

## **Your Health Unlocked Episode 52**

### **Health Care Discrimination - Your Rights And System Gaps**

Have you heard of Section 1557? Neither had I. If not, join us in this episode of Your Health Unlocked with Madeline Morcelle to learn how this legislation protects your civil rights to nondiscriminatory healthcare. Madeline, a senior attorney at the National Health Law Program, dives into the history of Section 1557 of the Affordable Care Act, recent changes, and real-world stories of how people are fighting against discrimination in health care. Listen to learn how this landmark rule affects you and holds health care to a higher standard against discrimination.

0:00:00 - Adele Scheiber

Welcome, welcome, Madeline to the Your Health Unlocked podcast.

0:00:07 - Madeline Morcelle

Thank you so much, Adele, it's good to be with you.

0:00:11 - Adele Scheiber

So why don't you tell our listeners a little bit about the woman, the myth, the legend and what you do for the National Health Law Program?

0:00:20 - Madeline Morcelle

Partly a legend, but I can certainly share. So, the National Health Law Program has been around for 55 years, and we fight to expand and defend equitable access to health care for low-income and underserved communities in the US, with a particular focus on Medicaid and civil rights. Our work involves litigation policy, lawyering and advocacy, and legal education to advance health and civil rights at the federal and state levels. I serve on NHELP's federal advocacy and sexual and reproductive health teams and focus my practice on health equity and reproductive justice issues regarding Medicaid eligibility and sex-based and intersectional discrimination. Before NHELP, I served as a community lawyer in Mississippi, and I started my career at the US Centers for Medicare and Medicaid Services, working on federal health policy.

0:01:22 - Adele Scheiber

That's just a few little jobs there. Clearly. That's awesome. You're fighting the good fight. I've interviewed what? Three lawyers this week, and you're all doing some great work. So, Medicaid, it's a bear. Right, it's an absolute bear. I feel like I hear the words Medicaid, Medicare and Affordable Care Act all squished together a lot of the times, and we're here today specifically because a recent change was made to a rule called 1557 that informs Medicaid. Am I right? Can you just kind of unpack the definitions and the relationships here first?

0:01:59 - Madeline Morcelle

Yeah, absolutely. So The Patient Protection and Affordable Care Act, often referred to as Obamacare, is a federal law that was passed in 2010 and included a range of really expansive federal health care reforms that had implications for a number of health insurance programs and plans, as well as civil rights, and so Section 1557 of the Affordable Care Act is the ACA's non-discrimination provision. It prohibits discrimination in covered health programs and activities on the basis of sex. That includes sex stereotypes, pregnancy or related conditions, sexual orientation, gender identity and sex characteristics, including intersex traits. Discrimination on the basis of race, color, national origin, that includes limited English proficiency and primary language. Discrimination related to disability, age and any combination thereof. So, it was really important in that it was the first federal law to prohibit intersectional discrimination for people who have multiple marginalized identities, and it also was the first federal law to broadly prohibit sex discrimination in health care.

Its protections apply to most health programs and activities that receive federal funds, so that means most health insurance, such as Medicaid, which is the federal and state partnership program that provides health coverage to people with low incomes in the United States. Medicare, which covers older adults and also people with disabilities, and is administered on the federal level. Most healthcare providers, most healthcare systems, offices and their staff, so even the person who sits at the front desk of your doctor's office may be covered by section 1557. Among, like, even some clinical trials are covered, and among other entities and activities, and a good rule of thumb is that if your doctor's office or your pharmacist accepts Medicare which most do, you're going to be protected by Section 1557, even if that's not your form of insurance. And if they don't take any insurance,

there's a good chance that they are- If they don't take any insurance, then you're not going to be protected by Section 1557.

0:04:46 - Adele Scheiber

I got it. It reminds me of what I think people are a little more familiar with, which are like the mandates attached to public school funding, right? So essentially any public federal dollars. If you touch any federal dollars at all as a medical provider, basically you're covered by Section 1557, which I had never heard of until you told me about but it's essentially our discrimination protections, it's our civil rights. You're protected, your civil rights are protected. Bottom line. If your medical provider accepts a dollar of federal money. That's kind of what it boils down to, right? [Madeline - That's right.]

Well, and it sounds like 1557. So, sounds like a rule that I mean- I always thought, call me naive, I always thought we were protected in some way anyway. But it sounds like this rule has been gone through a few iterations. Can you talk to us about the history of this rule and specifically, what changed a few months ago about it? What changed a few months ago about it?

0:05:46 - Madeline Morcelle

Yeah, absolutely so, Section 1557, some protections in health care have been around. So, Section 1557 integrates and expands off of some pre-existing federal civil rights laws such as the Civil Rights Act, the Rehabilitation Act, the Age Discrimination Act and Title IX. However, it is the first federal protection broadly against discrimination in healthcare on the basis of sex, and so before the ACA, before Section 1557, insurers could charge women more for health coverage and they can't do that anymore because of this law. The National Health Law Program helped craft Section 1557 as part of our work on the ACA and we've continued to fight for its full implementation. But, as you just said, there's been a lot of back and forth, so there was a really robust public input process during the Obama administration that culminated in the first final rule on Section 1557. So, what is a rule? A rule is basically just a set of regulations that implements a law.

So very often we need regulations to implement a law. In Section 1557's case we actually don't need regulations, but the regulations provide really critical clarity about the parameters of these protections.

0:07:09 - Adele Scheiber

I just want to pause on that really quickly about the relationship between laws, rules and regulations, because I, you know, I used to. I studied public administration and let me tell you I don't know why, but I always thought, like okay, before that, like the judge makes a law, we're done, Right? But that's just the start of the process, right? Often these laws don't specify at all how we're actually going to do the law, and so the regulations are essentially so. I guess you know one way- One analogy I like, is like there are rules to football, right and soccer, but then like the regulations, that's what like the coaches are there for, that's what like the, you know what I mean, and they are constantly regulating the games.

Is that kind of?

0:07:58 - Madeline Morcelle

I mean, so often in health policy the devil's in the details and the regs are where we really get into the details.

0:08:08 - Adele Scheiber

Right, right, well, so this latest update. What does this mean? It was passed. Remind us when it was passed, this update to 1557. What does it mean critically for the American people?

0:08:20 - Madeline Morcelle

Yeah, so during the Trump years there was a second final rule that really, really rolled back the regulations, including completely eliminating the regulatory definition of sex discrimination. And so this final rule restores that definition, as well as other regulatory provisions that really spell out the details about what these non-discrimination protections entail.

And what's really important about all of this right is, discrimination has no place in health care but it's pervasive for so many people, whether you're a woman or non-binary person, or an LGBTQI plus person, or a Black, indigenous or other person of color, or you are an immigrant or you're a young person, it's not rare to experience discrimination in healthcare and as a queer disabled woman, I have experienced sex discrimination in health care and that's not rare and it's that experience that is really helpful in this work.

But it's also an experience that I wish none of us had to have. So, we're really encouraged by the Biden-Harris administration's really robust implementation and enforcement of these protections through this newest final rule, which was just finalized about a month ago. It – Most of the provisions of this final rule go into effect July 5<sup>th</sup>, so coming soon and you know after it, it means a number of things for various forms of health care discrimination. So, for example, after the Supreme Court overturned the constitutional right to abortion, longstanding discriminatory barriers to health care only intensified for women and people capable of pregnancy, and especially people of color, people with chronic health conditions and other disabilities, and immigrants, and we've seen a surge in anti-LGBTQI plus discrimination, especially in anti-trans and anti-gender affirming care context.

The new regulations take essential measures to clarify protections against sex discrimination, both in the context of sexual and reproductive health care, LGBTQI plus health and beyond. Section 1557 also ensures that people with limited English proficiency have access to vital health care information. Health care entities under this part of the ACA are required to provide language services, breaking down language barriers for diverse communities so that they can truly access health care.

Further it prohibits discrimination on the basis of race and ethnicity, and so the new regulations clarify those protections as well. And finally, section 1557 helps ensure that health care programs and services provide physical access, effective communication and community integration for people with disabilities. For people with disabilities, and the new final rule affirms that people with disabilities are protected not only from coverage denials for the care that we need, but also from discriminatory pricing practices, including discriminatory copayments, prescription tiering and coverage limits. So, the new final rule again like, really spells out the details around these protections, raising the bar on what these protections will mean day in and day out when we're accessing care in our system.

0:12:17 - Adele Scheiber

Yeah, no, that sounds, I mean, it sounds like a really good set of regs, like I often read regs and I'm like, what about this group? What about? What about this group? What about? It really sounds super robust, and I guess, hold on, let me find what I was going to ask. So it's yeah, you you kind of referred to.

I'm glad you called out this kind of tug of war that's been going on with a couple of things both the protections against discrimination in the federal government and the and the protected classes, right. So, when you were talking about gender identity, sexual orientation particularly, this is something that has been, we've been fighting over as a federal government and our increasingly polarized you know society now for decades. And actually we're just we're working on an analysis of Project 2025, which is that Heritage Foundation House of Horrors playbook about what they would love the next conservative president to do, and I mean they spell out in black and white and I'll put it in the show notes that they would like to erase the very terms gender, sexual identity, sexual orientation from all federal documentation. So, essentially, take 1557 and set it on fire. That's essentially what they're proposing, really. So, related to that, and not only that we need section 1557, because it's not just that this, this discrimination and these weird moments. You know, like I one time had a nurse, she's doing my pelvic exam. Okay, she's like in my body.

And she's like Are you sure you're bisexual? Don't you just have really good female friendships? I'm like I didn't recall bringing this up, man, like I don't you know what I mean, like just those little moments that are kind of funny now or like like that's not even. There are actually laws called healthcare refusal laws, right or conscience laws that actually, I mean, they're kind of like meant to be like exceptions to these discrimination rules on the book. So can you talk a little bit about those and how they interact with 1557?

0:14:18 - Madeline Morcelle

Yeah well, first of all, happy pride from a fellow bi woman and person who had to explain to this man in a dating app this morning that bi people are not confused. Super fun times. So federal health care refusal laws are laws that govern when and how covered entities refuse to cover, deliver, provide information on or offer referrals for healthcare services that they object to based on their religious or moral beliefs. These laws contribute to really dangerous barriers to essential health care for many people who are already marginalized and underserved or just outright neglected by our health care system.

In particular, religious refusals systematically undermine and prevent access to health care for LGBTQIA plus people and women, including those of us who are trying to access sexual, reproductive or gender affirming health care services, such as abortion and hormone replacement therapy.

It has implications for people with disabilities, such as substance use disorder, people living with HIV, and it also has broad implications, especially for people in rural areas or who have limited access to transportation, who just don't have a lot of alternatives, if any, from the health care provider that they're going to who's refusing to deliver care. The new final rule sets forth a process for these covered entities to request exemptions from the federal government for Section 1557 requirements, so you know, in the past, HHS has not itself, overseen federal the implementation of federal health care refusal laws. There has been a bit of a shift on that in recent years. The good news is that the federal government is going to examine requests for exemptions and apply the legal standards set forth in the applicable federal health care refusal law on a case-by-case basis. So, what this means is there will be no categorical blanket exemptions from these protections granted.

0:17:05 - Adele Scheiber

Are there now or were there before, I guess?

0:17:08 - Madeline Morcelle

No, the Trump administration tried to do that.

0:17:11 - Adele Scheiber

I see, I see.

0:17:12 - Madeline Morcelle

Ultimately, were not successful.

0:17:15 - Adele Scheiber

Well, and we know, I was a student of the civil rights movement, right. We know that just because it doesn't... There were whole groups of activists who were testing federal laws and regs, right?

So that's what the freedom rides were about. Like it would say in black and white you can't discriminate against people on the bus, but we still needed to have these people test that because in these little jurisdictions people didn't give a crap right and so this makes it on the books. In black and white, I feel like harder for discrimination to happen, but it's still gonna happen and it just makes it harder. Right, it gives. It gives people who are going to discriminate less room to move lawfully.

0:17:50 - Madeline Morcelle

It sounds like that's right and you know, to what you raised about project 2025, I just want to stress that you know, if this tug of war does continue in the future, section 1557 is self-implementing, which means that this final rule and HHS the US Department of Health and Human Services regulations on Section 1557 has to do with HHS's enforcement of these protections. But people also have a kind of a private right of action under section 1557, which means, even if these rules go away, this rule goes away, these regs go away right people can still enforce their rights in the courts.

[Adele - Really?] yes.

0:18:39 - Adele Scheiber

So even if, like, let's say, a blanket, like we, we set it on fire, people can still... that's interesting. They can claim like a civil, like discrimination in the. That's interesting. That's a nice example of checks and balances, ladies and gentlemen. That's good to know, and I feel like people wouldn't have known. I didn't know that, so that's good to hear. So, okay, we've talked a lot about regs and laws. Can you give us a couple of examples of what NHLP has been seeing, maybe case studies of how this discrimination might play out for different groups? Like, tell us some stories, because I think people will really be able to relate.



0:19:25 - Madeline Morcelle

Yeah, absolutely. So, one example of intersectional discrimination, which I mentioned earlier, that we see a lot of, unfortunately, in a maternal health context because it is separate violence. So the really gross mistreatment of especially Black women and people in maternity care, prenatal, postpartum, labor and delivery care, things like rough handling, shouting, dismissal, procedures that people feel coerced into, such as cesarean sections and for that reason we had asked for some acknowledgment that this could constitute prohibited intersectional discrimination under Section 1557 and in the final rule, in what is called the preamble to the final rule, which is where the government explains what is actually in the regulatory text, HHS acknowledged that, depending on the specific facts of the case, this could be prohibited under Section 1557. So long as that discrimination, that those behaviors are happening because of an individual's race and or sex.

0:20:44 - Adele Scheiber

Which is kind of hard to prove, though, isn't it? I mean, that's, that's a tall order, no, or?

0:20:48 - Madeline Morcelle

It depends on the specific facts of the case, right I mean we know that black and other people of color experience those kinds of behaviors at much higher rates.

0:21:02 - Adele Scheiber

Which is what you would argue as a defense attorney, right, I mean like give us? I mean I guess my question is like to play- how viable would it? How? How protective are these protections in your opinion as a lawyer? I mean, is that going to hold water in court? Have you seen it hold water in court?

0:21:17 - Madeline Morcelle

I think it can absolutely hold water in court and they're actually, currently, I don't know what the status is right now there is, I believe, some litigation on this exact issue, but I would have to, I'll have to look and I can pull that if it is helpful.

0:21:36 - Adele Scheiber

You can send me something later. It is helpful. I just think a lot of people, I just hear a lot of people be like, yeah, I think it was discrimination, but I don't, I can't do anything. People feel really disempowered, right yeah. So I wanted to kind of hear your thoughts as a lawyer, like, how empowered are they?

0:21:53 - Madeline Morcelle

I think, if that has happened to you. You have a strong case, especially because people you know in those circumstances, if you're experiencing that in a labor and delivery context, other people are around. [Adele - It's true. It's very true]. It's very rare that you're by yourself, so I think that you could have a very strong case. Another example of intersectional discrimination that we have seen post Dobbs, we've seen a surge in barriers to medications that treat chronic health conditions that have properties that can induce abortions or cause birth defects.

0:22:32 - Adele Scheiber

So talk about that because people do not know about this and it's scary as heck. Like give this a scenario. Like Jane walks into the hospital and needs x.

0:22:41 - Madeline Morcelle

It's very scary, so you know, women, girls, and presumably non-binary and transgender people have been subjected to discriminatory denials of care, coverage, and also like delays in trying to get prescription refills on the basis of sex, regardless of whether their state has actually banned or even restricted abortion. These barriers have generally fallen into one of the following three categories. So, the first, some pharmacies within and beyond states that ban or severely restrict abortion have refused to fill prescriptions for drugs such as methotrexate, which treats rheumatoid arthritis, cancer, and some other chronic conditions.

0:23:31 - Adele Scheiber

So not related to abortion at all.

0:23:44 - Madeline Morcelle

Not related to abortion. Methotrexate is used in a reproductive health context to induce miscarriage in cases of ectopic pregnancy, which are almost never viable. But I think, like 90% of methotrexate prescriptions are for chronic health conditions. So, you know others have refused to fill these prescriptions until the prescribing provider verifies that the purpose of the prescription is to treat a chronic health condition and not abortion, resulting in delays. And you know we've seen this happen again in states that have protected abortion. We have seen this happen for kids who are like prepubescent, and we've also seen this happen for women who have already gone through menopause, who are not going to get pregnant.

So, these denials of care and barriers to care are broad, that's the first bucket. We're also seeing some healthcare providers and healthcare entities refuse to prescribe or refill medications that can either end or cause complications to pregnancies. So, for example, there's a woman who lives in upstate New York who has Ehlers-Danlos syndrome, a chronic genetic condition, which I also have.

0:24:55 - Adele Scheiber

Oh wow, you and our graphic designer, yeah.

0:24:58 - Madeline Morcelle

Went to a neurologist for cluster headaches, which are a common complication of Ehlers-Danlos syndrome, and said you know, I've already tried all of these medications. They haven't worked. What else do you have for me? And his response was, "well, I don't have anything else for you because all of the remaining things that we could try are teratogenic drugs, which means they can cause birth defects." And she said well, I'm not pregnant and if I get pregnant, I'm going to have an abortion. And his response was "well, the legal landscape around abortion is shifting" and you know, her partner has had a vasectomy like there's no pregnancy. I believe he was he like responded like trigger warning, like responded by saying "well, you could be raped," [Adele – What?!] um, so, like horrible conversation, and filed a private right of action under section 1557, and that litigation is ongoing.

0:25:58 - Adele Scheiber

Oh, I hope they win. I hope they win a lot of money.

0:26:02 - Madeline Morcelle

So that's number two. And then the third bucket is there have been some health insurance companies refusing to cover these medications. So, for example, there is a woman who lives in Baltimore, where I am, who has Crohn's disease, whose health insurance is refusing to cover methotrexate for Crohn's disease.

0:26:28 - Adele Scheiber

And that's really debilitating too. I mean that's the digestive one, right, yeah, yeah. So I mean, and this is just -there's so much to unpack there, thank you for going into such specific detail Because, again, people don't know this unless they have these diseases right. And we know that chronic, you know, autoimmune diseases particularly disproportionately impact women like three to one right. So, women are bearing the brunt of this intersectionally, both because of the chronic condition thing and because we're the ones who can get pregnant right. So, we've got it. You want to talk about intersectional discrimination? I mean that's a double whammy right there. And I mean, yeah, that conversation that that second lady, it's right out of the handmaid's tale. I mean it really is. I know that's like you, very white feminist of me, but it's literally like we must protect your womb ma'am, I'm sorry, at all costs. And like we have an episode on Ehlers-Danlos because, like I said, our graphic designer has it and it's serious business.

Like it hurts, like it is a lifetime, like I would not wish it on my worst enemy. I'll be honest with you. This isn't like oh, I'm in pain sometimes, like this is a freaking emergency, often right. And so to hear that we're worried about some hypothetical child over your ligaments literally melting in your body, like I just don't, that's- So, this is serious y'all. So, speaking of how serious it is, you know and, and how common apparently, this is what- lay us through free legal advice hour. Okay, it's not legal advice, I'm sure, but what can people do if they suspect that they're being discriminated against in a medical setting today? What is their recourse?

0:28:11 - Madeline Morcelle

Yeah. So yes, just as you said, I am a lawyer. I am not your lawyer. Find an attorney in your state for legal advice. But if you experience health care discrimination, even if you're not sure about whether they're covered under Section 1557, even if you're not sure if there's some evidence or whether you have a good claim, you have a right to file a complaint with the federal government. You have 180 days from when you know, the active discrimination or discriminatory omission, which could be like a denial of care or a denial of a prescription refill or a denial of health insurance coverage, 180 days from when you know that that occurred. So, whenever, you find out about it, the clock starts ticking.

0:29:06 - Adele Scheiber

That's six months, y'all. That's six months. It's a long time. That's longer than people think, right?

0:29:11 - Madeline Morcelle

It's a long time. So you know you can file a complaint with the Office for Civil Rights at the US Department of Health and Human Services. You can do that using an online complaint portal which I can share for the show notes. There are also options to you know file by mail and other means.

0:29:36 - Adele Scheiber

And what is the cost associated, really quick, with filing, because I think that's a lot of people.

0:29:41 - Madeline Morcelle

It's free to file a complaint.

0:29:42 - Adele Scheiber

It's free guys, Okay.

0:29:44 - Madeline Morcelle

Yeah, if you want to hire an attorney, there may be a cost associated with that, but if you are a person covered by Medicaid, you may be eligible to get support through your local legal aid organization, so that may also be an option for you. That could be free or low-cost legal support. So, there are options, and a legal aid attorney could also help you assess whether it makes more sense to file a complaint and/or file a case in federal court. So, again, both of those options are there.

0:30:29 - Adele Scheiber

Well, and you know, I know a lot of people I've heard firsthand, unfortunately, because you know this is so common right, "oh, I don't have the money to spend on a consultation," well, a, like you said, right, there's all kinds of sliding scale legal aid out there. We'll put a directory of some kind in the show notes. I'm sure it's a Google away. But let's say you don't qualify for the free legal aid or whatever. One time I needed to consult the labor rights attorney, okay, and, and that hour long consultation where they reviewed 10 pages of documents heard my whole story out. That cost me a hundred bucks. That was. That was very feasible for me, and it could have led, and I learned so much in just that one hour consultation. And I think people hear lawyer and they think TV, thousands of dollars in retainers and, like a lot of the time, legal help is more affordable than you think too, especially for that initial. Did this happen? Do I have standing question Right? So, and a lot of lawyers will waive that initial right? If they feel like you have a strong case cause, they think they'll win. Am I right about that?

0:31:31 - Madeline Morcelle

Yeah, that's right, and it's also true that you know, if you don't qualify for your legal services organization or their caseload is so high that they're not able to take on new cases, you can also try your state lawyers bar association often has a pro bono helpline or pro bono directory where you can get connected to pro bono support and that may have different eligibility criteria or, like you know, a different level of capacity than your local legal aid organization. So that's another potential option, depending on your situation.

0:32:15 - Adele Scheiber

You don't even have to leave your house, folks. And to quote Deadwood, my favorite show, pro bono means free, gratis, right. In case you don't know. But yeah, and so I mean it really is. If you, you have protections. There's people in your corner, there's institutions in your

corner, even if the rhetoric- It doesn't feel like when you're doom scrolling. Even if you know five people with a horror story.

There's recourse to these horror stories. The other thing I just wanted we didn't cover this, but I actually have like a follow up about 1557, which was isn't it true that now, with the case by case refusal law litigations, that isn't there a rule that says, if you get a refusal law exemption- so if the federal government says, okay, Catholic hospital, you don't have to treat gay people, for instance, don't they have to be transparent with that on the front end now? Or am I misinterpreting that?

0:33:15 - Madeline Morcelle

So they don't. We've pushed this.

0:33:18 - Adele Scheiber

Oh, rats.

0:33:22 - Madeline Morcelle

So there's an optional. so I would say, like you know, there's an optional notice that they can provide up front. Ah, okay, but it hasn't been made mandatory.

0:33:34 - Adele Scheiber

I see so it's guidance, but not all right, never mind. So you can't go to the website everybody and go "Do they treat" you know control F.

0:33:43 - Madeline Morcelle

I mean some healthcare entities will, you know, post if they have- if they don't provide certain care, there are sometimes good clues. So if you're looking for a hospital in your area and you are a pregnant person, for example, and you have a high risk pregnancy, and you have multiple hospital options, catholic hospitals, if you end up needing an abortion as emergency care, may not be willing to provide that emergency care for you. So, you know,

thinking about, is my healthcare entity a religious entity and does this religion, you know, have objections to my identity or to healthcare that I may need, can be a good clue. Unfortunately, not everybody has multiple options where they live in terms of their providers.

0:34:51 - Adele Scheiber

Well, and this is also causing like a chilling effect, right? So even providers, we've seen this especially in rural areas, even providers who don't they're like pediatricians, they don't provide this care at all, but like especially OBGYNs, they're just leaving these states. They're just leaving because, as you said, people are unsure, they're afraid, and I understand why they're afraid. Some of these laws, like the ones in Texas, are like if you even sort of do an abortion without 50 pages of documentation, we could sue your [bleep], like I mean, this is so. They're just leaving these states, which is causing the systematic shortage of care in these areas.

It's what we call in public admin "a negative feedback loop." Because of the rule it's getting worse and the rule is worse because it's getting worse and everything's worse. Like that's just how it's. So I mean, one thing I guess can folks do now - this is my question if you're not sure about what kind of care like let's say, you're a new mom and you're shopping around for prenatal care, you're considering driving three hours away, if you call up acme, catholic hospital limited and ask certain questions, so things like, if I need an abortion, what would be your procedure? Or like do you support gender affirming care. Do they legally have to tell you what they would do?

0:36:07 - Madeline Morcelle

That's a really good question. I think there's a legal argument to be made, but I don't know that there is an explicit legal requirement for them to disclose. However, I think that most probably would disclose.

0:36:26 - Adele Scheiber

That's what I'm thinking, right, Like why would they lie? Like what? It doesn't serve anybody right.



0:36:27 - Madeline Morcelle

If they have an objection to providing care, yeah.

0:36:31 - Adele Scheiber

Yeah, so it's not foolproof y'all, but if you have any questions, just ask. I mean, it goes back to- It goes back to being your own advocate and informed consent. If they're not giving you informed consent, that's a red flag. But, you can also seek out that information yourself, and it sucks that you have to do that, but it's what I would do, right?

So, Madeline, this has been incredible. You've really. What I like about these episodes is you take these dry laws, rules, regulations that nobody understands, and we're really putting them in a real world context for folks, because they matter.

So, with that in mind, is there anything else that you want our listeners, who is John and Jane Q public, to know?

0:37:11 - Madeline Morcelle

I mean, I'll just I'll mention a couple of things really briefly that that the final rule mentions and spells out in a sexual, reproductive and gender affirming care context, in particular, you know, very often in an assisted reproduction context. So this is things like IVF and other forms of care that help people build families. Very often there are insurers that will cover assisted reproduction services, such as fertility services, or providers who will provide those services to different sex couples but not to same sex couples, and the final rule spells out that that's a section 1557 violation. So that's one thing that I want to lift up.

0:38:01 - Adele Scheiber

That's a big deal y'all. That's cool, okay,

0:38:07 - Madeline Morcelle

It is a big deal. Another big deal is we had pushed the administration to acknowledge that so very often in pain management, so we were talking about Ehlers-Danlos Syndrome. Very often in pain management, if you are a woman or if you are a Black person or other person of color, you have trouble accessing the pain medications that you need. That would be provided to a cis white man and there are studies showing that-.

0:38:38 - Adele Scheiber

I was going to say that's not anyone's opinion. That's been proven over and over again.

0:38:41 - Madeline Morcelle

It's not anyone's opinion you know, this practice is rooted in millennia old sex stereotypes that have driven health care providers to discriminatorily diagnose women with hysteria, which is an umbrella evaluation crafted for a wide range of physical and behavioral symptoms that only affected people with uteruses.

0:39:04 - Adele Scheiber

Right, Cause the root of the word this is fun. The root of the word hysteria is hyster, which is the Greek word for your womb right. So hysterical is like womb madness.

0:39:17 - Madeline Morcelle

Right and actually, like this was a diagnosis, an official diagnosis in the united states until 1980. [Adele – What? My mom was alive.] In recent decades, like the, the language around medically unexplained symptoms has changed, but the training is still there in a lot of our healthcare providers.

0:39:41 - Adele Scheiber

Right Now we say psychosomatic pain syndrome, or maybe it's just anxiety. Right, we say different things.

0:39:49 - Madeline Morcelle

Right. And then you know, for Blacks and other people of color, there's so much anti-Blackness and racism in our healthcare system. So, you know, very often healthcare providers in a sex discrimination context label women, and especially black and other women of color, as chronic complainers, tell them that their symptoms are all in their head and, as a result, women, and especially women of color, often experience years or decades long delays in accurate diagnoses and treatments for serious conditions, issues, and pain management for serious conditions, issues in pain management. And we pushed the administration to acknowledge that the protections against sex discrimination, which includes discrimination related to sex stereotypes, addresses these forms of discrimination, and they did acknowledge that in the final rules. So that's another thing that I want to lift up.

0:40:38 - Adele Scheiber

Well, and that is huge because, again, like just unfun historical fact, that guy I forget his name, I'll put in- the father of gynecology, quote unquote I mean, first of all, he experimented, you know. Ok, yeah, he got to a good place when it comes to gyno health, but he experimented. Black women were his guinea pigs. I mean that's just facts.

Yeah that's, that's in the, that's a medical doctor. I mean sure it was 150 years ago, but we all know how these institutions make copies of copies, of copies, and even if the writing and the and the regs are different and all the, it's still, that's an institutional baggage piece to this field, and we need to fight it with other institutional language. Like exactly like what you did with 1557. So this is real, y'all. This isn't just like I. I was. I'm sorry, I'm all. I'm all full of piss and vinegar because I've been reading project 2025. This isn't just like woke imperialism. Okay, this is like in the historical record.

0:41:37 - Madeline Morcelle

Yeah, yeah studies that show that even today, like a lot of health care providers still believe that black people experience pain differently, which is so scary. [Adele -That's crazy!!] yeah. So it's really important that these civil rights protections exist, and it's also really really important that people know that they exist, because if we don't know that they exist, then they're not worth a lot. So, I really appreciate the opportunity to come on and share a bit about this. There's so much other good stuff in this final rule that I know we just-

0:42:14 - Adele Scheiber

Honestly send me all the things in the show notes, Madeline, because I will link.

And then what we also do, as our listeners know right, is we highlight different things in our pro tips every month, so we'll keep beating this drum. I just wanted to make sure there was like a hey, quick and dirty, this is what this is right, because I bet if you polled the American people nobody knows what section 1557 is, and it was such a beautiful set of regs that I just I wanted to make sure. But anyway, thank you so much for your time, your expertise and for putting this into a real-world context, Madeline.

0:42:48 - Madeline Morcelle

Thank you, Adele

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