

EMILY LADAU:

Hello and welcome to another episode of Disability Inclusion Required. It is such an exciting month for the disability community. It's Disability Pride month. It's the 34th anniversary of the Americans with Disabilities Act, and that means it's the perfect time to discuss the current state of disability rights in the United States, both reflecting on where we've been and also looking ahead to where we're going.

And as always, we're going to connect this to philanthropy because it's so essential for the sector to have their finger on the pulse of disability issues. And I couldn't think of a better person to be joining us for this conversation than Rebecca Williford, who is the president and CEO of Disability Rights Advocates, also known as DRA. And so to kick things off, Rebecca, I would love for you to share a bit more about yourself and also about the work of DRA with our audience, knowing that we'll dive deeper into it as the conversation goes on.

REBECCA WILLIFORD:

Thank you so much for having me, Emily. It's so wonderful to be on this podcast with you. This is a topic I think about a lot, and I'm so excited to be able to be your guest today and share a little bit about DRA's work with your listeners. So, I'll start with sort of about me and then about DRA because I think the stories are a little bit intertwined.

Starting about me, becoming a lawyer and running a national non-profit legal center was never the plan, and disability was the furthest thing from my mind until it became exactly what I wanted to do and what I'm very, very motivated and driven to do today. So, how did I get there? I acquired my disability as a teenager. Throughout high school, as my disability evolved, I contended with countless medical appointments, missing a lot of school and hospitalizations. I went from having a non-apparent disability to being a wheelchair user after a series of infections that led to nerve damage and neurological disorder. And at that point in my life, nobody had told me about disability rights, civil rights.

I was often the only disabled person or one of a few in a room. And it was really hard to find mentors who had similar experiences. And my experience of becoming disabled as a teenager and seeing how hard... I was lucky, I had parents who were advocating for me, but seeing how hard they had to advocate and on so many fronts. And then also meeting other teenagers who had just acquired their disabilities, usually in some medical center setting who were going through similar experiences of becoming disabled and trying to navigate the world as a newly disabled person. That all exposed me to this completely new universe. It was new to me. It had always been there, but it was very new to me. I just didn't know about it yet.

And it was a universe where so much advocacy for the most basic rights was desperately needed. And all of that ignited something in me. During college, I was living independently on my own with my disability for the first time and figuring out how to navigate that. And I thought a lot about different ways I might be a part of that advocacy. And I couldn't stop thinking about all that I had been exposed to and all that needed to happen in society on so many levels to really level the playing field for people with disabilities.

And that was when I began, I think, to fully embrace disability as part of my identity and something that I was truly proud of. I think up until then, it just felt like a medical experience that

was happening. Getting involved in student groups in college really helped that. And as I got more and more involved in the disability community, I realized, I thought about different jobs I might have after college. And I realized that becoming a lawyer would allow me to do a range of advocacy and it would allow me to help put a lot of good into a segment of society that needed it so badly.

People who are experiencing discrimination because of their disability, they need advocates, they need lawyers. And I learned about some of the ways lawyers were helping people and the disability and healthcare spaces and how critical that was. One example is you get that phase of life, so many disabled people are trying to get accommodations for standardized tests at that phase of life. You're trying to advance your educational and professional goals. And a lot of people needed a lawyer to help them advocate for accommodations, and some people were able to get lawyers and as a result, they got the accommodations they needed. Others were trying to find lawyers to help them, but they maybe couldn't afford one, and their path was much, much harder.

So, I started to see issues with the pipeline, who's getting shut out, who's getting through and all the intersectional identities and how they interplay with disability. And I realized that legal action plays a really, really important role in empowerment and enforcing rights. And I wanted to be part of that work that was moving the ball forward. And I wanted to do it in this really specific way, in a way that was a systemic way that would shake things up for the better. And that's what led me to law school and to DRA.

So, now sort of shifting over to about DRA. DRA's history is really, really intertwined with the ADA passage in 1990. So, our founders realize, and as we celebrate 34 years this year, boy have we come a long way, but boy, there's a long way to go. Our founders recognize the need for enforcement of the ADA to tackle the systemic barriers. And they started DRA in 1993. They started it in Berkeley. It was the perfect place, the birthplace of the disability rights movement in the U.S. So, that's where we began. And we are the legal arm of the disability community when it comes to fighting systemic discrimination.

We are a 30-person nonprofit legal center. And today we have offices in Berkeley, also in New York City and in Chicago. And we represent people with disabilities nationwide. We always have, even when we were based in Berkeley, we team up with local disability groups and attorneys and counsel when we're not operating in one of our home states. So, over the years we've done cases from Hawaii to Alaska to Boston and points in between, North Carolina, my home state. Tennessee, Arizona, and our impact cases have really transformed the fabric of American society in nearly all areas of life. Healthcare, employment, transportation, technology, emergency preparedness, education, incarceration, rights of people who are incarcerated. You name it, the DRA has probably made it more accessible for people with disabilities.

EMILY LADAU:

So, you know that I am a big believer in DRA's work, and I love how you shared the trajectory of your own story and recognizing that the work of being involved with disability from a legal perspective is empowering. I don't know that people have an understanding of why that is. Especially in philanthropy, they're so heavily focused on funding services and supports. And the Disability & Philanthropy Forum actually created a report on foundation giving for disability, and

we found that 94% of an already really small amount of philanthropic funding that's directed toward disability goes towards supports and services.

So, my question is, what about funding legal efforts? And I think that people can be really skittish when they hear the word litigation, but impact litigation, as you started to allude to, is so essential to progress for the disability community. It is a source of empowerment. And so I'd love for you to introduce that term to our audience a little bit more, impact litigation and share with us why it's such an important tool to push for change.

I just have to say before you dive into it, I had the chance to see you all in action in New York City court hearing on taxi accessibility. And I'm not kidding when I say that was witnessing a better version of Law & Order for me. I was blown away by the experience of seeing an argument for the good of the disability community and watching truly the impact of that. So, can you talk about why impact litigation is so crucial for creating change?

REBECCA WILLIFORD:

I am happy to, and it was so incredible to see how many members of the disability community showed up and really had packed the courtroom for that hearing. This stuff matters so much and the community is so, so mobilized around it. Yeah, it was good to be in community with so many folks at the hearing that day, and of course great to see you there. But yes, I am happy to talk about why impact litigation is such an important tool to push for change. It plays a really, really unique role, and I think it's important to think about the role that litigation itself plays and impact litigation plays in the larger disability rights movement.

So, what we're talking about with impact litigation is talking about moving mountains and creating social change and enforcing the laws that are on the books. And 99% of the time, the biggest barriers are only going to be fixed with a court order. So, a judge saying an entity has to do a certain thing. And why is that, why does it take a court order? And I think accessibility, as we all know, is not one of the things, unfortunately, that businesses, municipalities, et cetera, are often thinking about when they're building structures, when they're building systems, when they're creating new technologies.

And people with disabilities, even though they make up the world's largest minority, are often overlooked, ignored, and it's not baked in. It's really can be expensive to tack on. And that's where high impact litigation comes in. You need a judge to say that an entity has to fix a certain barrier by a date certain, and if not, you'll be back in court. And it's about having that accountability. And often in our cases, for those who are newer to impact litigation, at DRA, it always starts with a letter. We are representing clients with all types of disabilities and we send a letter to the entity where the clients experience discrimination and some entities come to the table and want to work out solutions without lawsuits.

And that's wonderful. We welcome that. We love that. We get some of our greatest results through that, but often for the biggest barriers, we don't get that kind of response and we have to file a lawsuit in order to get progress. And folks often ask me, "So, what have you actually gotten? What are the results?" A few highlights of things that have changed and that are starting to change because of impact litigation that we've done at DRA, just to name a few. So, colleges across the country are starting to provide accommodations to students with mental health

disabilities rather than telling them that they have to leave campus because of their disability. That started with a case we did against Stanford.

Juvenile detention facilities or doing a better job providing special ed and supports to youth with disabilities rather than putting them in solitary confinement and pepper spraying them. Streaming services or providing more audio description to blind users. Healthcare providers are also doing a better job providing interpreters to deaf people so that they can have effective communication for medical appointments. Cities are required to revamp their emergency preparedness plans so that they don't leave disabled people behind and the list goes on. But none of those things happened without litigation, a lawsuit.

And we're talking about class action lawsuits where we are often representing a class of hundreds of thousands of people with disabilities, but when we get a fix that's going to be for all of those people. And so that's what I love about thinking about as a teenager, navigating some of those systems that were so broken. Something inside me said, "I really, I want to fix the system. How do we fix the system and not just sort of fix for one person?" And the ADA is, as we celebrate it this month, it's a statute on the books. It was this bipartisan recognition by Congress that disabled people have a really robust set of rights, and that discrimination was so rampant that we needed this federal law to recognize and provide for a way to enforce those rights in so many spheres of society.

So, at that point we had the Rehabilitation Act that was protecting federally funded programs, preventing discrimination there. We had the IDEA, the Individuals with Disabilities and Education Act, but we didn't have this broad sweeping statute. The ADA sort of went into public and private entities, employment, transportation, technology to go further than the laws that we had on the books. But the ADA is written in very general terms and they've had to be defined over the years. And the way they've been defined is through litigation.

I'll give two examples. So, the ADA is divided into a variety of titles. Title II is the one that prohibits discrimination from public entities. It says that disabled people can't be excluded from participating in or receiving benefits of those services, programs or activities because of their disabilities. And that covers a lot, but it didn't say specifically all the ways the law could be used. And one powerful example, that was in 1999, the disability community, a lot of folks are familiar with Olmstead. The disability community gets a big win with the Olmstead case that laid the foundation to get a lot of disabled people who could be living in the community out of institutions.

But it took a case that was litigated all the way to the Supreme Court to get that ruling, that states should be eliminating the unnecessary segregation of disabled people and that they should be receiving services and in the most integrated settings that they could. So, that's one example. And then one other example is under Title III of the ADA. So, this is the title that prohibits discrimination in what we call places of public accommodation. That includes things like restaurants, doctor's offices, sports stadiums, private transportation.

An example here is the internet didn't exist when the ADA was passed, but it's really critical that the internet is accessible to people, especially people with print disabilities and people who are using other assistive technologies. Through litigation, legal requirements for internet access have evolved and they've improved. We've established a lot and we're also fighting to hold on to the ground that we've gained on this front.

In our Target.com case, that was a DRA case that first established that websites needed to be accessible when they were tied to brick and mortar facilities. Then you kind of fast-forward to today, in some jurisdictions that's expanded and requires websites not tied to physical locations also be accessible. So, we see with cases like Derry's case with Scribd. You also see Netflix getting captioning. So, you kind of see how it has taken lawyering and impact lawyering to get us there, pass the statute on the books.

EMILY LADAU:

Let's widen our lens a little bit because we've talked about how the ADA is being enforced 34 years on, but there is still so much to do. There's so much happening. There's so many ways that we need to operate within clearly flawed systems and do what we can to try to make them better. And one thing that I am so passionate about reminding people is that every issue is a disability issue because every issue impacts disabled people. And it seems like I am regularly getting updates from DRA about the multitude of issues that you're focusing on.

And you named so many issues even just in sharing some of the work that you do and why impact litigation is so important for making change. But for our audience in philanthropy, people are at so many different points in their journey and there are a lot of people who are still just diving into even learning about disability rights. When you're first coming to this conversation, I imagine it can be a lot, it can be overwhelming, but I also want people to know that they have a space in this work. That we welcome them to this fight, that they are a part of making the change. So, as they're beginning that journey, what are some of the issues that people should be paying attention to right now?

REBECCA WILLIFORD:

There's so many issues for folks to be paying attention to. I love this question. And yes, absolutely, disability is the most intersectional community, and as we all know, anyone can join at any time. And at DRA we're never just representing disabled people. Just disabled people have all the other identities too. I think one thing to be vigilant to is the fact that ableism is alive and well, and society needs to get better at recognizing it and fighting against it. Attitudes are some of the greatest barriers and they don't cost anything to fix.

You know this as well as I do. You literally wrote the book on demystifying disability, which I strongly recommend to folks all the time. But just by way of example, I am a trial lawyer by training, and I met ADA coordinators at two different courts when I've been called for jury duty, tell me that I'm too disabled to be on the jury and that people like me shouldn't be on juries. And they've taken it a step further and they've given me a lifetime exemption from jury duty in those courts. And that's completely counter to how our justice system should operate if the courts, or at least some of them are out of the gate, turning away potential jurors solely because of their disability.

And disabled people are also, I think another thing just to be cognizant of is disabled people are asked to endure all kinds of things that other marginalized communities are not. For example, going back to the taxi hearing. We are fighting to get at least 50% of the taxi fleet in New York City to be accessible to wheelchair users. And that's what our whole motion to enforce that settlement agreement is about.

And that's a huge win because it used to be practically non-existent to get an accessible taxi. But non-disabled people can take 100% of the taxis and society would never accept, for example, a rule that women could only hail half of the taxis, but men could hail all of them. So, these are sort of the lived experiences and the sacrifices that shape the disability community and that we are having to literally plan our lives around. I think these are all things to keep in mind.

EMILY LADAU:

I appreciate you giving an overview of what I imagine in such a broad ranging amount of topics that are swirling around in your head at any given time. But I often say that accessibility is really at the core of everything. And if you can't access, for example, transportation, how do you access employment opportunities? How do you access education or healthcare or socialization? And so when you start to think about it as each system impacts every other system, it becomes a really essential conversation to be thinking about what can I do to advocate for accessibility? What can I do as a funder to support the work of impact litigation and make meaningful change so that people can actually access the world around them?

And I know that our listeners are so often looking for an actionable takeaway because after we have conversations about what's going on in the realm of disability, people say to me, "Okay, what can I do? How can I help? What do you need?" What is it that you think needs to happen across the philanthropic sector right now to ensure that we're moving in the right direction to disability inclusion? If you had a specific call to action that you would like to leave our listeners with, what would that be?

REBECCA WILLIFORD:

So, we're all here because we care and we're all operating in a variety of spheres. And when it comes to the disability constellation, we've got direct service advocacy, we've got policy. Those are two really, really important pillars. And those are things where DRA is not working on those things, but lots of other amazing organizations are. But we do need this third pillar of impact litigation to bring about true systemic change. And a lot of entities need that nudge. They need the pressure of a lawsuit. The ADA was set up, so the only way to enforce it is through litigation or potential litigation.

I think funders need to start prioritizing funding for impact litigation, especially in the disability space where what we have to work with is what Congress gave us, which is the Americans with Disabilities Act. And doing this work is really time-consuming and also really costly, but also really, really impactful. For example, some of the results that we've gotten where we're representing the kids who were held in juvenile detention facilities. It took more than a year to visit kids in those facilities, understand what was going on, work up the cases, get the evidence that we need to demonstrate to the judge what's actually happening and how that's illegal and what we need to do to fix the problem.

So, I think just understanding... And what we're trying to do through impact litigation is we are trying to problem solve. And a lot of the times the judges are in there with us trying to problem solve. I think you kind of witnessed some of that firsthand. That's what it's all about. And we've also discussed intersectionality of disability, and I think just that sort of the last thought is just

remembering that disability does not live in a silo, and funders can and should include disability when they're thinking about funding issues that are going to help rural communities, people of color and so on. Any marginalized community also includes lots of people with disabilities. We're a very big, big community.

EMILY LADAU:

I think that everything you named is crucial for people to keep in mind, and I hope that they will look at this as an opportunity to learn more about the work of disability rights advocates and also just to understand all that is constantly going on in the world of impact litigation. And I hope that people will look to DRA as a resource.

So, I want to say thank you again, Rebecca for joining me in conversation for this episode of Disability Inclusion Required. But knowing that there's much more for people to do on the journey, where can people find you on social media? Where can people find DRA on social media to keep up with what's going on?

REBECCA WILLIFORD:

And thank you, Emily, it's been so wonderful to have this conversation with you. And people can find me on Instagram @Rebecca.Williford.DRA, and DRA is on Instagram @DRAlegal. That's where you can find us. We're also on LinkedIn and would love for folks to follow us. We also have an e-newsletter that folks can sign up for on our website at dralegal.org.

EMILY LADAU:

Amazing. Wonderful. And as someone who is a follower myself, I know that I am constantly appreciating all of the updates that I'm getting. So, don't hesitate to look to DRA as a resource for what's going on in the world of disability. And if you want to keep your learning journey going, you can visit the Disability & Philanthropy Forum as well at disabilityphilanthropy.org. I'm Emily Ladau, and this has been another episode of Disability Inclusion: Required. Thank you so much for tuning in and join us again next time.