

You First Podcast Episode 59: Say the Word: Disability

Keith Casebonne (00:00:00):

You're listening to You First: The Disability Rights Florida Podcast. In this episode, we talk with three guests, Lawrence Carter-Long, Damian Gregory, and Laura-Lee Minutello about the importance of disability language and inclusion. Hey, everyone. I'm Keith.

Maddie Crowley (00:00:32):

And I'm Maddie. And we're the hosts of You First. We have a great episode in store for you today, as we're talking with some disability rights legends regarding a really important topic in our community, language.

Keith Casebonne (00:00:43):

Yeah, we talk a lot about various language preferences within the disability community. For example, person-first versus identity-first language. We also talk about the #SayTheWord campaign and the importance of reclaiming disability and other terms for people in the disability community. And lastly, we talk about the need and importance of honoring people's language preferences and being mindful of the power that language has, especially in an institutional sense.

Maddie Crowley (00:01:09):

Yeah, definitely. Our guests do a really good job of explaining both their personal lived experiences with disability and language, but also, how we can see it manifest in things like policy, government, services, service provision, communications, marketing, all that kind of stuff. So it's a really great episode. But before we get started, we wanted to introduce our guests and tell you a little bit about them. So first up, we have Damian Gregory. Damian Gregory is a journalist and community advocate for people with disabilities. Mr. Gregory is a twin, who was born with cerebral palsy and uses a wheelchair as a result. He has been a self-advocate his entire life, and he has degrees in broadcast journalism and political science from the University of Miami. And he worked as a journalist for several South Florida-based publications, including the Chicago Tribune's South Florida Sun Sentinel and Caribbean Today.

(00:02:02):

For most of his life, he's worked in the disability advocacy arena, and his work has included stints as a Medicaid waiver support coordinator, travel trainer, and disability rights consultant. He's currently the founder of Nothing About Us, Without Us, LLC, that does disability consulting, advocacy, and education, and is also a consultant and adjunct faculty member for the University of

Miami's Mailman Center for Child Development. He served on plenty of different boards and commissions dedicated to disability and accessibility, including the Florida Self-Advocates Network'D, the Miami-Dade County Commission on Disability Issues, and is the chairperson of the University of South Florida's Florida Center for Inclusive Communities, also called the FCIC, Community Advisory Committee. So again, a legend, a rockstar, especially in Florida disability world.

Keith Casebonne (00:02:56):

For sure. For sure. Speaking of legends, the next guest I'm going to introduce here is Lawrence Carter-Long. Lawrence's lifetime of advocacy combines with a unique blend of the arts, public policy, and popular culture. He's an internationally respected authority on the history and evolution of disability in media, has provided feedback, guidance, curated or consulted on projects for SAG-AFTRA, National Endowment for the Arts, Sundance Institute, Tribeca, the American Film Institute, NPR, ITVS, BBC, along with many other notable names and initials, that unfortunately non-disclosure agreements don't allow us to mention. In 2012, again, in 2021, and most recently, every Sunday night, during July of 2023, Lawrence Carter-Long curated and co-hosted The Projected Image: A History of Disability on Film on Turner Classic Movies, reaching approximately 75 million people. His hashtag promoting disability awareness, #SayTheWord, went viral in 2016 and continues to be used today.

(00:04:01):

He has been written for academic journals, like Film Quarterly, has pieces commissioned by PBS and The Atlantic, and been published in major mainstream publications, like USA TODAY. A popular public speaker, panelist, and educator, Lawrence has lectured on disability, representation, and media at the Library of Congress, the Whitney Museum of Modern Art, the Academy of Motion Pictures Museum, and the United Nations, among others. In addition, Lawrence's insights are featured in the award-winning 2020 feature length documentary, Code of the Freaks, a radical reframing of disabled characters in film. As an actor, he appears in the 2021 New York Times Critic's Pick, Best Summer Ever, as Officer Gorinsky. Previously the communications lead for the National Council on Disability, the independent federal agency that drafted the Americans with Disabilities Act, during the Obama administration, he now works as the co-director of DisArt, based in Grand Rapids, Michigan. He lives in Oakland, California. Again, rock stars, right?

Maddie Crowley (00:05:01):

Yeah. And certainly, last but not least, we have our friend and coworker, Laura-Lee Minutello. Laura-Lee is a policy analyst at Disability Rights Florida. She holds a bachelor's degree in psychology and is currently pursuing her master's degree in nonprofit management at the University of Central Florida. With over 15 years of advocacy experience, she has primarily focused on the intellectual and developmental disabilities community and area. In her role as a public policy analyst at our organization, Laura-Lee utilizes both her academic, but also her lived

experiences with disability, to connect with the community and legislature. Her academic pursuits and dedication to her work reflect her strong commitment to making a lasting impact in the field of public policy, to make the world more accessible for people with disabilities.

Keith Casebonne (00:05:55):

Yeah, we're super honored that all three of them...

Maddie Crowley (00:05:56):

We love Laura.

Keith Casebonne (00:05:59):

Yeah, we do. And we're so happy that all three could be on this podcast. So we loved the conversation, and we know that you will too. Hey, Laura, Damian, and Lawrence. Thank you guys so much for being our guest. We are so pleased to have you here to talk about what should be a straightforward and simple, but yet somehow very complex and nuanced subject today. Let's kick it off just with an introduction. If you guys each want to tell us a little about yourself and what brings you here today.

Laura-Lee Minutello (00:06:26):

I'll kick it off. My name is Laura Minutello, and I am a public policy analyst at Disability Rights Florida, as well as a person with cerebral palsy, who has been steeped in this work all of my personal life, obviously, as well as probably about 15 years professionally. And just to give a quick visual description of myself, I am an Italian appearing woman in my mid thirties with freckles and really messy curly hair and glasses.

Damian Gregory (00:07:00):

I guess I'll go next. I'm Damian Gregory. I am a Black male, who uses a wheelchair. I wear glasses. Today, I have on gray and blue glasses. I am much older than Laura. I'm feeling older every day, about to turn 50 this year. Wow. I used to be the youngest person in the room, believe it or not, in most conversations. I have worked with people with disabilities in a professional capacity for the last 20 plus years, and I am a journalist by trade. So that is my background. I live with cerebral palsy and use a wheelchair as a result.

Lawrence Carter-Long (00:07:46):

And hello, good day everybody. Pleased to be here with you. My name is Lawrence Carter-Long. I'm a middle-aged white man, also with cerebral palsy, wearing a black shirt, and I'm older than both Damian and Laura. I'm 56 years old with cerebral palsy. So thanks for having this conversation. I'm thrilled to be here with you.

Maddie Crowley (00:08:08):

Yeah, and we're truly thrilled to be with you three. So thanks for introducing yourself. And again, my name is Maddie, I'm one of the hosts of You First. And as a visual description, I'm a white non-binary person with a disability. I have blonde hair with bangs, and I'm wearing bright red glasses and a black shirt. And we are going to jump right into this conversation, starting mostly just with some basics for folks who have never maybe considered language and the impact that language has in the disability world and the disability community. I guess, broadly, where should we start when explaining things? I think person-first language versus identity-first language is a really important distinction to make and is probably the foundation we should have to this conversation. So could one of y'all explain the difference between those and the importance that comes along with those?

Damian Gregory (00:09:11):

I guess I'll just jump in here. Person-first language is really putting the person ahead of the disability. "I am a person with cerebral palsy," or, "I am a person who uses a wheelchair," as opposed to identity-first language, which says puts the identity-first, meaning putting the wheelchair first, and then, the person. And there are two schools of thought as to which one is acceptable. For me personally, it just depends on what day, and it just depends on the shorthand that I choose to use on any given day. The big thing for me is why I like to be acknowledged as having a disability, to whatever means, whether identity-first or person-first language is, it's just a reflection that you see me and you acknowledge my experience. And that, for me, is a big thing.

Laura-Lee Minutello (00:10:21):

Yeah. To jump in and piggyback off of Damian, I think, for myself, I feel very much the same way. I will use them interchangeably. I think, for myself, I prefer to use identity-first language and consider myself a disabled person. But in a word context or a context where people may not be as familiar with that terminology, a lot of times, I will default to person-first language, just because there's a little bit more social consciousness around it. But I will say, that can, at least I find, and I'm curious to hear all of your thoughts on this, that that can change. I think, earlier in my journey as an individual, if you had said I was disabled, I would've been absolutely appalled, and now, it's something I take great pride in. So I think it's important to acknowledge that those concepts, even for ourselves, are fluid, sometimes.

Lawrence Carter-Long (00:11:22):

And I think that's a real, this is Lawrence, and I think that's a really important, and in fact, the essential distinction to make. Whatever preference, whatever mechanism one prefers, whatever one uses, I think, probably speaks to where they first heard it and what the conditions were in which they heard it, right? So if you think about something like person-first language, it does something really unique. I think it positions disability as anything but a defining characteristic in a person's life. It makes disability almost an accessory, right? And then, the identity-first language, where you say, "I am disabled," that purposefully centers disability as a cultural and a political influence. So it takes those surroundings and those circumstances and the opportunities, the

values, all of those things influence whichever preference or whichever choice somebody adopts. I think different countries or languages or historical perspectives or economic realities, they all add complications and tensions to these different views.

(00:12:33):

And so, like the others, I tend to use person-first language, identity-first language, and community-first language, sidestepping the debate, all in rotation, to honor the origins and the intentions and the evolution of each option. To me, it doesn't much matter where the words, "disabled," or, "disability," are placed, as long as they're used. And this is why. It's because wherever we put the prefix, claiming disability is really important, because it connects us to each other, it connects us to our common history, and it connects us to a lineage. All of those people who came before us, who fought and protested and persisted, so that, one day, we could be proud of being disabled as well.

(00:13:22):

That's something I want to honor, no matter where it comes from. And I think some of these attempts to euphemize, to come up with phrases, like "differently abled," or, "special needs," don't want to deal with that history. Because by looking at that history, you've got to also look at discrimination. You also got to look at disparity that disabled people face. And so, if you're saying that everyone has unique abilities, you erase that history. And that's because that's a history most people, disabled and non-disabled, are uncomfortable facing.

Maddie Crowley (00:13:58):

Yeah.

Laura-Lee Minutello (00:13:58):

Absolutely. This is Laura. I think you make such a great point, Lawrence. I was sitting here listening to you, so inspired, about the importance of community as well, and that's something that I wasn't even, until I heard you say it, thinking about in terms of this conversation. But we do have a long history, as people with disabilities, of, and a long lineage of ancestors, that have fought this fight, and it's still ongoing for this sort of personhood on our own terms. So I really thank you, just thank you for making that point, because I think that's a really important one.

Damian Gregory (00:14:36):

And this is Damian. And while the euphemisms are definitely not my favorite, and I feel when I hear the words, "unique abilities," like I should be speaking French and flying with a cape simultaneously with a wheelchair on my back, I definitely don't like the euphemisms, but it's also important to realize that that language has evolved. There was a time, early in my childhood, where it wouldn't be uncommon to hear the word, "cripple," banting about, especially by older folks, that were not comfortable with even the fact that I existed and I was in the same space as children that

were non-disabled. So it's important to certainly evolve with the language and be more sensitive, but I think we need to be careful about how much we pretty things up and how much we try to euphemistically cloak things to say what we're born to say.

(00:15:45):

Because like I said, not so long ago, it wasn't uncommon to hear the word, "crippled," regularly, or even, "handicapped," now, has become a word that some people use with a little bit of trepidation. And it's part of my evolution as people to just say, "See me and acknowledge me, and more importantly, call me what I want to be called." And don't make it be only, "You must be what I have imposed upon you as your label," but what do I, as a person with a disability or as a disabled person, feel comfortable being referred to as? Every other group has that privilege, and somehow, for people with disabilities, it has always just been thrust upon us, rather than asked. We've been given these descriptors without much of a say in it. And I think that's part of the larger conversation as well.

Laura-Lee Minutello (00:16:56):

Absolutely. This is Laura. And Damian, you, your example, as far as crippled, actually just made me think of something in my own childhood, that I think, for me, is why the reclamation movement is so important. And I know I've told you this story, but I'll just tell it publicly. I was about six or so and had run into a friend from school out getting ice cream. And we were just playing around chasing each other. He was chasing me in my chair. And his dad came up and said, "Son, we don't play with cripples." And it was the first time I'd ever heard the word. That young person, kindest young boy, never spoke to me again throughout our childhood. And for me, that just became such a slur and something that, when I would hear it, I would physically recoil.

(00:17:53):

And then, as language has evolved, and Lawrence, through your work, through the work of Alice Wong, and we had Andrew Pulrang and Gregg Beratan on our Voting Summit, but through #CripTheVote and just some of these leaders, that, for me, is the point of my journey when I realized this could be an identity that I take pride in and not something that was used against me to other me. I think that is an interesting point that you made about how we used to hear these words regularly, but the way in which we heard them was derogatory. And I think that was going to shift and something that we all, I know, embody, but I think was a larger consciousness or starting to embody, is that these words aren't derogatory.

Keith Casebonne (00:18:44):

It's a good example of the power of language, of course, and how a word can make or break everything for someone. And Damian, another thing you said that I found very interesting is that you specifically said, "Ask me, what do I want to be called?" There's so many groups that prefer person-first, and there's other groups that prefer identity-first. And if you don't know, just ask. It's more

respectful to ask someone how to refer to them versus just saying something. And often it's the wrong thing. Also, I apologize. When I opened the show, I didn't introduce myself and describe myself. And so, I'm Keith. I'm the other co-host, and I am also in the 50-year-old club. I'm 52 and have brown hair and a sort of salt and pepper beard at this point and wearing a black shirt.

(00:19:33):

Well, and then, we also talked about, for a brief moment, the reclamation movement. And so, let's turn to that here. And so, Lawrence, the first part of the question is specifically for you as your Twitter bio or X bio, if we must, refers to you as the #SayTheWord evangelist, which I think you couldn't put it better. Tell us a little bit about the #SayTheWord campaign, and then, I also like to hear from everyone, all three of you, what the reclamation movement means to all of you personally, how it affects each and every one of you.

Lawrence Carter-Long (00:20:06):

Thank you for asking, Keith. And interestingly enough, the campaign didn't start as a campaign. It started as a hissy fit. It started, because I was working at the federal government at the time, at the National Council on Disability, which is the federal agency, years before my time, the ADA came out of. And we were working with the White House specifically, this was 2016, to give you a little bit of a timeline, to make the State of the Union address that President Obama was going to give as accessible as we could. So audio description, captions, different sizes, different fonts, different colors, all of the above. So we're working with the White House to make that happen. And everybody was watching the web feed excited, because at the end of the speech, we'd done all this work to make the State of the Union address accessible, which should be for all Americans.

(00:21:00):

And at the end of the speech, the president was talking about constituency groups. He was talking about the LGBTQ communities, he was talking about Latinx communities, and senior citizens. And we thought, "Oh my goodness," at least I thought, "Now he's going to say it. He's going to say the disability community." Because fear of disability has always been the default, and the language that we use to communicate disability, whether we like it or not, reflects that. And so, I thought what this could be an opportunity, was an opportunity, to see that shift and see that change where you could talk about disabled folks as a constituency. And so, I was ready, I was primed. I was there at the edge of my seat, and it didn't happen. He didn't say it. So I got ticked off, and I sent out a tweet saying, "What's it going to take for somebody just to say the word, "disabled"? And there's a bunch of us out here, and we need to reflect that as a voting block in that context."

(00:22:05):

And the next day, I woke up, I had my little hissy fit, had a shot of whiskey, and went to bed, got up the next day, and people were using it in Wales. And they were using it in Australia. And all of a sudden, it's had this life of its own beyond the moment in which I first used it. And what I realized at

that point is that it resonated with other people who felt the same way for their own reasons and claimed it for their own reasons. And was at that stage, where disabled people, disability communities, made it a campaign. And so, I started thinking about, what are the reasons that this caught fire? My background, my skillset is in media and communications, so I'm always fascinated by what words work and what words don't, and why is that? How do we reframe and reclaim language? And so, it was happening right there before my eyes. And as a result of that, the campaign evolved organically, as people adopted it, started using it, started talking about it, we started seeing how and why this resonates. And it grew from there.

Damian Gregory (00:23:19):

And Lawrence, tip of the hat to you, because this is Damian, I remember that period of time very specifically. And I also remember always feeling like, even as part of stump speeches, we were not mentioned. And I must tell you, I was a bit of an Obama groupie, and I went to a lot of rallies and a lot of events. And I kept waiting, and I would see the speeches evolve, even as a candidate. And he would mention every other group, and I'm like, "Really? You can't mention us? It's either we're not thought of or you don't want to offend us or I'm not sure what." Tip of the hat to you for having your hissy fit, because that hissy fit was part of the train. Would like to say that I also tweeted many times about this issue as well, and it's good to see that it's finally happening, but to bring the conversation to present day, which I am concerned about.

(00:24:40):

It's interesting, because we're at this weird kind of moment in our history, particularly in Florida, where we're simultaneously trying to get rid of diversity, equity, and inclusion programs, because it's considered too woke. And we're euphemistically, from state law and websites, referring to people with disabilities as people with unique abilities. So it's a weird simultaneous, "Let's whitewash one thing and let's ignore the other." And as somebody who has multiple identities, I am a person of color and I am a person with disabilities, it's a weird moment for me. I feel like, "Okay, which part of me is acceptable to you? And which part is not?" And that is something that kind of makes me chuckle, but also drives me a bit crazy, because it's like, "Okay, let us decide what we want to do as a society and as a state."

Lawrence Carter-Long (00:25:59):

And if I could add that it's also just as important in letting us decide what we want to say. I don't know any disabled people, for example, in all the constituencies and all the groups that I've worked with through the years, who refer to themselves as special needs. That tells you something. And so, in first off, asking what we prefer, it's just as important, if not more, to get into the reasons why we prefer what we prefer and what the history of those phrases are, what the etymology of those histories are, what the baggage that comes with those histories tend to be. Because if you don't understand those histories, if you don't understand the damage that has been done, then you're not going to make an informed decision. Many people make a default decision, because that's what their mother, brother, teacher, preacher told them.

(00:26:52):

And so, I think part of our role as disability advocates and as communicators is to give people the reasons why we prefer this option over another or why we use the word, "disabled," instead of, "unique abilities." To my mind, to get back to Damian's point, unique abilities by definition are rare. To be unique, you have to be rare. Disability by definition is not. If you look at the Centers for Disease Control numbers, you'll see that the most recent numbers from the spring of last year say that disabled people make up 27% of the US population. That's more than 61 million. That's more than one in four. That is not rare. And so, we have to have a way to talk about that, which really, I think, powerfully demonstrates that we're a constituency, that we're communities, that this is something beyond... Disability has traditionally been framed as an individual burden, something that affects this person.

(00:27:59):

We don't think about what folks saw in the movie Crip Camp. What happens when disabled people come together and start sharing those experiences? They get ticked off and then, they protest, and then, we change laws and change the world. Once upon a time, disability was just a diagnosis. It's understandable to me why people would push back against that or why they would resist that. But something amazing has happened. Through the years after the passage of the ADA, the words, "disabled," or, "disability," have grown to encompass so much more than diagnosis. Identity, constituency, history, culture, I'd say most importantly, community, to name a few. So what this campaign, I think, has grown to do is open up the cognitive space for evolution, to become more, rather than less. It's really both a provocation and an invitation to get on board. Don't be stuck in the 1970s, but get on board with the program and where disability is now, as opposed to the nonsense that somebody else told you.

Laura-Lee Minutello (00:29:12):

Absolutely. This is Laura, and I think, to kind of harken back to your point, Lawrence, and pivot a little bit to the legislative side, exactly what you just said as far as understanding the history and understanding the broader context is important legislatively, because if we don't understand those things, and a lot of people don't, and a lot of people without disabilities don't, we, as a community, understand them, I think, by and large, but a lot of legislators don't. And a lot of the general public doesn't. That's how we come up with legislation that can be harmful. That's where policy becomes harmful. Because when we use euphemisms and terms of unique abilities or special needs, we're essentially erasing disability. And that might just be seen to someone outside the community as something terrible. And of course, we want to do that. But when you bring that into a policy context and create laws that do that, what you're doing is you are separating people with disabilities from society.

(00:30:26):

You are allowing this cognitive distance to grow, and when there's funding, when there's services, when there's needed things, beyond othering, you are making it harder to access these services. So we've seen that a little bit. There's a shift in language towards unique abilities and has been for a few years in Florida, but if you Google unique abilities, you don't find services related to disability. You find psychology blogs and ways to find your strength. You don't find these actual needed services and things that people need. So this is, to your point, a very dangerous thing, both personally and from a policy context.

Maddie Crowley (00:31:17):

This is Maddie.

Laura-Lee Minutello (00:31:19):

I jumped ahead a little bit, I'm sorry.

Maddie Crowley (00:31:21):

No, no, don't apologize, because this really all does tie together. And I just want to tie a bow on the conversation we had moments ago before we transitioned to the lawmaking part and just really sit with the fact that, and this was the thread, I feel like, through what all of you were saying is, in order to say the word, "disability," or identify as disabled, people really need to look at themselves and position themselves in society, question what expectations are out there for people's minds and bodies to work, go to school, do certain things.

(00:32:04):

And they really have to sit and reconcile with disability, because like Lawrence said, it's over one in four. But what would that actually be like if everybody counted having ADHD as a disability or long COVID as a disability or all of these things that are presently adapting and fluctuating? And that number is probably a lot higher, but society makes us scared of thinking of that as a strength or adopting that, because of how disability is used in the way you were just describing, Laura, take services away or make it seem like, if people don't identify within that category, they're safer from the loss of services and inaccess and all of these things.

(00:32:52):

So I really wanted to emphasize that. And transitioning a bit to the legislative part too, when candidates, I know y'all talked about briefly with the speech and Damian going to different events for Obama, but when candidates say, "Oh, I don't know disabled people, I don't need to..." Or "Disabled people don't come to my events," or, "Disabled people don't canvas for me." Okay, first of all, that's incorrect, because disability is not always visible. But maybe let's reflect on why you might not be seeing people with disabilities or having people involved and just unlearn some of those biases and those social norms to realize that these issues that we're talking about, whether you identify as disabled, disability, or with neither, impact everybody.

(00:33:41):

At the root of what we're talking about, this language impacts people with disabilities. It impacts every marginalized group, as these similar themes are seen across the spectrum of identity. And it impacts access to services or access to community and freedom and safety. So I know that's like a broad thought, but I just wanted to say that everything that y'all mentioned was so important and truly is so vital into framing what's going on in Florida right now.

Laura-Lee Minutello (00:34:18):

On that note, really quick, Maddie, this is Laura again, we don't talk about this often enough, but I really wanted to put out, just to piggyback off of your note about the impact and how disability affects everybody, a lot of people tend to shy away from the fact that, if you live long enough, the chances of you becoming disabled, even just from age, are almost 100%. So it really is... And yes, even if you're not disabled, chances are somebody in your life, that isn't... But not being disabled is a temporary state, a lot of the time. And I think that's also one of the shifts that need to take place is we need to look at this as something that everybody is going to confront most likely at some point in their life, because the chances of that are really high.

(00:35:13):

And I think, if we did that and it was seen as something that wasn't unique to this subset of people, but a part of the human condition generally, we'd flip this conversation on its head. Now that's easy to talk about and harder to manifest, but I do think it's important to acknowledge that disability is a part of the human condition, across a lot of stages of life. It's so intersectional. Damian touched on that. I know we touched on that a lot at DRF, but I think it's a really valid point, that we need to just state explicitly. You can become disabled at any point. It doesn't discriminate based on anything.

Damian Gregory (00:36:04):

This is Damian. I just wanted to say also that, when I hear euphemisms, like people with unique abilities, it is clearly designed to make others who are uncomfortable with the idea of disability be more comfortable. It's a way of making it palatable for me and Laura and Lawrence and millions of other people to exist. So if you call me something flowery and nice or what you perceive to be something flowery and nice, then it's okay that I exist. So that also is, in its own way, insulting, frankly, and offensive, because my existence should not be solely to make you comfortable that I exist. I am a person who uses a wheelchair and I have a disability, and that is fine. And it has taken a long time for me to get to the point where I am comfortable putting that out there and having no apology about it. So for you to then slap a label on me, so that it makes it palatable for you for me to exist, is just BS.

Lawrence Carter-Long (00:37:33):

I think that your points, both of those points, really get to the heart of what bothers me most about euphemisms. Because it assumes, by using a phrase like, "special needs," or, "unique abilities," it

assumes that there's a level playing field, which is ridiculous. It tries to level the playing field. It tries to make everything smooth and nice and pleasant and comfortable. And what that does is euphemisms, I should say, equal erasure, and that's really important. They don't challenge people to make changes to an inaccessible society. They don't require you to make any changes. And so, you can use those phrases, but what they essentially do, whether it's intentional or not, is it lets people and it lets society off the hook. You don't have to do anything if you are catering to people with unique abilities. And I agree, what does that evoke?

(00:38:36):

It evokes somebody riding a unicycle across a tightrope erected between two skyscrapers, while juggling bowling pins. So yeah, if you can do all that, I'd say you've got unique abilities, but reality with a disability is much more mundane. It's not tragic, and it's not heroic. It's somewhere in the messy middle, and what society refuses to deal with, by and large, and what these euphemisms make it easier to do is to get into that messy middle, where discrimination exists, where disparity exists. Because if you don't see disability, then you're not going to see disparity or discrimination. So it's very important, I think, at this stage and where our culture is to be specific about disability, because unless you do, you're not going to get to the heart of what the reality is that disabled people actually face.

Laura-Lee Minutello (00:39:33):

Absolutely. This is Laura. I can't co-sign that point enough. I can't say it any better than you just did, but you're absolutely correct in that euphemisms, they don't leave room to talk about the actual barriers and discrimination that we face as disabled people. And it's frankly, I think, you touched on intent, and I think intent is important, and I don't want to assign malicious intent, but at the same time, intent only goes so far. You have to look at what you actually are doing, whether you intend to do so or not. And the fact of the matter is, as, Lawrence, you just stated, you are making it difficult, if not impossible, to actually address these issues as a society, when you pretty them up in all these kind of cutesy terms.

Damian Gregory (00:40:29):

I don't know, in a weird way, this is Damian, it's also regressive. It is a way of, even though the language is not as harsh as, let's say, calling you cripple, it is also a way of getting away from what the reality of living with a disability is. It assigns some special attribute to you, that is only positive and only, "Yay yay, do it, regardless of whatever," without seeing the struggle and the history, and more importantly, just seeing it as actually doing something to freaking fix it, to do something about it, so that this does not happen forever and ever. Amen. So that it is addressed and addressed adequately and recognizes that there are disparities that exist, but it's more than just a recognition. It's the actual work of getting the fixes made.

Laura-Lee Minutello (00:41:58):

I am curious. I have a question that I'm going to, and Maddie and Keith, feel free to jump in too, do you all, because I have my own thoughts on it, but do you all feel like, I agree, Damian, but do you feel like it's purposely regressive? Do you feel like we, as a society, are trying to be oppressive? Or do you just feel like we, as people with disabilities, are more of an afterthought?

Damian Gregory (00:42:22):

I guess I'll go first, as the person of color and the person with a disability, I'll go first, and I elected myself, so I'll jump in. I will say, I can't help but feel that it is intentionally regressive. I think we're at an inflection point where, like I mentioned earlier in the conversation, where we're simultaneously trying to paper over the ideals of diversity, equity, and inclusion. And I see that as a regressive step, and then, simultaneously, we're trying to make it more palatable by calling us unique abilities. There's something about the two things happening at the same time, which makes me feel like it is something intentional. There's not a way for me to think about it other than that, because it's almost as a way of not only not seeing me, but not acknowledging any of my experiences that exist every day and just saying, "La, la, la, la. Let's live in a great utopia where everybody's equal." That is what, ideally, I would like, but we ain't there yet, so let's not pretend that we are and let us do the work of trying to get there.

Lawrence Carter-Long (00:44:00):

Yeah, I would add that, whether it's intentional or not, the effect is still the same. The impact is still the same. It's interesting to me that, as disabled folks, we didn't even get the option. Damian mentioned being a person of color. Imagine what the difference would be if we would call ourselves people of disabilities, people of disability, rather than people with disabilities. Disability would no longer be an accessory. It would no longer be something you could leave behind. It would be something that would be integral to your personality, your identity, your experience, would honor all of those things. The ecosystem that we all swim in is such where disability and denial is so deep, where we didn't even get the option to embrace it, until very, very recently in history. So I think that's important to bring up. I'd also bring up, coming from a legal context or a public policy context, terms like, "special needs," or, "unique abilities," they don't have any teeth.

(00:45:03):

They're not legal terms. You look at the legislative language, the law is called the Americans with Disabilities Act. So if you use, "disabilities," that means you've got some muscle, you've got some might, you've got some leverage. You start talking about special needs, it doesn't give you any of that. And so, I think claiming disability not only has philosophical benefits and hopefully personal benefits, but it definitely has legal benefits. You're guaranteed certain rights as a result, whether it's movie theater seating or Medicaid or more. Unique abilities, special needs doesn't offer any of those same kinds of legal protections. And so, I think, whether they know they're doing it, I think it's so seeped within the culture that it's there within the back of their mind. So they're not going to claim it and they're not going to own it, and they're going to make it harder for us to do that, because they would then have to be held to that standard. And they would have to guarantee the

same rights and responsibilities that come with a law. And I think that's just more than a lot of policymakers are willing to do.

Laura-Lee Minutello (00:46:11):

Absolutely. This is Laura again, and I think, Lawrence, you make such a good point, and it's one that we often try to make in our work as well, is that disability, the ADA uses, "disability," that we fought as a community to have the word, "disability," included in the ADA and get rid of some of the more regressive language. And disability doesn't unfortunately have a universal definition, but it is a familiar one. It is one that has, as you put it, teeth, and there are legal ramifications when people with disabilities are denied rights, where, to your point, unique abilities, there's no definition of that.

(00:46:56):

I think, as we're talking about legislation though, I think one of the things that frustrates me, particularly from a policy standpoint, is the fact that there's this disconnect sometimes, even within the definition of disability itself. It just comes back to, that is, I guess, that's the heart of the policy [inaudible 00:47:21], in terms like this, is that there's no way to define what that is. And what language means to us personally is one thing, but when you're talking about an agency or these governmental aspects, those need to be very well-defined for a reason. And it is to avoid that discrimination and help lessen a lot of those barriers that we face, that we've talked about.

(00:47:48):

And so, just for me, where I get nervous and the tipping point we are particularly in our state, is that, when we try to redefine certain aspects of our structure for services for people with disabilities, legislatively, that is concerning, not only because it doesn't, from a personal aspect, but you're talking about state agencies, you're talking about things that serve a lot of people and serve the community as a whole. It goes far beyond personal preference. It goes now to, do people actually get what they need? Or don't they? And I think there is far too much wiggle room when you use words like, "unique abilities," or, "special needs," or whatever other words you want to come up with, so that people will fall through the cracks and not know how to access those services.

Damian Gregory (00:48:47):

This is Damian. A thought, Laura, as you were talking, that came to me, instead of changing it to unique abilities in state law, let us just focus on thousands and thousands of people on the APD waiting list, that have been waiting for services for years and years, sometimes decades. Let us worry about seeing those people and making sure that those people are served. Let us not do this BS, where we're going to have to reeducate an entire population about what it means to be a person with unique abilities. Because let's not forget that the more this is used, the more people are going to say, "What the hell does that mean? What does it mean?" Because I, as a person who's lived on this planet now for almost 50 years, when you say to me, "person with a unique ability," I

really don't know what that means, and I'm not being facetious, it could mean any number of abilities.

(00:49:59):

And I could go off color, and I could take them so many dark places and light places. And I'm sorry, my mind has went somewhere completely dirty. But it's crazy that we're at this point in 2024 now, where we're talking about people not for who they are, which are people that don't have the same abilities as everybody else or get things done in a different way, and we're trying to euphemistically categorize them as something light and fluffy and that could go dark or light. It's just bizarre to me. Anyway.

Laura-Lee Minutello (00:50:54):

Absolutely. And I'm sorry to monopolize, Lawrence, feel free to jump in, this is Laura, but Damian's point actually made me think of something that I read in your work, and that was the etymology of disability and the fact that the literal meaning of disability is a different way of doing something. I think, to me, that just spoke volumes, because it's like disability already describes what we're trying to describe as... But unique abilities or special needs or... What is that? And it comes back to, as Damian was saying, what is that? But people without disabilities typically ascribe derogatory meaning to the word, "disability," but at its heart, and I would love to hear you talk a little bit about, because I know you probably dug into the etymology far more than most of us, but that was eyeopening to me that the actual definition itself just is plain and simple. And we've, as a society, kind of ascribed all of these different things to it, that just really, I'm not sure that they're there.

Lawrence Carter-Long (00:52:04):

Yeah, I think people assume, been conditioned to assume, that the prefix, dis-, is negative, but it depends upon how it's used and it depends upon the context. For example, if one becomes disillusioned, yes, that's a painful process. It's not fun for anybody, but all of a sudden, your eyes are open, you know the truth, you know the reality, if you're disillusioned. So ultimately, that's a positive thing. So if we liberate ability from the narrow parameters in which we've been taught to think about it or conditioned to think about it, then it becomes more expansive, it becomes broader, it becomes more. And so, I think our roles as people that do public policy or that do advocacy is to link disability, not just a diagnosis, in the way that it's been done historically, but to larger systems or to context or to cultures. Because we're not going to stop discrimination, injustice, stigma, or bigotry in society until we do that.

(00:53:09):

And to do that, we have to call it out. And owning disability, I think, takes away a weapon. And that weapon is stigma, that those in power have tried and will continue to try, whether they do it knowingly or not, to use against us. The effect is always the same, as I said earlier. It's marginalization, it's more distancing. So ultimately, I think somebody who's, let's say, really putting

forth the phrase and advocating a phrase, like "special needs," or, "different abilities," talks about their uncomfortableness and their stigma and their shame. And I don't want to focus on that. I'd rather focus on the disabled people that I know and the communities that I know and the work that we've done, because ultimately, fairness, equity, and responsibility shouldn't be delayed or denied due to somebody else's shame. And that's what's happening when people adopt these phrases and try to get them to put into law.

(00:54:13):

They're really focusing on where they're uncomfortable and they're really pointing out what they don't understand. So it's more important, I think, to center disability communities, because there's more than one of us out here, and the needs of disability communities, so that we can have actual progress, rather than the illusion of progress, which is what these euphemisms actually are. We're not changing society. We're not making things better for disabled people. We're just putting flowery language on it. I'd rather it be a little tough, a little difficult, a little painful at the onset, while we recognize the reality of this situation, but actually get it changed, than to cover it up with pink paint. No offense to the Barbie movie, by the way.

Damian Gregory (00:55:00):

And the church said, "Amen."

Laura-Lee Minutello (00:55:01):

A good movie. Good [inaudible 00:55:05] Can't put it better.

Maddie Crowley (00:55:06):

Yeah. This is Maddie. There was a couple times that I was going to unmute to transition off of a question or thought, but I really have just loved to just sit back and enjoy this conversation and just the knowledge, academic knowledge, lived experience, like the multiplicity of identities present, that can speak to disability, yeah. And I'm just having a lot of gratitude in this moment for y'all's conversation. And I think one thing that I'd like to add/clarify is, although it's been said, I think it warrants being explicitly said, even if you listening or reading are a person with a disability who prefers terms like "unique ability," or you don't like identifying as disability and you prefer other terms, that's okay. That is your prerogative. That is your experience. And that is your identity. No one here is trying to take that from you. And also, people within the disability community shouldn't be shaming or denying you that experience and that label, if that's what you believe and want your experience to be reflected at. That is okay.

(00:56:37):

I think the difference and what's really important, that Damian, Laura, and Lawrence have all three drove home really, was that the issue begins when those euphemisms are then used in a bigger context by people without disabilities, who have power to shape the lives of people with disabilities

or however you identify and really impact the reality of your life in a negative way. And I think that is a really important difference, I don't know the word, difference, that I think needs to be just drove home. Because I think, as we talk about changes to groups in Florida or things that are being adopted in Florida, nobody's taking that language away from you personally. However you want to identify is valid. It just goes beyond individual's experiences to ensure that we're all safe and well supported. Do y'all have any other ideas or thoughts and response to that that you would like to kind of name just...

Laura-Lee Minutello (00:57:56):

I actually have a quick one I feel, but this is Laura again, I also just didn't want to neglect, while we're clarifying things, to mention that we've talked a lot about the ways that language can negatively be used in legislation, and there are instances and examples of positive ways that can be used. And I think that comes down to, just as Lawrence and Damian have both mentioned at different points, involving the disability community, an interesting thing that we're seeing also in Florida is more, we need to see more of it, but we're starting to see legislation around competitive integrated employment and the ending of sheltered workshops and things like that, use the words, "competitive," and, "integrated employment," and use those terms that accurately reflect what's being discussed. And I think it's so important to acknowledge that, just as legislation, just as anything, in any context, legislatively or not, these words can be used negatively, the power of language can also, and it goes back to what we talked around in the reclamation movement as well, can be positive as well.

(00:59:12):

We see a lot of that in different states that have passed supportive decision-making laws and the honoring of the chosen word supporter and decision maker that are embraced by the disability community, particularly those with intellectual disabilities. And so, most laws include that language, and that's something that the community has fought for. So I think, just to avoid saying that it can all be negative, I think there's an opportunity in the legislature, in life in general, to just sit down and have those conversations and talk to people with disabilities and the community at large and say, "What can we do to actually fix these issues? And how can language be one of the vehicles towards that?"

Lawrence Carter-Long (01:00:04):

Yeah, I would echo that sentiment. I think it's really important to be precise and to be specific and to use plain language, so that everybody knows what we're talking about. I think, if you're going to wallow or wade into this debate, then it's important that you know the history, the context, that people are using it, rather than making assumptions about those sorts of things. People have long assumed that disability is a negative, disabled people are faulty, in adequate, less of a person somehow. And I think, just as we've encouraged society and forced society actually to push back against that, we've got to do the same with the language that we use. And so, that means, if you're going to adopt this phrase or that phrase, you should know about its history, you should know

about why it was first used. You should know how it's evolved and how it's changed and why people are using it now.

(01:00:57):

And you should also know what these euphemisms do. There was a 2016 study that found use of the phrase, "special needs," was looked upon more negatively than, "disabled." So what people think they're doing by adopting a phrase or pushing a phrase, like, "special needs," does exactly the opposite. And so, if you're not achieving your goal through these tactics, then those tactics and those strategies need to be rethought, so that it requires, I think, some due diligence in terms of the work that we do and the thinking behind it, so that we're not lazy in doing this work. We've got to understand that history and that context in the evolution of what we want to change in order to make those changes meaningful. In this context, what is an example? I think, if you want to use the word like, "unique," with context of disability, what does that mean?

(01:01:54):

That would mean that paratransit arrives on time or that a subway elevator works or that sign language interpreters are provided just as a matter of course, that captions are accurate, that the award-winning play is audio described, that service animals have easy to find designated places to pee, and that politicians and celebrities remember to include disability and their impassion please for greater diversity. That would be unique. I would like to see a day when it wouldn't be unique, where it is no longer unique, but we are not, as Damian said, we are not there yet.

(01:02:35):

So I think it's really important that the disability communities have adopted the phrase decades ago, borrowed from the Polish in like the 1500s, "Nothing about us, without us." I would say we're at the stage, now in 2024, to just simply go with, "Nothing without us." Because everything should include disabled people. So if we say, "Nothing about us, without us," people then assume that there can be things that don't include us. I think we could and should be beyond that at this point, and it's time for nothing without us. And that means that disabled folks, disability communities, are going to be interjecting ourselves into places where it's uncomfortable, and whether you like it or not, that's a sure sign of progress.

Maddie Crowley (01:03:24):

I'm sorry, I'm just sitting with how awesome that was.

Laura-Lee Minutello (01:03:29):

I don't know what to say to that, other than amen.

Maddie Crowley (01:03:30):

Yeah, literally. Yeah, because it's like, what else is there to be said? You said it, and it's perfect. There's so many moments where I'm just in my head, and y'all who have visually watched me react to this whole interview, you'll see me pointing my finger or snapping my fingers. Because I'm just resonating and appreciative of all of these really good points. So another important part of lawmaking, and just thinking, as Florida goes into its legislative session, but it's not just Florida. It's a bigger, broader conversation across the country, either individual states, territories, the entire United States of America as a whole. The conversation of, yes, language is important, as we think about identity markers and preferred language for the disability community or other communities, but there's other things to consider when we're talking about language and disability. Using, I don't know, certain words to make policies regarding disability specific legislation more or less appealing. Could y'all speak a bit more broadly about language access for the disability community, when we're talking about policy and people getting involved with legislation and making their voices heard?

Laura-Lee Minutello (01:04:59):

I think I have two schools of thought on it, because yes, it is incumbent upon people, to a certain extent, to self-advocate. But it's also incumbent upon policymakers. As Lawrence said, we're past nothing without, I love that, Lawrence, by the way, we're past nothing about us, without us. Just nothing without us. Start by just simply speaking to the disability community, I think, would go a long way and actually craft legislation around the needs and barriers that we face. But that's what I would like to see. As far as where we are, I think it's what we've always done as a disability community is where we've just been really grassroots. And I think, people with disabilities, I can understand this, even just speaking for myself, you get tired, you encounter these barriers in your life and all these issues, and you start to feel like your voice doesn't matter. But it does, and I think that's an important reminder for the disability community is to just continue to engage.

(01:06:13):

As far as language and policy, I think, Maddie, you have a great point, and Lawrence, you made it earlier, is you want to make policy accessible to people with disabilities and good policy. Start with plain language explainers and things like that. And a lot of that is on other... The legislature's not going to create that, but it's incumbent upon us, as a disability community, to advocate for ourselves. But policy, by and large, is not, I don't want to be controversial when I say this, but it's just not accessible to people without disabilities. It's just not accessible, a lot of times, to the regular and average Joe. And we need to make policy more accessible in general, and I think that, if we do that, it would go a long way.

Lawrence Carter-Long (01:07:05):

Yeah, I would add that it's not unlike somebody who worked in federal politics and did public policy in New York City, it's not unlike the curb cut effect, which benefits everybody. Folks who use wheelchairs fought, scratched, demonstrated, passed legislation. Now who uses curb cuts? Not only folks who use wheelchairs, but people who have baby strollers and people taking their

suitcases to the subway and pretzel vendors. There's not anybody in society that probably doesn't benefit from a curb cut. Text messages first developed as a result of for deaf folks are now something everybody uses. I text more on my phone than I talk on the darn thing. Accessibility benefits everybody. I would agree with Laura, by saying that plain language is a demonstration, an example of your commitment. If people putting together these laws and these policies put forth a plain language brief, it shows that you actually want to reach real people and that you want to reach the greatest number of people.

(01:08:14):

If you don't provide plain language, it also shows your lack of commitment. The other questions I would ask policymakers or folks involved in public policy based on my experience is, "What's your budget? What's the amount of money that you're going to put behind this policy, once it is enacted? And who's on your team that's going to make this a reality?" If you don't have a variety of disabled folks with a variety of disabilities from a variety of backgrounds on your team making these decisions, then you've got to ask, how informed is it? And unless we put into place, all of the places where I've seen issues and problems have been places that haven't thought through those questions or haven't answered those questions for themselves. And so, I think plain language can demonstrate commitment, so can budget, so can who the members of your team are to make this a reality. But we have to push for all of those things in order to make progress and to make public policy actually meaningful.

Laura-Lee Minutello (01:09:11):

I also just, Lawrence, you've sparked a thought for me, I would add, this is Laura again, that I see, and I don't know what Damian and Lawrence, if you see this as well, a lot of times, the disability community in the eyes of those outside of the disability community is conflated with anybody who has a loved one or a child with a disability. What we are talking about, and I'm not invalidating those experiences, because the experiences of the parents or people with loved ones with disabilities are valid, but they are very different. I think, from a legislative context particularly, it's incumbent up here on the legislature to remember that, just because you talk to a parent or somebody who has a person with a disability in their life and they're telling you this, they're not a member of disability community. Members of the disability community are those who have disabilities themselves. And that's, when Lawrence talks about having people inform those policies, that's who, I don't want to assume that's who you mean, but I would assume that's what you mean is actual disabled people.

Lawrence Carter-Long (01:10:28):

Yes. And just to clarify, and thank you, Laura, for bringing up that point, actual disabled people means, yes, the guy down the block that you know, the person in the wheelchair that you know from church, but also, somebody that has a history of working in disability policy for the past 20 years. You need both. So I don't want to exclude anybody from the process. I think what makes the policy stronger is when you've got folks from a variety of different backgrounds with different levels of expertise and experience who can help inform those decisions that are made. You can't leave

anybody out of that equation. And I think asking yourself who's not in the room as we begin the process is a good way to start.

Laura-Lee Minutello (01:11:10):

And I think, just to further clarify my comments, because I don't want anybody to take that wrong, I'm not suggesting that we leave parents or those that have connections to disability out of the process entirely in some context either. I've encountered a lot where people will say they've talked to the disability community, and what they mean is they've talked to a parent. And those are two different things.

Lawrence Carter-Long (01:11:38):

When people tell me they've talked to... Or usually, they say, "I talked to a disabled person," they haven't talked to a community. But if they say, "I've talked to the disability community," my response to them is usually, "Which one?" Because the disability community in Berkeley, California is going to be very different from the disability community in Dubuque, Iowa or somebody in Sarasota, Florida. And it's going to be different depending on your zip code. And it's going to be different depending on your income. And it's going to be different depending on your ethnicity or your age. And so, when somebody says they talk to the disability community, I'd say, "Which ones?" And see if they can give me 4, 5, 6 number of different types of disabled folks or communities as an answer. If they haven't, then you haven't done enough yet.

Laura-Lee Minutello (01:12:21):

Yeah, and I think, to that point, just we talk a lot, at least at DRF, and try to make our work as intersectional as possible. To your point, you need a variety and you need that intersection of disabled people that hold identities outside of disabilities as well. I wanted to echo that, but I did want to make the point that, for the purposes of this discussion anyway, when we talk about the disability community or disabled people, we're talking about people with disabilities.

Lawrence Carter-Long (01:12:55):

And people who own that, I think, is really important too, people who are informed about not only their disabilities, but these public policy positions that they're taking and what the impacts are, be it positive or negative.

Damian Gregory (01:13:10):

It's interesting, because people with disabilities are also, in no way, not to overemphasize the point, but we are by no means a monolithic community. We are so many things. And it is important, when we have these discussions, that we not only include people that are across the disability spectrum, that we also include people with a variety of life experiences, people that are married, people that are unmarried, people that are gay, people that are straight, people that are college educated, people that aren't, people that have intellectual disabilities, physical disabilities, or

both. Because so often, what we end up doing is getting a sliver of that community and using that sliver to say it represents the experiences of all.

(01:14:13):

And each person's experience is different and valid and deserves to be heard. And where we're at in this point in our history where some disabilities seem to be more validated than others, where people that have one disability, it sometimes feels as if people with disabilities are pitted against each other, intracommunity wise. So we listen to the needs of one group and not the needs of the other group. It's important for all the voices to be heard as much as possible. And even those that don't have the ability to verbalize their voices also be included in the conversation, because their experiences are as important and as valid as those of us that run off at the mouth, like me, all the time. It's just we need to be cognizant of that.

Lawrence Carter-Long (01:15:12):

And I think the bottom line to that is, not only is it best practice, it's a good thing to do, but it's going to make that policy better, at the end of the day. It's going to make it more robust. It's going to make it more comprehensive. It's going to make it something... Your odds of it being something that's actually going to work increase when you include a greater number of people from a variety of backgrounds, experiences, and perspectives.

Damian Gregory (01:15:36):

And from my perspective, as long as we make policy and realize that there will always be unintended consequences, we should never start out to make that policy. But we should always be willing to make sure that policy evolves, so that it addresses blind spots, so that it sees things that we don't necessarily see at first drafting. If you come up with a euphemism that sounds wonderful and it's well intentioned and it's "people with unique abilities," let's say, and you are saying that, and then, all of a sudden, you get pushback from the community, respond to that, reflect that, kill that bill, if it needs to be killed, if it's something that people feel strongly about. Don't be so stuck in your ideas that you are not willing to evolve over time. Because when we know better, we should do better.

Laura-Lee Minutello (01:16:40):

Absolutely. And to piggyback off of that, I think it's applicable to a number of things, but it's also applicable to laws that are already in statute. Sometimes you don't see the unintended consequences till years down the road, months out, whatever. And just that willingness to go back and say, "Hey, we got that wrong," would go a long way.

Damian Gregory (01:17:08):

I promise I'm going to tiptoe toward the political, but I am not going to walk over the line. I will say that we have elected officials at all levels who think that acknowledging that you are wrong is

somehow a lack of character, that it is a sign of weakness, rather than strength. We need to be at that point where we realize our humanity and where we use that humanity to say, "Yeah, I screwed up there, but I'll do better tomorrow," or, "I'll do better next time." Be okay and move on, rather than doubling down on your bullheadedness and wrongness, because there are lots of things that I freely admit I don't know. And I think that would be a strength, if we all just decided that we're on this journey together. And sometimes we screw up, and that's fine. But what is wrong is not screwing up. It's refusing not to correct when we do screw up.

Lawrence Carter-Long (01:18:18):

Yeah. If there's one thing that the #SayTheWord campaign has taught me, I think more than anything else, it's that language is always evolving, and wise people do too. They embrace that process. I'm not at the same place I was in 2016 when I had that hissy fit, and that shows, to my mind, some growth. I'm more proud of the growth that has occurred and the conversations that I've had surrounding #SayTheWord than I am in creating the hashtag in the first place. And I think that we've got to embrace that evolution, those changes, that growth, with a sense of curiosity and wanting to continue growing. It's not the position that we held, but it's where do we end up that's most important and the journey that's most important. And language is one of the ways that we can do that, but not the only way. And so, I think learning from these conversations and making those adaptations or evolving along with them is a true sign of progress.

Laura-Lee Minutello (01:19:20):

Absolutely. I couldn't agree more. I think, and this is Laura, by the way, I just, listening to the two of you, Damian, you had said, and I wholeheartedly agree, that, a lot of times, it feels like the disability is we're pitted against each other. And I think that's something, not only for lawmakers to take away, but for something for us to take away, is what you just said, Lawrence, is just being willing to have those conversations with each other, with other people, with people outside of the community, with lawmakers, but also very honestly with each other and being able to look inside ourselves and see our own bias and how even our own experiences with disability have shaped us in a way that may be, unintentionally, but might be harmful or might minimize experiences of others within the community.

Keith Casebonne (01:20:14):

This has just been an incredible conversation. Let's say you're talking to a legislator right now. What are the things that you would want to tell that legislator about language and the impact that's going to have? And of course, we've touched on, throughout the whole conversation, that's what we've been talking about, but if you had a couple minutes to just talk one-on-one with your legislator about this issue, what are the types of things that you would say to them, regarding the disability community's involvement with lawmaking and how language can shape the laws and the outcomes from those laws?

Damian Gregory (01:20:44):

I'll go first. I'll say, just remember that we are a part of the community. And that sounds very basic, but it has to do with the fact that, often, laws are not designed with people with disabilities in mind. And so often, we are the folks that are affected most by public policy, but we are the last group to be asked how it will affect us. And I feel like, every time society gets a cold, people with disabilities get pneumonia, because the effects are often so dire on us and are on our communities.

(01:21:33):

I think what I would say to lawmakers, first and foremost, is you need to remember that people with disabilities, even though they may not be at your town hall meetings or at different venues where you see folks, people with disabilities do exist and we should be considered at all times when it comes to not only public policy, but just life in general. What would it be like if people with disabilities were not part of society? It would be, I would say, it would be a not only an inaccessible place for some folks, but it would be a more drab, colorless place without us. So that's what I would say. We are a constituency group, and our considerations need to be mentioned.

Lawrence Carter-Long (01:22:38):

I think I would ask, "Who does this policy serve? Who is it benefiting? Who was part of the process informing the process as a result of their experience or their expertise? Who wasn't in the room? And how can you get them there? What is the expected result of this legislation? How can you get, if people with disabilities are 27% of the population, that we know of, that we've been able to count, are disabled folks 27% of the process? Are they one in four of the people in the room or engaged in the debate? And if they're not, how are you going to get there? Let's help each other to get there together." I think that's what we really need to be thinking about is, how can this policy, how can the process, that informs the policy, be more representative of our society as a whole? And that's the eye on the prize, if you will, what we should keep our attention focused on.

Laura-Lee Minutello (01:23:35):

Absolutely. Those are so good. I think, just to add to that, I think I would just provide a gentle reminder to challenge your assumptions, and I think that's something we should all do. That's not unique to a lawmaker, but particularly in policy, it seems, at least in my experience, that a lot of disability policy is crafted with the idea of caring for people with disabilities. But similar to Damian's point, "What would it look like to consider people with disabilities as part of society? And are you crafting legislation that is going to further that aim? Are you crafting legislation that is going to bring out the inherent strength that there is in disability? Or is this born out of an assumption that people with disabilities need to be cared for in a way that's different than the rest of society?" And just challenge those assumptions of disability on the whole, which, I think, again, I think we should all do. That's not unique to the legislature, but that would be my kind of advice to somebody crafting the policy is, "How does this benefit people with disabilities?" And to Lawrence's point, "Who does it benefit?"

Maddie Crowley (01:24:53):

I think that is a wonderful sendoff on a incredible conversation, and I really hope that this conversation gets to all of the people that deserve to hear it, need to hear it, want to hear it. I think there's so much rich information and perspective that has come up in the hour and a half that we've been chatting. It's been honestly monumental, even in my own framing of disability, and has helped me just by listening. So I really appreciate you all taking the time to talk with us today and to shed some light on this topic. And we really hope to stay tuned and have y'all on the podcast again sometime soon.

Keith Casebonne (01:25:44):

Yes, indeed. Thank you guys so much.

Damian Gregory (01:25:46):

So grateful for the opportunity, and I hope that this conversation continues amongst people who listen to this podcast and people who don't. Because I think conversations like this need to happen often. It doesn't need to be a one and done, so thank you.

Lawrence Carter-Long (01:26:06):

Yeah, I would ask people to sit with this and see what resonated with them, what they felt good about, but more importantly, maybe to spend a little time with what makes them uncomfortable about this conversation and why they're uncomfortable. And there may be opportunities within that reflection to ask, "Wow, I never thought about the words, "disabled," or, "disability," quite like that before. And I wonder, who taught me to be ashamed of it? And how can it be different? Or how can it be more?" And spend a little time with the emotions and the thoughts that pop up, because they're there to teach you something. And hopefully, this process that we're all on can become more expansive and more inclusive, the more that we do it, and that those changes will be reflected in the public policies that are enacted into law.

(01:26:57):

So yeah, really thank you to everybody here, to You First and to Disability Rights Florida for having this conversation. I had no way of knowing, in 2016, when I had my little temper tantrum that this would be a gift that keeps on giving, but there's really nothing in life that I think I'm prouder than to see the conversations that have emerged and what these kinds of discussions have taught me as a result. So thank you very much from the bottom of my heart. I really appreciate it.

Laura-Lee Minutello (01:27:25):

It's been awesome, you guys. To echo, Maddie, I think just this conversation surpassed my own ideas and expectations of what this could be, and I just can't thank both of you enough. I selfishly love DRF's podcast in general, but just that opportunity to be part of this conversation has been amazing with all of you.

Keith Casebonne (01:27:52):

It's guests like y'all that hopefully make it as amazing as you say it is. So again, thank you guys so much. We really appreciate it. And yeah, the conversation continues and will continue probably for a very long time. Thanks again so much to Damian, Lawrence, and Laura for being on today's episode. We had such a great time chatting with all of you.

Maddie Crowley (01:28:14):

Yes. And for more information about each of them and how to get in touch with them or learn more about their work, check out the show notes on our website or wherever you're listening.

Keith Casebonne (01:28:23):

Yes, indeed. We have some really great episodes in store for you this year, so be sure to subscribe to the podcast wherever you're listening. So you'll get notifications when those new episodes drop.

Maddie Crowley (01:28:32):

We're on all of the podcast platforms, and you can also listen or read the transcript of each episode on our website at disabilityrightsflorida.org/podcast.

Keith Casebonne (01:28:43):

Thanks for listening, and always please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org. See you next time.

Announcer (01:28:55):

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