

# You First Podcast Episode 72: Disability & Gender Equity – with Marissa Ditkowski

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**Maddie Crowley (00:00):**

You're listening to You First: The Disability Rights Florida Podcast. In this episode of You First, we talk with Marissa Ditkowski about the intersection of gender and disability and disabled women's access to healthcare, financial freedom, and employment equity. Hey, everyone, I'm Maddie.

**Keith Casebonne (00:36):**

And I'm Keith, and we're the hosts of You First. Welcome back for another episode. Today, we are talking with Marissa Ditkowski, who is a disabled activist and attorney. She serves as the Disability Economic Justice Counsel at the National Partnership for Women & Families.

**Maddie Crowley (00:51):**

Prior to her time at the National Partnership, she was a staff attorney at Tzedek DC, a non-profit dedicated to safeguarding the legal rights and financial health of D.C. residents with low incomes, dealing with debt and consumer issues. There, she led and formed Tzedek DC's Disability Community Project. Prior to joining Tzedek DC, Marissa served as a litigation fellow at the AARP Foundation, where she assisted with legal research on cases involving age discrimination, reverse mortgages, nursing facilities, elder abuse, and other issues facing Americans ages 50 and older. Marissa's legal research on issues regarding disability rights, reproductive justice, and workers' rights has been featured in publications, such as the National Lawyers Guild Review, the Journal of Gender, Social Policy & the Law, and the UCLA Women's Law Journal. Marissa is a former leader of the National Disabled Law Students Association and organizer and founder of the National Disabled Legal Professionals Association, which we actually had a podcast that talked a little bit about the National Disabled Law Students Association earlier this year.

**Keith Casebonne (01:58):**

[inaudible 00:01:59].

**Maddie Crowley (01:58):**

So that's super cool.

**Keith Casebonne (02:02):**

Yes, we did. It really is cool. Marissa's cool, and she talks in depth about the inequities that women with disabilities face in America, in employment, the ability to save and build wealth, healthcare, and much, much more. So we hope you enjoy our conversations with Marissa. Hey, Marissa, thank you so much for being our guest today. Please, for our listeners, introduce yourself, name, pronouns, what you do, and the identities and the visual description.

**Marissa Ditekowsky (02:26):**

Hi, my name is Marissa Ditekowsky. My pronouns are she, her. I am the Disability Economic Justice Counsel at the National Partnership for Women & Families. I focus on advancing policies that support the economic health of disabled women, particularly disabled women of color. I am a white woman with long, dark hair, and glasses.

**Maddie Crowley (02:49):**

Great. Thank you so much, Marissa. We're so excited to have you on. I'm Maddie. I'm a white person with blonde and brown hair, wearing a black button-up and black headphones with glasses, and we're just going to jump right in and start talking about how you got into this space and what your current role is at your organization, and how and why is your organization focusing on disability-related work?

**Marissa Ditekowsky (03:15):**

Yeah, so I got into this space primarily because of my own experiences. So I am multiply disabled, and I am a woman, so obviously, a lot of my experiences have been at the intersection of those identities. I have had a lot of issues in my life obtaining accommodations or getting the things that I need to access the world. And so having those experiences, I decided that I wanted to go to law school and I wanted to make things better for the folks who came after me, so folks don't really have to reinvent the wheel. And so that's my goal consistently, is to make things better for other folks going through similar things.

(04:02):

But when this opportunity arose, it felt like a perfect way to synthesize all of my interests and all of my goals to support disabled women going through some of the same things that

I have, whether that's an issue with a healthcare provider, gaslighting me, or being unable to obtain employment in some way. It's just, it really synthesizes a lot of my interests. And Jocelyn Frye, our president at the National Partnership has been really committed to making sure that our work is intersectional and has been really supportive of our disability work. And the reason that we are doing this work is we can't achieve equity for all women without including disabled women. So that really has been at the heart of this work at the National Partnership.

**Keith Casebonne (04:58):**

Yeah, it's really important work, for sure, and thanks for sharing that information with us. And so again, this is Keith, the cohost of the podcast. I'm a white male with dark brown hair and a salt and pepper beard, wearing a gray shirt and black headphones. So we'd love to hear a little more about the connections between disability and gender. You mentioned some of the challenges that you encountered and the reasons that you wanted to make that better for other people. So what are those intersectional experiences of women with disabilities, and how can the partnership, the National Partnership for Women & Families help make a difference for them?

**Marissa Ditkowsky (05:37):**

Yeah. So all issues are disability issues. So that's employment, that's healthcare, that's housing, that's climate change, that's everything. And the same applies to gender issues. So every single way I show up or experience the world is going to be impacted by my identity as a disabled woman.

(06:01):

So I think that's really important to start out with as a framework. But in terms of the intersectional experiences, women are more likely to have a disability than men, and for people of color, particularly Black and Indigenous folks, they're also more likely to have a disability than white folks. So we already know that disability disproportionately affects women, especially Black and Indigenous women. So just starting right there with the amount of folks who are affected and who is affected. And then, we also know that women, disabled folks, people of color are all more likely to live in poverty as well.

(06:43):

So we're living at the intersections of all these identities, increasing that potential chance of living in poverty, and there are a lot of factors that contribute to that. There's employment, and wages, public benefits that have so many barriers to access and are just

not really sufficient to live on, increased costs of living with the disability, we call that the Crip tax, and just so many other things are systems transformation guides to disability economic justice that we started putting out last July, get pretty into the weeds on these barriers, and we can talk a little bit more about them throughout this podcast, but all of these things come together in how we show up in the world and how we experience the world. But just higher level examples, we also experience barriers to healthcare access, including sexual and reproductive healthcare, where disabled women are more likely to experience violence, including gender-based violence than non-disabled women. So there are all these things that kind of come together in the way that we experience the world that really make this work super important to focus on.

**Maddie Crowley (07:54):**

Definitely. Thank you for that higher level kind of web that you were putting together for our audience. I think sometimes folks can have a hard time making these connections and seeing how these systems overlap and impact folks, but thank you for taking the time to set the stage for how the conversation is going to continue moving on. So like you mentioned, when it comes to benefits, when it comes to payment, when it comes to healthcare access, these are all huge issues within both the disability community and all other intersecting identities. And one big theme, I think, behind all of that is the financial inequity, and inequality, and how that is both a huge issue in women's rights and disabilities rights, and disabled women's rights. So can you talk about how being both a woman and disabled impacts someone's ability to have financial stability and freedom?

**Marissa Ditekowsky (09:00):**

Yeah. So as we know, disability affects all the things that allow us to be economically secure, and our systems transformation guides really go into a lot of these issues very in the weeds. But just the systemic oppression and discrimination that disabled folks experience, these are systemic problems. So we can't just make one change or have some sort of band-aid put in place and think that will magically fix it. These really are systemic issues.

(09:36):

So first off, it's just really more expensive to be disabled. We have so many additional costs, whether that's durable medical equipment, or whether that's assistive technology, or whether that's a ramp in somebody's home, or changes somebody has to make their apartment accessible for them. So there are so many added costs of being disabled, and then as a result of that, there's also this debt that can accrue. So medical debt, for example, is a really big one that disabled folks experience. And for disabled women, in

particular, we're thinking about preventive care, we're thinking about the cost of pregnancy.

(10:26):

The cost of pregnancy are exorbitant as it is, but imagine also adding onto that a complication, right? And we know that disabled women are more likely to experience these kinds of complications. So I think you have all of these different factors playing in, and there you have the debt, then you have barriers to wealth building in and of itself. So not only are the expenses more, but it's harder to save, and it's harder to build that wealth. We have these draconian, outdated public benefits roles that keep disabled women in poverty.

(11:03):

We have these asset limits, we have these work disincentives, and the benefits themselves are so meager, it's just impossible to live on. And then, on top of that, it's difficult to actually access credit for so many reasons, but our credit system is incredibly broken and our credit histories can be impacted by our ability to pay. And if you miss a payment because you can't afford it or anything to that effect, then that will impact your credit history and your ability to access credit in the future. We have, in terms of financial freedom, barriers to being allowed to make our own decisions in the first place. I know people were extremely focused on the Free Britney movement and what that meant, but disabled folks are maybe placed under really overly restrictive guardianships or conservatorships where their ability to make any kind of decision, including financial decisions, is stripped from them, and so the actual ability to make any choices just does not exist for a lot of disabled women.

(12:26):

And then, when we're talking about employment, disabled women experience discrimination and occupational segregation in employment, meaning they're kind of relegated to jobs that are "Meant for disabled people," and those jobs are often lower paid and not valued in a way that they really should be, and so we get lower wages overall. And disabled women are also experiencing literal segregation, and sheltered workshops, and can earn sub-minimum wages under the Fair Labor Standards Act. There is an exception to the sub-minimum wage requirements for certain disabled workers, and so certain disabled workers, working for certain employers can make below the minimum wage, earning pennies on the dollar. And then, disabled women who give and receive care just need better access to paid leave and adequate supports. Our care economy is also completely broken, and folks who need to give and receive care just aren't able to do that in a way that is financially supportive or generally supportive.

(13:41):

And we also know that disabled folks are more likely to need time to care for chosen family, and right now, there really aren't protections for that. So I think those are the higher level issues that prevent disabled folks from achieving financial security in a really big way.

**Maddie Crowley** (14:07):

Yeah, thank you so much for that. This is Maddie, and also, as a multiply disabled, fem-presenting person who experiences a lot of the same things that you're naming, one thing that was coming up for me, as you were describing all of these examples that I think about a lot of the time, is not necessarily just the cost of being disabled. I mean, it's a part of that, like a part of the Crip tax. But the income and wealth, being that people with disabilities, specifically multiply marginalized people with disabilities experience, just because of the time lost to quite literally with the hours wasted on the phone with insurance, on the phone with benefits folks, in care settings, in hospitals, at doctor's appointments, trying to fight your way for assistive technology and the hours spent on the phones, arguing that, "This is something you need." And I love that you brought up taking care of a loved one, the broken care provider complex, and then also taking care of chosen family, because as we know, women is not just cis women, it's trans women, it's non-presenting femme folks.

(15:23):

It's everybody but men, brought into a feminist space that we're talking about. So I was just curious if any of that resonated with you or if you wanted to elaborate on just the amount of time that is lost, the amount of potential income that is just lost and it's all kind of a part of the system and how it works.

**Marissa Ditekowsky** (15:50):

So the system is designed to keep disabled folks in poverty, and that includes the barriers to actually accessing these services. And so sometimes trying to get these kinds of benefits or stay on these kinds of benefits even, you have continuing disability reviews or all these kinds of things is a full-time job, and when you already have to work in order to pay your bills. And then on top of that, with your disability, perhaps you also have additional doctor's appointments, or perhaps you simply have less energy or less energy to do things than other folks might have. And so you add in all these barriers to accessing supports that you need, and it's incredibly difficult. And then, when we talk about disabled women, we are talking about trans women as well.

(17:03):

Trans women are women. I will say that a lot of the data is lacking when it comes to trans and non-binary folks, though we do know that trans and non-binary folks are more likely to be disabled, and we do know that there are significant barriers to economic and financial security for trans and non-binary folks. So I think right now, we just want the data to support that, and once we do, I think it'll be much easier to talk about the very real impact. Right now, a lot of it is anecdotal, things that we know, things that we're seeing, and so I think a lot of our data advocacy really comes in there. So we've been doing a lot of work when it comes to counting disabled folks in a way that's actually inclusive and accurate.

(17:59):

And that's really important for our work, because when we are trying to make changes for disabled women, it's really hard to do that without the appropriate data to back up our position on what disabled women need. So I think there was a controversial proposal by the Census Bureau to change the disability questions for the American Community Survey to new questions that would have severely undercounted disabled folks, including disabled women. And so we joined coalitions to get that paused, and right now, the disability questions for 2025 will be paused, and left at the current six questions on the American Community Survey, but we want to make sure that in the future, there is an opportunity to change the way we collect these data to make sure that it is fully accurate, inclusive, and that includes data on sexual orientation and gender identity. These are really important things that we know we need to do our work.

**Keith Casebonne** (19:20):

Marissa, thanks so much for that overview, and really starting to get a little bit more into the deeper issues there and the more granular issues, breaking down how the gap in financial equity is and the challenges that women with disabilities are facing on a daily basis, just trying to get through the day essentially, and have enough money to eat and just live a full life, and it just shouldn't be that way. And so one of the ways that these things will be talked about more nationally and brought to light is the fact that Women's Equality Day is around the corner, August 26th. Can you talk a little bit about that day and how we can center women with disabilities in that conversation?

**Marissa Ditkowsky** (20:00):

Yeah, sure. So I think the first thing that I want to address is the name itself, Women's Equality Day. And when we talk about equality, we're talking about everybody getting the same treatment, everybody, for example, getting the same amount of money or the same services and benefits, but I think what we really want to focus on is equity and justice. So

equity, as opposed to equality, means that everybody gets what they need. So that might be more for some folks, that might be less for other folks.

(20:39):

It just really depends. So when we talk about disabled women especially, just giving us equal opportunity, or equal amounts of money, or equal pay is not enough. We talked about how disabled folks have additional costs of living. So if you pay us the same amount of money as a non-disabled person, that money is not going to go as far. So I think I really view things more in an equity and justice frame, but I do think it's still important, when we talk about things like Women's Equality Day, to focus on this intersectional lens of, "How can we talk about disabled women?," and women generally, right?

(21:30):

Equity for women is also important. We have the pink tax, we have all these additional costs as well that would require an equity frame in order to get to a place where we actually come out the same, or come out with equal opportunity, or come out similarly, financially secure. One of the things that we are working on is the first ever Disabled Women's Equal Pay Day, which will likely be sometime this September. So there are a number of equal pay days, set up throughout the year for different groups of women and LGBTQI+ folks to kind of recognize the fact that these groups are just not making the same amount as non-disabled, typically white and non-Hispanic men. And so we are going to be releasing data and information on the wage gap for disabled women and the things that we can do to achieve equity for disabled women when it comes to wages, when it comes to pay, when it comes to access to the workplace, when it comes to public benefits and the systems that disincentivize work and make it impossible to save, because when you're working and there's an asset limit, there's always that concern, "What if I go over the asset limit because I make too much?," or, "What if I make too much, and then become ineligible because my income is over the limit?"

(23:14):

So I think there's a lot there that we are going to be talking about and focusing on. And in addition to that, when we talk about Women's Equality Day, we talked a lot about intersectional issues earlier, and so making sure that those intersections are clear, making sure that they are upfront, making sure that they are discussed is really critical to the work. And that's a lot of what I do and we do at the National Partnership, is just making sure that these intersections show up in these conversations, because it's often overlooked, and so we want to make sure that it is not overlooked and that this is a part of the conversation. And that's where we want to start, is actually being a part of the conversation.

**Maddie Crowley (24:05):**

Yeah, and one important conversation that disabled folks were very much at the center, at its core, as like the main driver of bodily autonomy and privacy, but were unfortunately not really included in the discussion was specifically about the overturning of *Roe v. Wade*, which is now approximately two years ago. And we had an episode with a few disability activists back when that happened, and talking about the experiences of disabled women, of their experience in healthcare, navigating pregnancy care, and what that was all like. So can you talk about abortion and sexual healthcare, and access, and disabled women's and people's reproductive rights?

**Marissa Ditekowsky (25:00):**

Absolutely. And before we get into the weeds, when we talk about access to reproductive and sexual healthcare for disabled folks, we really have to put it in the context of this country's history of eugenics. We still have *Buck v. Bell* that has technically not been expressly overturned, which basically was a Supreme Court decision that allowed for the involuntary sterilization of an institutionalized woman in Virginia. And some of the language in this decision, talking about how three generations of imbeciles is enough. It is incredibly damaging, and this is in our history.

(25:50):

This can't be erased, and these kinds of sentiments still remain, that it hasn't gone away. And when we talk about *Roe v. Wade* itself, the plaintiff, Norma McCorvey was institutionalized, was a ward of the state, experienced significant trauma throughout her life and so we're thinking about how these issues can't be disconnected. And even the plaintiff herself had this connection to the disability community. And then, when we talk about *Roe* being overturned right after *Roe* was overturned, we have now about three million disabled women who are in states that have banned or are likely to ban abortion, and not being able to access abortion care is incredibly dangerous for so many disabled pregnant people. It could be dangerous for me as well if I ever became pregnant.

(26:49):

There are lots of complications that disabled folks and disabled pregnant people face that non-disabled pregnant people may not face, whether that is a heart issue or some other condition that can be damaging to the health of the pregnant person or literally risk their lives. And so there's been a lot of fear throughout the disability community related to that, but even then, we know that *Roe v. Wade* was not enough. So not only do we no longer have *Roe v. Wade*, but *Roe v. Wade* itself was really the floor. We had cases like *Harris v.*

McRae, for example, where the Hyde Amendment was applied to basically ensure that folks on Medicaid or Medicare would not be able to access abortion care, because any use of federal funds just was not allowed for abortion. So for anyone with Medicaid, it is very state-dependent on whether you can access abortion care, because those funds would have to come from the state and not the federal money.

(28:04):

Since Medicaid is a federal state program, they both kind of contribute funds to those programs, so it would have to come from state funds. And for Medicare, you're out of luck, it's all federal funds. So if that's your only insurance, it can be very difficult to access abortion care. And we know that disabled folks are more likely to be on Medicare and Medicaid, and so when disabled folks can't access this abortion and it becomes very cost-prohibitive, it's dangerous. And the other issue too is with transportation.

(28:39):

So if you are being forced to cross four state lines and you're a disabled person, accessible transportation is expensive and difficult to come by. And so there's just a lot of barriers here when it comes to disabled folks following Dobbs. And when we talked about Free Britney earlier, and we talk about overly restrictive guardianships and the impact on all decision-making, that also includes bodily autonomy. And so whether that means Britney Spears didn't want an IUD, she wanted to have a child, the freedom to do so, right? It's not just about the freedom to access abortion care, it's also the decisions that we make to have children that are often second-guessed and questioned.

(29:29):

So it's about all bodily autonomy and our ability to make the decisions that we want to make. That's not being forcibly sterilized or not being told we can't have children, if we want to have children, or being able to access an abortion if that is what we want to do. So it's very multi-pronged.

**Keith Casebonne** (29:50):

Yeah, there's a lot of complexities and intricacies there that we're not just talking about a barrier or two. There's so many interwoven issues here. Very happy that you were able to share all that and provide our listeners with that overview of the challenges that are faced in that regard. So is there anything else that you would like to highlight or resources, information about either yourself or the National Partnership for Women & Families, other organizations, and anything you'd like to, final thoughts you'd like to share?

**Marissa Ditekowsky (30:22):**

Yeah, we are going to continue this work. We are going to show up in spaces that perhaps we weren't in before or perhaps weren't talking about these issues before, and make sure that this is on folks' radar, that this is an issue that we are talking about, that we are understanding the intersections of gender, disability, race, and having that be front and center. You can follow us on Twitter, Instagram, and TikTok, @NPWF. You can also follow me on Twitter @mditekowsky. I also want to point folks again to the Systems Transformation Guides and a lot of the resources that the National Partnership for Women & Families has put out on disability.

(31:11):

We did a lot of work as well related to Dobbs and disability, and even participated in the first ever Disability Reproductive Equity Day this May, and published some resources on that, including a blog that I wrote with my personal story and why that day is so important to me, and the experiences that I have been through. The Center for American Progress' Disability Justice Initiative also has some really great resources on disability and gender, and the National Women's Law Center also has a really great report on sterilization of disabled folks across the country and the laws that still remain in place. So lots of great work going on and lots of great collaboration, and we look forward to continuing that work.

**Maddie Crowley (32:03):**

Well, thank you so much. As folks who listen to the podcast already know, but for new listeners, we provide relevant links to everything that's being discussed in the episode, so all the great resources that Marissa just touched upon will be in our show notes so you'll be able to go to their website, go to social media, and also find information about some of the court cases we talked about, these different various awareness days and equity days, and specifically these transformation guides that we'll link to as well. So thank you so, so much, Marissa. This has been fantastic. Thank you so much for the work that you do for our community and continuing to push for things to move in the right direction and for the rights of all folks that your organization cares for. We really appreciate it, and thank you so much for your time.

**Marissa Ditekowsky (32:56):**

Thank you.

**Keith Casebonne (32:59):**

Thank you, Marissa, for teaching us so much about this intersection and for all the work you do at the National Partnership for Women & Families. For those who are interested, of course, we have a list of all the various things we mentioned in the podcast, in our episode show notes for you to peruse and explore and learn more about what we discussed.

**Maddie Crowley (33:16):**

And be sure to like, comment, subscribe wherever you're listening. We're on all the major podcast platforms, and as always, the recording and transcript are also available on our website for free.

**Keith Casebonne (33:26):**

Yes, indeed. And as always, if you have any questions or comments about the show, please email us at [podcast@disabilityrightsflorida.org](mailto:podcast@disabilityrightsflorida.org).

**Announcer (33:34):**

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