning and how it will affect disabled persons.

We could have all these conversations and have people in leadership, and all of these different levels, we have to be dual-purpose, speaking and moving and constantly trying to get the message across, but fighting people on the same lateral level.

It always feels like we're being thwarted in some way. I was just thinking about the work that is continuous that doesn't have to be so hard, if you can get these people to understand, recognizing you and all of our glorious granularity, as I like to say. Going back to that valuing us as a whole.

It's just so infuriating, tiring, and frustrating. It just seems like it's unceasing. I just wanted to add that in really quickly.

Maddie: Some of you have mentioned having kids. Some of you are parents. Some may want to be parents in the future. Can you talk a little bit about your experience in treatment as parents with disabilities and how the overturning of Roe may impact you and how you see this issue potentially in a new light know?

Keith Jones: [laughs] I'm sorry. I'm just giggling, because as a parent, earlier, when we were talking about the kids being messy and things like that, as a father, it changes my perspective. As a son, it changes my perspective.

I think, even though as a Black man in this country, understanding how Black women and women of color, indigenous women have been treated, and how it seems that the only time those fears about their concern, their healthcare is only tied to whether or not White women are involved.

The frustration for me as a parent raising daughters was and is how do I instill body positivity? How do I get them to dodge colorism? How do I get them to dodge misogyny, [inaudible 33:27] ? Then on top of that, living in society, they're literally saying, "The thing that you exist in, you can't have control over."

As a parent, particularly as a parent with a physical disability, nobody ever thinks that those are my kids, anyway. I'm completely dismissed from the entire discussion. Going back to, because when we went in to find out that we were having twins, which is crazy, we went in, and their mother laid on the table to do the ultrasound.

The doctor looked at me and said, "So, what the hell happened to you?" Those kind of encounters...When I look at this post-Roe era, it's not really post-Roe. It has always been this way. It's just now it's more prevalent, more pronounced, and the people who have access to megaphones are talking about it.

As a parent, my concern is that we're in the state where they've taken sex ed out of schools. They're taking books out of school. They're saying in Texas that slavery was involuntary relocation. We're having those kind of discussions. How do I talk about having my daughters make healthy reproductive choices and just being able to understand that your sexuality is OK?

That's the challenge.

Maddie: It's such a focus now on such a White-centric movement, now that Roe has been overturned, but that wasn't the situation in reality for so many people, like you mentioned. Just because this is now a reality for more folks, and questioning people's access to healthcare and equitable healthcare, these have been issues for generations, and since the birth of this country.

Acknowledge not just how it's impacting us now, but just how it has always been, from the displacement of indigenous folks until today. I wanted to give space to other folks who might want to talk a little bit about their experience as a parent with a disability and how being a parent with a disability has been for you.

Heather: This is Heather. I just think about how so much of our decisions as disabled persons are side-eyed and second-guessed, and that would extend to parenting as well, or choosing to parent. Even within our own families. Even if you have a partner who is supportive, let's suppose if you break up.

I was taken to court regarding custody rights, and he was trying to use my disability as the sole factor of gaining custody. No other evidence of mistreatment of my child, neglect, or anything like that, but like, "Oh, I think she'd be better off with me."

Luckily, in my case, it was thrown out twice, but I think about all of those kinds of things, where you need a lot of support. Sometimes, that doesn't come from your own network. You have to seek out outside networking sources to support you in things like tips and resources and life hacks and frustrations.

My experience as a disabled parent was fraught with so much fear and anxiety, because I was trying to keep myself physically safe, and also making sure that I didn't make any "mistakes" raising my child, because I knew there was going to be that scrutiny. "Oh, we knew you couldn't do it," because I had a physical disability.

Luckily, none of my fears came to manifest, but it was just, had I been supported across the board in that way, or had a support system that was composed of other disabled parents, then I could have alleviated some of that internal terrorism, and looking at myself through a non-disabled gaze, instead of one that was more meaningful and better-informed from other disabled persons and parents at that time.

That's why I'm really glad that all of us here are on the advisory board of the National Research Center of Parents with Disabilities, because that was sorely needed back then, that kind of support. We all come from diverse backgrounds and have different disabilities.

That has informed not only my own self-awareness, but my advocacy skills as well. That has been my parenting experience. I don't think I would have been the kind of person I am today or the parent I am without having had my disability, because it's contributed to the way I see the world, my worldview, my personal perspective, and just other people in general.

I am a more mindful person and have those kinds of intentions, because I wanted to build a blueprint for my child. Not for them to be a clone, but just have that nod, like, "This is what my mother's doing. This is her example," and feel confident to go out and conquer the world in the way she sees it. That has been my parenting experience.

Rebecca: I would just say, this conversation is really radical in itself for the disability community. I think generations prior to ours didn't have...Most folks weren't parents. Most folks were fighting to get out of institutions, their families' basements, were dealing with different forms of incarceration.

I remember talking to somebody once and them being like, "Yeah, I always wanted to be a mom, but I was fighting to be able to get a job, so that didn't happen." I remember, even when my husband and I started dating, and I brought him down to Florida to a meeting of the Florida Youth Council.

I had planned to take him to Disney World for his birthday. He came in the room at one point, brought me coffee or something, and then left. All the young women in the room were like, "Who was that?" I was like, "Oh, that's my boyfriend, Patrick."

It was like a needle went off the record. They were like, "You have a boyfriend? Are you going to get married? What's that like?" That's literally like taking a beat, having a conversation, and being like, "No, you have the right to be in a relationship. You have the right to find someone to love."

They all talk about how they watch us date, they watch us get married, they watch us have kids, and how shifted their expectations. I remember meeting all three of the people I'm on this call with. The small talk we had at the beginning, where it's like, "Oh, my gosh, these kids are driving me crazy. I might kill these children."

[laughter]

Rebecca: Totally kidding. There is no violence in this household. As Heather said, that's also, you have to make that clarification, because we know in over 20 states, you can lose custody of your child solely on the basis of a disability diagnosis.

You have to be at a heightened state of insecurity in preparation for how you handle things, the non-disabled parents.

Heather: This is Heather again. I'd just throw in the fact that, in so many communities of color, we live interdependently. In my household, not only was I raising my daughter, I took in my nephew, who has an intellectual disability.

He came through by way of a kinship placement through the Department of Children and Family Services. Then, at the same time, I was caregiving for my father for the last 11 years of his life. Each one of us was helping each other out and relying on one another to get our needs met.

While I was managing my father's healthcare, he was helping me out physically, maybe when we go grocery shopping, or helping around the house and things like that. Each person had a role to play. I think it's just something that needs to be highlighted when we're talking about people of color and their complexities of having a disability.

It's all of these dual roles you play in terms of home management and your own healthcare. So many of us are in need of care, caregivers and community builders all at once, and nobody really thinks about it in that way and having a disability as contributing to the community.

I think it's due in large part to not seeing those depictions across the media landscape. When Rebecca talks about her dating experience and people asking her those inane questions, would they ask them less if they saw that in media in meaningful ways?

Where we're running households and running board meetings, and we're partygoers and planners. Then you see us with storylines that are fully developed, because the writers are disabled. They're informing those storylines. I just wonder about all of that stuff.

I just want to add also, how would we have seen ourselves in terms of budding self-awareness at young ages if we were taught about this in grade school, taught about disabled icons like Fannie Lou Hamer, like Sojourner Truth, like Harriet Tubman, like Brad Lomax?

How would that impact young minds in building their own self-awareness and newly disabled persons? I think about all of those things and how they impact the way we conceive and conceptualize disabled persons in their entirety.

Maddie: Heather, I think that's a really great transition. I know we've touched on education and access to equitable education and information about our bodies and sexuality and education when it comes to being informed about what that can look like when we become adults, and how people with disabilities have been denied the same sex education and information about their bodies as their non-disabled peers.

I feel like, like Keith mentioned, there's this culture war going on right now, not just about sex education, talking about our textbooks, and anti-racist theory. There's all of this compounding all at the same time in our present day.

I just want to turn the conversation to talk a little bit about how has this conversation about sex ed and protection left disabled folks out in the past, and how can we shift that narrative to protect our youth with disabilities and educate them about consent, protection, violence, and healthy relationships, and show them the representation that they need in order to have healthy, loving partners, relationships, whatever in the future?

Morénike: I really agree with everything that's been shared thus far, and I really wanted to hone in for this question on what was already discussed about the representation. I think that it's hard for someone to want to be what you can't see, what you don't [inaudible 44:49] .

Yes, and with regard to disability, either there's the infantilization, where we're just adult bodies, but we're really kids inside, and we need to be protected, or we have no desires or interests. Or there's the flipside, and we're just really wanton.

There's no in-between. It's these extremes. I think about movies that I saw growing up, that the few that depicted anyone who had a disability as being in a relationship or being a parent.

I think about, first, a lot of these were played by people who were non-disabled, but aside from that part, which is a conversation in and of itself, there were situations like "The Other Sister," where the mother was discouraging her daughter to date another person who had ID, because she thought he, "couldn't take care of her daughter."

Then there were things like "I Am Sam," where basically it was a transactional sex arrangement between him and someone who had unstable housing or things of that nature. I just feel like, or it's a situation where there's savior situation, where it's this person who falls for the disabled person with the heart of gold. It's just disgusting.

I'm like, "We are just like everybody else. We've got jerks among us. We've got [inaudible 46:07] among us. We've got good people. We need to be depicted as such." If people have any wonder why there's a lot of confusion amongst youth today in terms of disabled and not, in terms of their sexuality or what is acceptable and what it is, it's because of the mixed messages that we're sending in society and the lack of representation of humanity overall.

I just think of how powerful it would have been for me growing up. As an adult, it's almost like I started to see things of the real world. I started to realize, "Oh, wow, this teacher had a hearing aid," or, "This person had a cane, and they made it seem like it was a cool thing, like for style, but it was for mobility."

Because of ableism, people downplay these things. If only people could have seen the other people around them who have disabilities as well, and how rich it would have made everyone's lives, whether they had a disability or not.

Keith Jones: One of the things that, if I dated, they used to go, "Oh, you should date her, because she's in a wheelchair, just like you." Wait, but I don't like her, and she don't like..."Come on, baby, I'm kind of hot." [laughs] It's that, what you just said.

It's that, going back to how do you...I never saw myself on TV. My mother told me two months ago, a couple years ago, we had a discussion, where they asked her what was her expectation me. She was like, "He's going to graduate high school, graduate college, and get the hell out of my house."

They sent her to a psychologist and a psychiatrist, because they thought she was unstable. Then when I hit puberty, I guess they thought, they were like, "Oh, it'll pass." No, it won't. I like what I like, but you are never seen as having those.

Even with kids, people go, [gasps] "You have children? Wow. How did that happen?" I'm like, "I really don't have the energy to explain the nuances of this." At this stage of the game, we're still asking people with disabilities to impress us with just being human.

My frustration is that we have allowed people to intellectualize their hate and their bias and end up actuated through policy and weaponize it through discrimination. That's my problem with not being able to give my kids, my daughters and my sons, those kind of, be proud about your body, be proud of who you are. Love who you love, irrespective of that.

If you add a disability to it, people will say, "Well, maybe you don't really know what you're getting into." I think that, for me, is the frustration about teaching sex ed, teaching good things on TV, having these discussions about what is it like to be a child with a disability who wants to transition to the gender that they feel they are.

Then you have to go through that whole process of where people actively try to tell you that your emotions are not what they are. That's what so maddening about all of it.

Rebecca: Keith, this is Rebecca. I was laughing about your, "Oh, you need to date that person, because they're disabled, too." To me, I remember in junior high, there was another girl with a disability in my school, who was a total B. Not a nice person, is still not a nice person.

I remember literally the principal, the vice principal, the counselor, and like three other people calling me in and being like, "You should be friends with her." I was like, "But she's not nice." They were like, "But she's not nice, because maybe she hasn't had friends before."

I was like, "That's not my job." To me, hearing you even talk about that, it is, as Morénike and Heather were talking earlier, it's that additional extension of bodily control. It's a way that society tries to control us.

I can tell you, when it comes to the sex education conversation, I make my 11-year-old son really uncomfortable, because we all know 11-year-old boys. They're all about, "Can I shock my mom?" He'll walk in the room and be like, "Penis." I'm like, "OK, so, let's talk about it. Want to talk about testicles, too? Let's go." He's like, "No," and he'll run out the room. I was like, "No, we're going to have this conversation."

I grew up in San Francisco in the early '80s at the height of the HIV epidemic. I watched friends of my parents die. We are not going to grow another generation of sexual ignoramuses. We are going to make sure that you understand how your body works.

Every time he says, he'll try to shock me with something and be like, "Hey, Mom, what's 69?" I'm like, "OK, let's talk about this." Turns bright red and runs out the room. I'm like, "Look, this is never going to be a space where...It's going to be awkward. I will have the conversation with you, because you will be informed."

We actually just bought a whole, a couple of different books for him. I put them on his bed, and I was like, "All right, before you come to me with your next question and try to shock and awe me, take a look at the books, and let's have a conversation."

It's because we know that our kids won't get it in school. As people with disabilities, we're taught that we don't have the right to consent. From the time that we're little kids when it comes to doctors, when it comes to teachers, "Oh, make sure..."

You're going to have this person wipe your butt for you. You're going to have this person make food for you. Do you have a decision-making voice in those conversations? No, often, you don't. How do you grow that skill set, and how do you grow that skill set in our young people to be able to be like, "No, if you don't like the person who cuts up your food, you can fire them, but what are the consequences if you do?"

How do we have those very real consent conversations as early on as possible?

Heather: That's so true. This is Heather. I was just thinking about the time when I was 13, 14 years old, and I would go to the local public health center here in Boston, the Mattapan Community Health Center, shouting out to all the local public health centers that give family planning education.

I would see a Black woman by the name of Nyna who answered all my questions about reproductive healthcare. I remember being in a little classroom with other young Black women sitting around the table that had leaflets and pamphlets and anatomical uterus and vaginas on the table.

We're just asking questions, and they were answering in a very non-judgmental way. It was community-based care that was culturally competent by a provider that looked like us. Before we get contraceptives, you had to be educated about it.

I just really appreciated that at that time. Years later, a friend said to me, "Oh, I just remember us going down to the health center, and you were just so responsible about learning about your body and getting educated about it." I had completely forgotten about it.

When she reminded me of that, I was like, "Wow." I had to be proactive about learning the history and making these kinds of decisions early on. We weren't getting that kind of education in school. I was just thankful for that bit of public healthcare that was locally based.

Maddie: Yeah, I'm hearing from your early childhood to your parents, to now, being able to provide those resources and that care to your children, I'm just hearing these strong themes of the disability community and other communities that you're a part of, just the importance of community care, respect, love, and providing access for those folks, because it's not concrete, and definitely not a given from the folks that should be providing those things.

It's really important that we continue to have these conversations with our youth to ensure that they have the proper knowledge to protect themselves, make informed choices, and also know that, if they have disabilities, that they have the same rights, access, and choices to love and care and have sexual relationships and things like that as their non-disabled counterparts.

Thank you so much for all of your vulnerability when talking about this. I wanted to just name that all of these issues that we've gotten to discuss today are incredibly heavy. I thank you a lot for your honesty when talking about them. I want to wrap up our conversation with a bit of futurism and hope where we are now and what we've seen in the past.

My question for you, and maybe we can all touch on this before we head out today, what does a liberated future where people with disabilities have full autonomy of their bodies and choices look like to you, and what kind of steps do we need to take to get to that world?

Morénike: This is Morénike. I would say that, truthfully, it's hard for me to envision, because it looks completely different than anything that I think any of us have ever envisioned. I think that it starts from valuing humans, period, regardless of their "contribution" or lack thereof, which is ableist in and of itself in terms of a person's contribution.

It depends on whether they're disabled or not. The things such as, I think a lot of things that are well-intended, like the right to die, is it really us wanting to die, or is it people thinking that we should die? Early sterilization, or shaming people for having sexual desires or needs, or all of those things, I think that it looks like a society where we actually think about the way things are designed and processed and who's involved, and that we're looking out for everyone's needs.

Where universal design is not just a nice phrase, but it's something that we use as our minimal standard.

Keith Jones: What do I see the future? I have hope. I have hope, but it's a hope rooted in reality that the work is exceedingly hard to get people to undo their chosen stupidity, to let go of the rationale that they have for hating how our community shows up.

That's work. I can't convince a White person to get over their white fragility if their white fragility is based on them needing to be better than me. I think in terms of where we can go futuristically, even we are in the future now with this conversation.

This is groundbreaking. This leap forward of acknowledge that we actually are in reproductive rights fight, for the kids, I guess we are the ones we've been waiting for, is probably the best way that I can say it. Saying that teaching my daughters, teaching our sons, showing them, their friends seeing us as active parents, like Rebecca, like [inaudible 57:22] that we, the human condition is not definitive of your humanity.

Your humanity is definitive of how you interact, engage, and uplift your community. I think that will be the beauty of it. Once we get rid of people, once we break the psychology of, "We can only vote for this person, because they are here, or we can only do this," we just have to be ones to do it.

We have to be the agents of change in order to be better. I am hopeful, because I know the people on this call.

Rebecca: This is Rebecca. I want to be Dick Clark. I want all disabled people to move about the world with the unencumbered ego and freedom of a rich White man. I think about when Dick Clark had his stroke, and about how when he came back for New Year's Eve, you saw all the ableds on Twitter being like, "We don't want to see that dude on TV. Why does he talk like that?"

The ableism was rampant, and a bunch of us pushed back and were like, "Dick Clark owns New Year's Eve. He gets paid whether or not he's there. How much do you want to bet that entire set is completely designed...It's not designed for Seacrest. It's designed for Dick Clark. The production company is called Dick Clark Productions.

The fact that he knew he was able to still contribute, and he wanted to be there. It was his gig. There's no way in hell the network would want to...Let's be real, the network wouldn't want to lose the money if they fired him, and he sued under the ADA.

To think about what it would be like to move about the world with that freedom, with that, "Oh, I just go places, and as a disabled person, I don't have to look up ahead of time, is it accessible. I don't have to look up ahead of time, does the bathroom have a step. I don't have to plan to be discriminated against by Uber or Lyft on my way out the door."

I can imagine what that would be like.

Rebecca: This is Heather, yes. To all of that, where we have to think less about how we move about, a future that is medically accessible, economically accessible, structurally accessible, and requires far less thought and anxiety, and this internal terrorism that we have to go through on a daily basis when planning our day, our lives, our schedules, and how we want that to look like.

I think about all of that. Like Keith, I have hope, even though it seems like a marathon in terms of fighting for our rights and volumizing our needs and the kinds of care we need to live our lives and be a part of a grand mosaic. I just think about all of those little pieces that construct

who we are and how much we are deconstructed by all of these outside factors that are so unnecessary, but also prove very violent to who we are.

That's my hope is that they eventually come together, so that we can move forward as one.

Maddie: It just sounds like a future that's so radically different from where we are now, but that's what it has to be for a society that's built for all of us, and cares for all of us, and values all of us. I think that's such a great and wonderful send-off.

Again, I appreciate you all being here so much and sharing not just your knowledge, but your lived experiences and your insight with me and our listeners, and again, thank you so much for being here today.

Keith Jones: Thank you for having me.

Rebecca: It was so good to be in space with you.

Heather: Yeah, I loved this. I loved this. I appreciate this conversation and all of you.

Maddie: Thank you all so much. Thanks again to Heather Watkins, Keith Jones, Morénike Giwa Onaiwu, and Rebecca Cokley for being on the podcast. We really appreciate their vulnerability and care when talking about such an important and timely topic.

Keith Casebonne: Indeed. If you want to learn more about this topic, we will have links to more resources and information about our speakers and the topics in the show notes. All speakers are active on social media and are great leaders in the disability community. Make sure to give them each a follow.

Maddie: Definitely. Also, be sure to subscribe to the podcast, so you get notifications about new episodes and stay up-to-date with our show. We're on all podcast platforms, Apple Podcasts, Spotify, Google, Amazon, YouTube, and so much more. You can also find us on our website at disabilityrightsflorida.org/podcast.

Keith Casebonne: Stay tuned to the next few weeks for our new series, "Voting with a Disability," where we talk to people about election accessibility, voting access, disability voting trends, and more. Thank you for listening to the You First podcast or reading the transcript online.

Please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org.

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