Disability Deep Dive Episode 108: Visible and Unapologetic: Nila Morton on Disability, Desire, and Creator Culture

Jodi Beckstine (00:13):

What happens when a Black disabled woman chooses to be fully visible in public, not just as an advocate, but as desirable, confident, and completely herself? And why does that make so many people uncomfortable? Today, we're talking about disability, desirability, visibility, and public perception with Nila Morton on Disability Deep Dive.

Keith Casebonne (00:35):

Welcome to Disability Deep Dive. I'm Keith.

Jodi Beckstine (00:38):

And Jodi.

Keith Casebonne (00:39):

Today, we're talking with Nila Morton, a creator, social worker, and disability advocate whose work challenges the way people think about beauty, adulthood, sexuality, and disability.

Jodi Beckstine (00:50):

We get into what it means to be visible online as a Black disabled woman, how creator culture shapes public perception, and why conversations about desire, confidence, and autonomy still feel so loaded when disabled people lead them.

Keith Casebonne (01:05):

It's a thoughtful, honest conversation about being seen, being misunderstood, and claiming space on your own terms.

Jodi Beckstine (01:12):

Let's dive into it with Nila Morton.

Keith Casebonne (01:13):

Before we get started, we like to begin with a quick visual description for listeners who are blind or have low vision. I'm Keith, and I'm a white man with brown eyes, brown hair, a grain beard, and a dark green shirt.

Jodi Beckstine (01:27):

I'm Jodi, a white woman with dark blonde hair and a braid. I have blue eyes and wear glasses, and I'm wearing a brown shirt with light blue stripes.

Keith Casebonne (01:35):

Nila, if you're comfortable, would you like to share a brief description of yourself?

Nila Morton (01:39):

Yes. I'm Nila. I am a Black woman who have long black hair, and I have a white headband on, and I'm also wearing a pink shirt with white outlines.

Keith Casebonne (01:50):

Awesome. Well, welcome to Disability Deep Dive. For listeners who may be meeting you for the first time, kind of introduce yourself, share a little bit about your work and what led you to use your platform the way you do.

Nila Morton (02:03):

Yes. As I said, my name is Nila. I am a disability advocate. I'm also a content creator, and I'm a social worker. Yes, I do social work here in DC and also in Maryland. I'm licensed in Maryland, so I can do therapy there. And also, my day job is being a youth coordinator for a nonprofit. The nonprofit focus on helping students with disabilities when it comes to educational rights, especially if they're going through any type of discrimination with the school system, and we did provide guidance and also referrals or anything that they need so they can be able to know their rights and fight the best way they can.

(02:48):

I graduated from Howard University with my master's in social work. I've only been in my big girl job for almost a year now. It's such a different world being an adult. Oh, my gosh. Like I said, I'm also a content creator. Most of my content focus on fashion, disability rights, and also talking about disability and desirability. I feel like those three things are

something that are very important to discuss, especially when it comes to fashion. When it comes to the fashion industry, they don't really think about disabled people and how clothes fit us, and the thing is disabled people are allowed to be hot. I always try to remind and say to people, "It's okay to be fashionable and hot," and I want the industry to understand that we are people too and we deserve to feel good.

Jodi Beckstine (03:39):

That's right. You've got a lot on your plate.

Nila Morton (03:43):

Love it.

Jodi Beckstine (03:43):

A lot of your public presence pushes back on the idea that disabled women are not seen as desirable or confident or sometimes even fully adult. When did you start noticing these assumptions, and what made you decide to challenge them in such a direct way that you do?

Nila Morton (04:04):

When I was on Twitter, I used to talk about my sexcapades, just like anybody else, like, "Oh, yeah, I hung up with this dude and we had a great night," type of thing, never really went into details, but I noticed a lot of pushback. I was just shocked because I'm like, "I'm doing what anybody else would do, so why is it a whole issue?" And it got to the point where it would be a whole discourse, it would be a whole debate, or if I should be having sex, and why am I sharing it. There have been times where people would block me because they were like, "Oh, this is just too much," and it was just shocking because I'm thinking... I'm really not saying much. All I said was, "I hooked up with this guy, and it was great." Not even in details of what's going on. But I have seen people not care and go in details and I'm like, "They don't really get any pushback." And then I realized, I'm like, "It's because I'm disabled."

(04:57):

Because if I wasn't disabled, I know for a fact a lot of people wouldn't be as upset. And instead of taking that moment to feel defeated, I took that to empower me and also to empower others because I felt like it was a very educational moment for everybody. I really wanted people to understand that disabled people are people, and I was really seeing that they did not see disabled people as humans. They just saw us as diseases, and I was like,

"No, we are more than our disability. It's a part of our life, but it's not all of who we are." With that being said, when it comes to sex, we have the right to have that because we are humans.

Keith Casebonne (05:38):

Absolutely. It's sad how much people project unto people with disabilities, especially disabled women, before they really know anything about them. Once you start challenging those assumptions, visibility becomes, I guess, a much more layered experience. Let's talk a little bit about that, about visibility itself, because being seen is not always as simple as it sounds. When people talk about visibility, they often mean representation. But when visibility can also change the way you move through the world, how has your relationship to being seen changed as your platform has grown?

Nila Morton (06:15):

I would say that it really helped me be able to be proud of who I am. At first, I didn't like to be seen. I just felt like, "Oh, this is a bit too much for me. I can't." But I felt like it was very important to be seen because I want people to normalize disabled people, normalize disability. I feel like that's very important. They have this thing where they feel like disabled people should be hidden or that we shouldn't exist in society, especially whenever I would talk about lack of accessibility in certain areas, and a lot of non-disabled people would be like, "Oh, well, maybe you need to stay home."

(06:55):

I remember when I had a flight incident where I was dropped because I was traveling by myself. People's Magazine was sharing my story, and there was a lot of people that was like, "Oh, you shouldn't be trying to travel by yourself. You need to be staying home. Nobody should be needing to help you. You need to have a nurse," all these things, and it's like people don't value disabled people. They don't see us as value human being.

(07:25):

Whenever I hear people talk about me going out and talking about the importance of accessibility and the importance of inclusion and whenever they say, "Oh, you shouldn't be out," I'd be like, "No, I should because I'm human. I have that right. I shouldn't have to be inside my home because people can't understand the importance of inclusion. No, I'm not going to be hidden." I try to explain that on my platform, the importance of showing yourself. I know there's a lot of disabled people who feel like it's better to be hidden than

seen, but I really want disabled people to really understand it's important to be seen because you deserve to be seen and you deserve to be respected.

Jodi Beckstine (08:07):

Absolutely. As more and more people start being on social media and kind of stepping out into their own platforms, it makes me think about creator culture a little bit. When you talk openly about beauty and desire or relationships or just confidence in general, what kind of reactions tend to come up the most often for you, and how do those reactions reflect the public assumptions about not only disability but race and the desirability that comes with both of those?

Nila Morton (08:44):

Oh, yes. When it comes to fashion, I don't really get as much pushback because I think it's one of those things everybody can kind of relate to where it's like, "Oh, okay, I like what you're wearing. I like your content." I can get an idea. They see it more kind of like shopping in a way, if that makes sense, and so it's not really much of negativity around that. When it comes to talking about relationship and desirability, especially when I talk about race and disability, that's when I get the most pushback. Especially when I talk about desirability and disability, people are very uncomfortable and they are very quick to try to shut me down, which I always have a problem with because they never use that moment to educate themselves. They always use that moment to express their discomfort and how they want me to just hush because it's like, "Ew, this is gross. Nobody don't need to know about this."

(09:41):

But then never take a step back and be like, "Okay, it's the reason why she's talking about this. It's the reason why she is sharing her experiences. It's because disabled people are not in the conversation when it comes to sex, especially when it comes to sex education." I always talk about how disabled people are not really given sex education. I remember when I was younger, and my mom had to advocate for me because teachers were like, "Oh, don't worry about that. You don't have to attend," and my mom would say, "Yes, she do."

Keith Casebonne (10:14):

My gosh.

Nila Morton (10:15):

"She does. She has to. She need to know about her body. She need to know about consent, all those things."

Jodi Beckstine (10:19):

Yeah.

Nila Morton (10:21):

I always try to explain to people like, "This is why I share my story because it's much more than me just saying, 'Oh, yeah, I had a good time.'" I want people to understand, and not just not disabled people, but also disabled people, the importance of knowing what pleasure is for you and knowing how to advocate for yourself in a very intimate place and understanding that you have the right to have sex and you deserve the right to feel good during sex.

(10:49):

When I talk about sex... I mean, not sex, race and disability, it's a lot of tension. I don't get as much pushback, but I notice I don't get as much of a response. I don't know if that's a good thing or a bad thing, but I know it can make the room very uncomfortable because people don't really realize that Black disabled people are not always part of the conversation. They're not always a thought, honestly. It's like in the back burner. We're really forgotten. And I noticed that when it was Beyonce and Lizzo, they say a ableist slur, spaz, and they saw them, and a lot of white disabled people felt the need to bully Beyonce and Lizzo for that.

(11:39):

I thought it was very uncomfortable and very racist because they didn't take into account... When it comes to Black culture, we say certain words that we don't really mean. Like the slur spaz, that usually mean I'm about to crash out, I'm about to go off on this person. It's we don't really have knowledge that something is ableist. And instead of taking that moment to educate us, they took that as to be racist and, excuse my language, to shit on two Black women. That's when I really realized, I'm like, "Wow, it's really a division within the disability community because not one white person ever stopped to think, 'Okay, this is part of their culture. This is how they talk.'" Instead, they was like, "No, you ableist, you're wrong, you this and that," and I'm like, "Whoa, that's too much." But also, too, they never allow Black disabled people to lead the conversation. They always feel the need to lead the conversation, and that's when things start going left.

Jodi Beckstine (12:43):

They like to think about the disability community as just all-in-one basket or all just in the same box, and they don't see it as different cultures and different ideas and different thoughts. You really hit the nail on the head with that.

Keith Casebonne (13:01):

Yeah. That's one of the most beautiful things about disability is that it is such... I mean, it's cross-cultural, it's cross-gender, it's cross-race, it's cross everything. It's kind of the one demographic... It's not really a demographic in the sense of all those other things. But because of that, things do seem to get kind of lost in the shuffle there. I think it's great that people like you, Nila, are talking specifically about those interactions between disability and sex and disability and gender. That's huge. You said there is discomfort and people get really upset and kind of strike back when you would go into talking about sex and desirability as a person with disability. How do you respond to those people? How do you respond to those comments?

Nila Morton (13:58):

Usually, I respond with them with grace. I always try to keep in mind they're not educated, and that's okay. But also, those who are not willing to be educated, I just let them be. I had to learn to just letting them be, because there would be moments... I would be on Twitter, I'd be going off. Going off, I'd be like, "Yeah, you're not going to talk to me this way, da da da," but then I had to stop, and I was like... There are some people who won't be willing to learn. There are some people who may disagree at the beginning, but at the end they will have an understanding. And there's some people who are just stuck in their ways, and that's okay. It's not okay, but for the sake of my peace, it's just going to have to be okay because I can't want it more than them. I really can't.

(14:43):

I want them to be more understanding, I want them to be more open-minded, but there are some people that's just stuck in their ways, and I just usually just have to block them and ignore them. I try to engage whenever I feel like someone's saying something harmful. Because the way I look at things, even though I may get ignored, I know there are disabled people who are looking at my content and may get real trigger, and that's when I engage and be like, "Hey, this is wrong. You're wrong for saying this. This is why you're wrong." Even though it's a little back and forth, I still feel like it's very important to still tell people like, "Hey, just thinking, it's ableist."

(15:23):

I know it was one person, this one guy, he felt like that the person, whoever... Because at the time, I had a partner and I was just sharing something that we discovered during sex that I find very pleasurable. I remember this one person retweet it and was like, "Oh, the person who having sex with you, he need to be put down like a dog. He just basically need to be killed," and I was like, "So he needs to be killed for having consensual sex with the woman he find attractive all because I'm in a wheelchair? Make that make sense." And it'd be the same people who would be silence when it comes to sexual abuse, sexual assault, and things like that, or support predators, and I just find that very interesting and very upsetting. When I see people like that, I realize I have to either keep my distance or I can engage and try to educate, but then I'm like, "These people are supporting people who have harmed people. There's no way they can actually see me having consensual sex with somebody is okay." They're far gone.

Jodi Beckstine (16:36):

Yeah, right.

Keith Casebonne (16:38):

Yeah, wow.

Jodi Beckstine (16:39):

Underneath all of that, you touched on this a few times talking about who society gives full humanity to. On this podcast, we like to touch quite a bit on the intersectionality of things. For listeners who may not really have thought about disability and desirability through not only being disabled but through race, what do you want them to understand about the way that racism and ableism really shape in the society, who gets to be seen as beautiful, who gets to be seen as desirable, or even worthy of attention at all?

Nila Morton (17:23):

Yes. As a Black disabled woman, I will say I have encountered a lot of... Especially just dating and all that, me being a Black woman, Black women are always told that we're not desirable That's an everyday thing that we're told, that we need to look a certain way to be... we need to be able to present ourselves a certain way to be accepted by society. And then with me being disabled, it's like I'm told all the time like, "Oh, nobody wants you. Nobody wants to deal with you. People don't deserve to have to take care of you," things like that. It can become very disheartening because, to me, I feel like I'm the shit. I'm that girl, period.

Jodi Beckstine (18:06):

Right.

Nila Morton (18:08):

I'm your favorite disabled hottie for a reason, but I also want people to really understand that, one, beauty's in the eye of the beholder. We cannot tell people what is attractive, what is desirable. We can't because it is up to the person. And also, we have to stop telling people that they're not desirable because of our own biases and also our own internal racism and ableism or any other things that people are dealing with. Because when we say those things, we just go on off by what society has told us and also how we feel about people. Why tell me that nobody wants me when I have a whole list of people right now in my DMs just asking me to just reply? And that is because people are confident in who they are, and I want people to realize that.

(19:09):

When people are telling someone like, "Hey, you're not desirable, you're not this and that," all I see is someone that's insecure and they're projecting, because it's like just because no one talked to you doesn't mean it's the same for me. People talk to me because people not only see me for my beauty, but they'll also see me for who I am as a person. I really want people to understand that looks are subjective, plus you're going to change as you get older, and that's why it's important to have a personality. I remember I said this on Twitter. I said, "I feel like a lot of non-disabled people are always shocked that I'm able to date successfully and have fun with sex. It's because I actually have a personality. They don't have a personality." They don't have a personality, and that's basically what it is. It's like, "No, actually, people can talk to me, which is why they always want to come back."

Keith Casebonne (20:05):

Absolutely. I love how well framed, how thoughtful that whole response is. It's a really powerful way to look at it. Thanks for sharing that. It's incredible. Well, before we wrap up, we have a second segment on our show, what we call a Deep Cut, where we talk about media in disability spaces. We always like to ask our guests, is there a book, a TV show, a film, it can even be a song, that has resonated with you lately or that you'd like to share with our listeners?

Nila Morton (20:37):

Oh, yes. A lot of people probably know this. I love Beyonce. Beyonce, she's just that girl. I love her so much. I have a Beyonce song of the month. Right now, it's really Schoolin' Life, and that's because life mean [inaudible 00:20:57], but that song just really reminds me

like, "Hey, it's okay. Let's just celebrate where you are." Schoolin' Life, it always reminds me like, "It's okay if I'm feeling a little worried, but also make sure to enjoy life. It's not over yet. You're just starting." Especially when she be like << Those in their twenty-something >> and I'll be like, "You know what? I'm still 27, so I'm in my 20s. Let's calm down." Right now, that song.

(21:25):

And then when I'm feeling a little spicy a little bit, I would say Alien Superstar because then it remind me I'm forever that girl.

Jodi Beckstine (21:33):

Absolutely. Absolutely.

Keith Casebonne (21:34):

Nice.

Jodi Beckstine (21:34):

Great choices. Those are great.

Keith Casebonne (21:36):

Nice. Love it.

(21:40):

All right. Thank you so much, Nila. This has been a great conversation on some really interesting topics that don't get discussed enough, and I'm glad that you're a voice out there talking about these things, being open, unfortunately dealing with those out there that hate and sounds like you've done a good job putting up boundaries to keep that from interfering too much with things. Anyway, again, wonderful talk, and thank you again so much for being our guest.

Jodi Beckstine (22:06):

Thank you so much.

Nila Morton (22:06):

Thank you so much.

Keith Casebonne (22:09):

Take a quick break, and then it's time for our Deep Cut.

Jodi Beckstine (22:18):

For today's Deep Cut, we're talking about Patrice: The Movie, a documentary rom-com directed by Ted Passon. The film follows Patrice Jetter and Gary Wickham, a couple who love each other and want a future together. They want to get married. They want to live together. They want the ordinary things many couples are allowed to plan without needing a legal and financial risk assessment first. But Patrice and Gary are people with disabilities who rely on benefits, and in the film, marriage or even living together can put the benefits they need to survive at risk.

Keith Casebonne (22:49):

That is the center of this story. This is not only about whether two people can have a wedding. It's about whether people with disabilities are allowed to build families, share homes, save money, work, travel, and make long-term plans without being punished by outdated rules.

Jodi Beckstine (23:05):

What makes the movie so powerful is that Patrice is not presented as a policy example first. She is funny, creative, loving, emotional, frustrated, determined, and fully herself. The movie gives us romance, friendship, art, advocacy, and anger, sometimes all in the same moment.

Keith Casebonne (23:23):

Today, we're talking about love, benefits, the marriage penalty, the $2,000 savings limit, accessible transportation, institutional abuse, and why this movie asks such a clear question. Why are people with disabilities still being forced to choose between support and living a full life?

Jodi Beckstine (23:42):

Right. When we hear the phrase marriage equality, they may think about same-sex marriage, interracial marriage, or even particular court cases, and those conversations are still very real in the United States right now, but Patrice: The Movie asks us to kind of widen the lens a little bit. For many people with disabilities, marriage can still come with some serious financial and medical dangers. How does this film expand the way that we think about marriage equality?

Keith Casebonne (24:13):

Yeah. I mean, the show, it shows... This is not just about two people who want to legally be able to get married. They could get married if they wanted to. No one's stopping them from having a ceremony and becoming a married couple, but the problem is these outdated rules. When you do that, you then end up losing benefits, like healthcare and income. It makes affording housing harder. It's more of a penalty than a celebration.

Jodi Beckstine (24:46):

That goes beyond tax things or student loans, stuff that you take on as your spouse. This is legit a penalty. You lose things by getting married. Being married doesn't become a benefit at all. There's so many people that I've talked to, not only just seeing this movie, but in the past, they have no idea that it even exists, that it's a problem for people with disabilities to get married. It's so frustrating that... The movie's so great because it brings forth this conversation to the forefront that a lot of people don't even know about.

Keith Casebonne (25:29):

Right. I think that's what's so important about this is that there's many people who have never heard about this. Every time it get brought out into the public, I think that's a good thing.

Jodi Beckstine (25:38):

Absolutely.

Keith Casebonne (25:39):

Yeah. So this is where the Marriage Equality for Disabled Adults Act matters. That's the bill that's been introduced to Congress, but like so many other disability rights bills, it just keeps coming back without becoming law. Why is it important for viewers to connect Patrice and Gary's personal story to that larger policy fight?

Jodi Beckstine (25:58):

Well, again, we're talking about it brings it to the forefront. From what I'd gather with the movie and my limited knowledge on this, the original laws and the original thing about this was when majority of people with disabilities lived in institutions. In their mind, the lawmakers did not envision disabled people marrying and living independently in life.

Keith Casebonne (26:26):

Its own problem in itself.

Jodi Beckstine (26:28):

Yeah, exactly, exactly. It shows how far we've come and how dated the rules are and how important this act is. But just like a lot of things, it starts going through the process and gets stalled for whatever reason. But I think the more people that know about it, the more conversations we have about it, the more likely it can start possibly moving again and actually being accomplished.

Keith Casebonne (27:00):

Yeah, because it does really fully address these penalties and makes it so that you can marry and not have a financial crisis immediately because you lose all your benefits and your savings get taken away or it's limited how much savings you can have. You know?

Jodi Beckstine (27:21):

Yeah.

Keith Casebonne (27:21):

Patrice and Gary's story, they show what happens while this legislation just sits in Congress. They have to delay, they have to compromise, and they have to reshape their lives around these really old-fashioned out-of-touch rules.

Jodi Beckstine (27:36):

Yeah. They're constantly coming up with new ideas for things and how to... They don't complain. They just kind of, "All right, this is what's happened. This sucks, but let's figure out how to solve this problem." Along with that bill, there's other related bills including, you had touched on it a moment there, the SSI Savings Penalty Elimination Act and Eliminating the Marriage Penalty in SSI Act. The film is pointing out this cluster of problems. You have marriage penalties, you have savings limits, and it keeps disabled people kind of financially trapped where they are. Again, it's very important for us to talk about these together with the act. Do you feel that that's important as well?

Keith Casebonne (28:30):

Yeah. I mean, all this stuff, really, it combines to form this one sort of overarching problem. I mean, there's different aspects to the problem. One involves the amount of benefits you get, another involves the amount of savings you can have, and so on and so forth. I mean, really, in the end, it's all connected. The point is that if two people who are disabled, who both have benefits, get married, they suffer. They have problems. They can't just plan like any other couple does to, I don't know, just move on together as a couple and combine

their finances. For many people, you get married and everything's a plus. Now, we have two incomes and now we have more money in the bank and so on, and it's just not the case. So yeah, all these bills, they all address specific issues, but in the end, it's this big problem that just affects couples in love and that's just sad.

Jodi Beckstine (29:33):

They touched on it a moment in the film where they went and spoke to a legislator and they were talking about how does this benefit the government not allowing the benefits to continue if people get married. You're paying for them now, two people. They get married and you continue to pay for them. There's no additional costs. It's the same cost that you have. What is the benefit to the government? He pretty much said, "We take the benefits away and that saves us money." He's not agreeing with it. He's trying to push the bill through, but he's essentially saying that it's a savings to take away these benefits instead of just leaving them intact how they are, and it was just shocking to hear that. Because it's not understandable in my mind, but you could see where they're coming from if it's an additional costing to the government, but it's not.

Keith Casebonne (30:33):

At least there's an argument there. I mean, maybe you don't agree, but at least there's something to argue back. Right?

Jodi Beckstine (30:37):

Yes. Yes. There's no ground there for that at all, and that's what I think is the most frustrating.

Keith Casebonne (30:43):

It's absurd. Well, one of the most frustrating parts of the film is the savings limit, as we've touched on. Patrice is trying to solve real problems, but she has to stay under this very strict resource cap. What is the $2,000 limit? Help viewers understand.

Jodi Beckstine (31:00):

I don't think people even realize that that exists. In the movie, she really talks about that a lot. She shows what her annual income is, and it's not a lot, and she has to deal with things... We talk about disabled people end up paying a lot of money for things. We joke it's the disability tax. If you want an accessible van, it's two, three, four times as much as a regular van, so you have to have a savings and have the ability to buy these things. But if they're capping your savings, if you don't have the ability to make money over a certain

limit, how could you possibly save up for a home, for a car, for repairs on anything, for a mobility device? It's so unreasonable.

Keith Casebonne (32:01):

Even just emergencies.

Jodi Beckstine (32:02):

Yeah. Yeah, exactly.

Keith Casebonne (32:03):

Yeah. What do you do? Right.

Jodi Beckstine (32:06):

It's so frustrating, but again it's the lack of information that the general public has about this. When I bring it up, they're, "No way. $2,000? That's all you can save? It's my [inaudible 00:32:23]-"

Keith Casebonne (32:24):

And 3,000 as a couple, not even doubled. It's actually less. Again, penalty, it's-

Jodi Beckstine (32:27):

Exactly. Exactly. It's so frustrating.

Keith Casebonne (32:34):

It is. The film really makes it feel real when you see Patrice needs an accessible van, and a van certainly costs a lot more than $2,000. Again, this is the point. What do you do? It creates this impossible situation. People are told to be independent, but then you need savings. You need financial stability to help be and maintain that level of independence.

Jodi Beckstine (33:01):

Absolutely. The movie kind of frames it as that trap. Patrice is not necessarily careless with money. She's surviving within the rules that make financial stability almost unreachable for her. How does the movie challenge the way people talk about benefits?

Keith Casebonne (33:23):

Well, I think sometimes we have people out there that think benefits are just so easy to get and the people are living the life and not working because they're getting all these government benefits. That's just not the case. These benefits are not... They're not handouts. They're not just super easy. They're very restrictive, and they're very limited, and sometimes they're actually not even all that easy to get. I think this movie really shows that, that these are two people who are really restricted by this situation. They're not enjoying it. They wish they could do more.

Jodi Beckstine (34:00):

Yeah. I think the term benefit is such a misnomer. Assistance is better because they are helping, but benefits make it seem like I'm getting something that you're not getting. I have something that you don't have. And then the whole, "It's unfair," and all that comes into play. One of the surprising things that I did not know was that Patrice, to raise money for the van that she has currently in the film, she did a GoFundMe. Whatever she raised for the GoFundMe came out of what she was allowed to declare as her income, so income capture, and she lost her benefits. I was just like, "These are people wanting to give her money to help her, and she loses her benefits from it."

Keith Casebonne (34:50):

Yeah.

Jodi Beckstine (34:50):

I just could not. I was so mad.

Keith Casebonne (34:53):

I was too. I was too. I had no idea that it would work that way. Very shocking. I think viewers need to understand from this movie that these rules, these essentially poverty rules, they keep people poor, and that's by design. I mean, what we call a safety net, it's not a safety net. There's too many holes in that net that we call the safety net.

Jodi Beckstine (35:20):

Safety string?

Keith Casebonne (35:22):

Yeah, right. Exactly. Maybe that's it. Well, the van is one of these very clear examples of how access connects to everything else. So when Patrice loses her transportation, she loses a lot more than just the vehicles. What does the van represent in the film to you?

Jodi Beckstine (35:42):

Well, she takes the van in to get it... There's some northern states where you have to, every year, make sure that it's running and the emissions are good and everything is great. She goes up there and does that. The guy and the mechanic pretty much tells her, "Do not drive this vehicle anymore. It's done," and so she's talking about what is she going to do. She ends up having to take time off from her job because her job is too far away to walk to. She's a crossing guard. It limits her ability to go see Gary because that's how she drives back and forth, because they can't live together.

(36:22):

Her losing a job starts putting stress and tension on her being able to pay for where she lives, and she talks about that, and she talks about becoming homeless and going to have to be like her friend who lives in her car, but now she no longer has that car. You can see this looming, "You're going to have to go back to live in an institution," just kind of coming up behind her, and you can see that stress on her. Now, she can't do a GoFundMe because she's done that before, so she resorts to getting 10 cents a can for aluminum cans to try to... Very creative, very willing to do what it takes to make it happen and put the blood, sweat, and tears in, but very limited to what she can do.

(37:13):

That section of the movie just had me... I was so angry and so upset, but it's also... Their light and joy and problem-solving and love for each other also brought that to this section. You're angry and happy and frustrated and laughing all at the same time. It's an emotional ride. But I think that van represents that independence that she's fought so hard for just being stripped away so easily and with almost no recourse.

Keith Casebonne (37:50):

Yeah, no, totally. I mean, all that work... I mean, again, this is emotional energy and time and even vulnerability that they have to deal with and go through. It just shouldn't be the case at all with these rules that are in place. Someone wants to donate money. I mean, come on. I don't even have words. It just makes me so mad.

Jodi Beckstine (38:17):

The film looks at Patrice's past, including her abuse that she endured in an institution. How did those scenes change the way you understood what Patrice is fighting for in the present?

Keith Casebonne (38:31):

Yeah. The scenes from her past, they show that her independence was not handed to her. She fought for it. She had a very grueling childhood, if you ask me. It was rough. And the fact that she was able to get out despite all these barriers and whatnot, she was able to get out and become independent and live on her own, is huge. That abuse she endured, it gives more weight for that desire to have safety at home and work. That's all she wants is to... Now that she has it, she just wants to keep it. And is that so much to ask?

Jodi Beckstine (39:18):

Really.

Keith Casebonne (39:19):

Right.

Jodi Beckstine (39:20):

Really. It lets you know how the threat of what's going on in her life present in the movie is such a big threat because she doesn't want to go back to that. As a viewer, you don't want her to go back to that. You understand how horrible it is. But also, in the same token, her mom has passed away. Going to her mother to live is not really a good option for her either because their relationship was very tumultuous and almost toxic. It really puts in the forefront, yeah, this is not a good thing. You could see the stress and you can understand the stress deeply.

Keith Casebonne (40:09):

Absolutely. Oh, yeah, absolutely, and that connects directly to the present. When you've got a person who survived institutional abuse and then they're being told by the systems where they can live and who they can live with and how much money they can keep, it just has a different emotional weight. You handle it different, you experience it differently than we even can imagine. There is also the living threat of having to return to an institution. What should we be careful to name here?

Jodi Beckstine (40:44):

It's important, especially in today's world, for the general public to understand the need for independent living, if the possibility is there, to understand the harm that institutional living can cause. It's not just part of our history. It's something that is present day. It's not distant or unrelated. And I think everyone should have the ability to do that, to live independently, to make their own decisions for themselves. When they have the ability to do it, except for

financial things that we are imposing upon them, it's so frustrating to see that because she has the ability to live on her own, she has the ability to pay her bills and go to a job and be a functioning member of society, doing all these things, and it's the money and the rules that we've placed on her that is preventing her from really just blossoming and doing so much more.

(42:10):

I mean, I just think about all the things that she could do if she were allowed, without having all these restrictions on her with her income, et cetera, because she's an artist and a tremendous artist and such a personality. It's hard to see her so stifled. Even though she's not living in an institution, it's an institution in another form in my mind.

Keith Casebonne (42:36):

Yeah, yeah, yeah. Yeah, no, I agree. It just shows how she values what she has now so much more considering what the alternative is, and the film does a really good job of helping the viewer understand that and feel that along with her, that this is... Yeah, it's disability history, but it's also not all that distant or unrelated of an issue right now today for her.

Jodi Beckstine (43:09):

Absolutely.

Keith Casebonne (43:10):

Yeah.

Jodi Beckstine (43:10):

One of the most distinctive choices in the film that I just absolutely love is the way that Patrice's past is recreated. The movie uses children to play many of the adults while the adult Patrice plays herself at different ages. How did that creative choice land for you?

Keith Casebonne (43:30):

I thought it was so clever and unique. That's one of my favorite parts of the film. I mean, the story is incredible. Everything it shares is incredible. Tears of sadness, tears of joy throughout, I mean, it's incredible, but the way they structured the flashbacks is so creatively unique and it's so her. When you get to know who she is, it just feels right. You can tell that this really is who she is and how she sees things.

(44:02):

Yeah, I love that choice. I thought it was really great. Having her play her own younger self, it gives herself real ownership of the memory. This isn't just someone else pretending to be her. This is her. She's not just acting, she's feeling it. I mean, she was there. This is her life.

Jodi Beckstine (44:17):

Yeah.

Keith Casebonne (44:20):

Yeah, yeah. It's really cool. It's really, really fun. I enjoyed it so much.

Jodi Beckstine (44:24):

Yeah. I feel like the reenactments were little moments of her memory filtered through how she would have drawn them or written about them and through her humor and her sense of self. So yeah, it was one of my favorite parts. When I first saw the first one, I was like, "Oh, this is fantastic." I loved it so much.

Keith Casebonne (44:47):

Yeah, yeah. Oh, yeah, me too. I think using children to play adults, I think that helps show how confusing and sort of outsized adult power can feel to a child.

Jodi Beckstine (44:59):

Absolutely.

Keith Casebonne (45:00):

It's an interesting creative choice.

Jodi Beckstine (45:02):

Yeah.

Keith Casebonne (45:03):

Yeah, and that choice could have felt very strange in another film, but here it really does feel connected to Patrice's own imagination and her artwork. So why does that matter?

Jodi Beckstine (45:14):

I feel like it was showing and giving Patrice creative control of what was being told about her story. A lot of times with a documentary, it's the director shaping the story and showing how the viewer is going to see it. Even though there was a director that wasn't Patrice, it kind of gave her still that creative control and that creative way of shaping how her life is done. There's painful things in it and Patrice, outside the reenactments, shows her pain and frustration, but there's also this... I keep calling it a light. There's this lightness about her that, "I'm going to solve this problem. Yes, this is horrible and it sucks, but I'm going to make the best of it." And I think by having the reenactment that way, it kind of brought her light to that as well.

(46:21):

Again, I can gush over it for the whole conversation. I just think it was such a great creative choice. I don't know who made that decision, but it was a good one.

Keith Casebonne (46:32):

It was brilliant, yeah. I mean, it had a handmade style to it. And again, it just felt like it really mirrored her and her artsy abilities, her artistic sense... what I'm trying to say is her artistic sensibilities, and that really transferred over into these scenes. I think also what I found amazing was that when they talked about her past and some of the abusive situations she was in, they were still filmed using the same structure, the same art style, et cetera, but it didn't make you feel it any less. I mean, some movies will go into... lights go dark and it's like a silhouette and there's a person in the background, and they put all this effort into making it look dark and foreboding and scary and distant. She didn't do any of that in her movie. I still felt it. She didn't need to, I think that would've been trite, and instead this was creative and unique and makes it stand out compared to other similar stories and movies that I've seen.

Jodi Beckstine (47:36):

Absolutely. I agree.

Keith Casebonne (47:37):

Yeah.

Jodi Beckstine (47:38):

Well, moving on to another thing. The film gave some space to Patrice's friend who has autism, her name is Elizabeth, and we see her perspective when she gets dysregulated. Why is that important to include in this conversation?

Keith Casebonne (47:56):

Well, I like how the film doesn't just focus on Patrice and Gary. It shows there's a wider community around them and other people with disabilities. They have other friends as well that don't play as big a role, but other friends that they interact with a lot that have disabilities, and they all sort of work together to help with the fundraising and the different things that happen in the movie. But I think that friend's perspective, it helps viewers understand that stress, it's not only intellectual or emotional, it can be sensory, it can be physical as well. I think that friend... Elizabeth does a good job of showing that.

Jodi Beckstine (48:34):

Absolutely. She talks about not wanting to get married. That's just a decision she's made. She's not interested in that, and that's fine, but she is fighting tooth and nail for this marriage equality act so that... She wants this to happen for her community, for her friends, and she's putting everything she has into it. I talked about them speaking to the legislator. She goes with Patrice there. They're in the office and you can see this stress and overwhelm to start hitting Elizabeth and you can see her physically reacting to that, and I think that's important for people to understand. Where Patrice is sitting there calmly trying to understand what he's saying and trying to find the loopholes and find how they can solve this problem, and her friend is physically reacting to this stress. It was just a really important, I think, moment in the story.

(49:37):

Again, we're talking about gathering cans for however many cents it is. She was out there doing it. It gave her such sensory overload. She didn't like it, but she did it anyways because she loves Patrice and Gary and she wants to help them so much. I think that was just such a nice addition to the story that there's such a big community around them.

Keith Casebonne (50:03):

Yeah. Including that perspective, I think, really shows another layer to the level of disability representation in the film without making her friend just seem like a side note or a quick lesson to throw in. It's really integral to the story.

Jodi Beckstine (50:16):

Yeah.

Keith Casebonne (50:16):

Yeah. I think it reminds us that advocacy spaces can still be overwhelming. Even when the goal is positive, the process can be downright exhausting. What does the film show about the emotional cost of constantly having to fight?

Jodi Beckstine (50:32):

You can see it. In the beginning, these bad things are happening and Patrice is like, "Well, we're just going to do this instead. Well, we're just going to try this. Well..." and you can slowly see it exhausting her. Even Gary says, "She's in a very low spot right now, and I don't know how to help her. I don't know what to do." For someone who's normally the beacon shining light in a room to be so dimmed by the stress and most... I could speak from my experience. Having to explain yourself and your situation and every single thing that you're going to all the time, it does get overwhelming and it does get... "I just want to grocery shop without explaining to you about my disability. Can I just..." You know?

Keith Casebonne (51:24):

Right.

Jodi Beckstine (51:27):

And that's just a minor inconvenience. I think it does give an example to the general public on how exhausting it really is to just constantly have to fight for every little thing.

(51:46):

It goes back to the it's not benefits. These are just, "I just want to live, I just want to be independent, I just want to contribute, and you're making it so difficult for me."

Keith Casebonne (51:58):

Yeah. I mean, the film really shows the power of the community together, but also the toll that they all start to feel needing to organize, and unfortunately for which just be basic rights. You know?

Jodi Beckstine (52:17):

Yeah.

Keith Casebonne (52:23):

There's also you need to rest, you need to regulate, you need to have emotional safety. You do have to find those things so you can stay as centered as you can even with all these

things going on around you. You don't want to lose it if you can, but it's rough. They show it really clearly.

Jodi Beckstine (52:46):

Yeah, very much.

Keith Casebonne (52:46):

It's very rough, yeah.

Jodi Beckstine (52:47):

Very much. After seeing the policy barriers and the van crisis and the issues with Patrice's past, the relationship with Patrice and Gary feels even more meaningful. What did you notice about them as a couple?

Keith Casebonne (53:04):

Well, their love just never waivers. I mean, they're just so fun and funny together. They're so affectionate. I mean, the movie even opens just with them being so silly, just going to bed for the night, but they just seem like such a fun couple. The things that are going on around them are challenging, but when they're together, they really do feel that love for each other. I think that's great. But I think another important thing to mention is that the film doesn't make it seem like, "Oh, my god, they're disabled people and they're a couple. They have a relationship and there's love and... Really?" It's just normal. It's just, "Here's two people. They're in love just like so many other couples in this world, and that's it. That's all it is. Nothing to label it. It's just people."

Jodi Beckstine (53:59):

Yeah. I love that they gave a little story about who fell in love first and that type of thing and how she cared for him when they were just friends at the time because he needed someone. I felt that so deeply, the care that they have for each other. She was caring for him when he was at his low, and now she's at a really super low spot and he is trying to care for her. It breaks your heart to know that they can't do what they want and be married and live together. That was the other thing we hadn't mentioned. It's not only that they can't even get married, they can't even cohabitate because that'll ruin it, so he has to live somewhere else. They can't even be roommates and pay their own way... and the mortgage and the groceries and all. They can't even do that. It's so frustrating.

(55:03):

The one thing, like you said, their love never waivers through it. It's consistent and it's there and it's real and it's beautiful I just love them together, and they could be our new best friends this time.

Keith Casebonne (55:15):

There you go. Exactly.

Jodi Beckstine (55:16):

We keep saying that every episode.

Keith Casebonne (55:20):

That's right. That's right though. They could be. They could be. I love it.

Jodi Beckstine (55:23):

Patrice: The Movie is joyful, funny, romantic, creative, and deeply frustrating. It gives us a love story, but it also gives us a clear look at the rules that can make love financially and medically dangerous for people with disabilities.

Keith Casebonne (55:38):

Film shows that marriage penalties are not abstract. They affect whether Patrice and Gary can marry, live together, save money, keep benefits, and just plan for a future together. And when we add in the van, the $2,000 savings limit, the GoFundMe issue, and Patrice's history of institutional abuse, the larger point just becomes impossible to ignore.

Jodi Beckstine (55:59):

People with disabilities should not have to choose between love and benefits. They should not have to choose between saving money and keeping healthcare. They should not have to fundraise for basic transportation and then be punished for receiving help.

Keith Casebonne (56:12):

And that is why this film matters. It asks us to look at marriage equality through a disability lens, it asks us to look at independence through access, and it asks us to understand that a full life includes love, home, work, safety, money, transportation, and choice.

(56:32):

Thanks for joining us for this episode of Disability Deep Dive.

Jodi Beckstine (56:36):

You can find this episode, additional resources, and more conversations like this one at disabilityrightsflorida.org/podcast.

Keith Casebonne (56:45):

If this conversation stayed with you, we hope you'll share it with someone else.

Jodi Beckstine (56:49):

Thanks for listening, and we'll see you next time.

(56:51):

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