



A conversation with Lydia X.Z. Brown

Voice Over:

(Hip-Hop music plays)

Barry Whaley:

Hi everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, I want to welcome you to “504 at 50.” I’m Barry Whaley. I’m the project director of the Southeast ADA Center. “Section 504 at 50” is a special interview series created in recognition of the 50th anniversary of the Rehabilitation Act of 1973. In our series we speak with leaders of the disability rights movement who advance the cause of equal rights through their tireless work. Today we’re talking with Lydia X.Z. Brown.

Lydia is a policy council with the Center for Democracy and Technology’s Privacy and Data Project. Lydia’s work at CDT focuses on disability rights and algorithmic fairness and justice. Outside of their work at CDT Lydia is an adjunct lecturer and core faculty in disability studies at Georgetown University and the founding director of the Fund for Community Reparations for Autistic People of Color’s Interdependence, Survival, and Empowerment. Joining us to talk with Lydia today is our host, Jonathan Martinis, the senior Director for Law and Policy at the Burton Blatt Institute at Syracuse University. Pleased to have you both with us today, and Jonathan, I’ll turn it over to you.

Jonathan Martinis:

Thank you so much, Barry and Lydia, thank you so much for being with us today. It’s absolutely an honor. For those who aren’t familiar with your work and to our audience if you’re not, I strongly recommend that you read up on Lydia’s work, especially her incredibly thought-provoking writing. Would you please tell us a bit about your background and how you became a disability advocate?



Lydia X.Z. Brown:

This is Lydia. Thank you so much, Barry and Jonathan, for inviting me and for hosting this conversation. When people ask me how I became an advocate, I sometimes struggle to answer that question, I think in large part because I didn't set out in my life thinking, "ah, yes, I am planning to be an advocate." I don't think very many people do, at least not in early childhood, but as a disabled person who is deeply embedded in disability community, my spouse is disabled, my closest friends are all disabled, I don't think it would be possible to live my life and not to be advocating. Advocacy, after all is about the ability to fight for what you want, to fight for self-determination and autonomy as well as to fight for the betterment of your community.

And I've believed as I have for my entire life, that every single one of us has an obligation to use whatever resources we have available to us, whether that's time or money or knowledge or skills or space or any other kind of resource that you might be able to conceptualize as having in service of justice and against injustice or oppression in any of its possible forms. And I believe that the choices that I've made in my life where I've done my work and how I've done my work and the kind of work I've done have tried to reflect my commitment to that value, that we have a responsibility to use our resources in service of justice and against injustice.

Jonathan Martinis:

Thank you for that, Lydia. Your work, Barry touched on a little bit, really focuses on state and interpersonal violence targeting disabled people, particularly those living at the intersection of areas like race, class, sexuality, faith, language, and religion. There are statistics that are pretty horrifying that people with disabilities face violence almost four times more frequently than people without disabilities. So a two-part question. One, based on your experience in research, why is that horrible fact true? And two, are there unique or even worse issues faced by people who are intersectional?

Lydia X.Z. Brown:

This is Lydia. The problem that disabled people face ultimately comes back to ableism, which most people would define as discrimination or bias or prejudice, but I think is better understood as structural oppression. That is, ableism is a system of power relations and power differentials that treat some people as fully human and having personhood and others as lacking personhood or only able to obtain



conditional, temporary personhood. Ableism, in other words is a value system that teaches us what kinds of people count as valuable, as worthy, and desirable, and what kinds of people count instead as expendable and disposable. Ableism teaches us how we should assess our own value as well as the value of others, how we should configure our relationships, how we should configure society. And in a profoundly ableist society, such as the one that we live in now, violence against disabled people is inevitable.

Whether that is over extreme interpersonal violence, child abuse, abuse by teachers or medical professionals, intimate partner abuse, abuse, and violence by strangers, by police, or by other institutions of the state or government, or whether that is violence that occurs on a larger, slower scale. The violence of large scale, systematic deprivation of access to necessary home care and long-term supports and services, the violence of long-term institutionalization and incarceration, the violence of social policies that trap disabled people in poverty at higher rates than non-disabled people and then punish us for experiencing poverty, experiencing illness, experiencing trauma.

Now the second part of the question that you asked are realities different for those of us who live at the intersections of multiple forms of marginalization or oppression. And the answer is of course that is the case. And while we don't always have statistics that will demonstrate what those realities are, we know that across many different marginalized communities, rates of sexual assault are higher than in communities that largely have experienced more social advantages or access to privilege or resources.

We know that communities that are marginalized experience higher rates of police violence and incarceration than those that have better proximity to power or to privilege. We know that communities that are marginalized have higher rates of poverty, higher rates of homelessness, experience higher rates financial abuse and physical abuse, as well as what I've mentioned earlier about sexual violence. And so it's no stretch to imagine that if we were able to reliably and consistently disaggregate our data, that data about the rates of disabled people that experience abuse in their families or by intimate partners or the rates of disabled people who are killed by police are always going to be higher when you break those down by race or by gender, by immigration status, or even by whether a particular disabled person is institutionalized versus integrated into their community. And we do have some of those numbers that can point at what those realities are, but by and large,



researchers are not capturing reliable, comprehensive information about the experiences of disabled people who are living at the intersections.

Jonathan Martinis:

Thank you, Lydia. There's a law, the Hate Crimes Protection Act, that in 2009 was amended to include, ostensibly at least protections, for people with disabilities. So again, a two-part question. One, in your opinion, has that law helped or has it only papered over the awful reality you just talked about? And two, even if it has helped or if it has not, what are some ways that we can prevent people with disabilities from being targeted as you described?

Lydia X.Z. Brown:

This is Lydia. Hate crimes legislation is important symbolically, and when I say symbolically, I don't mean that it is an empty gesture. Symbols are very powerful and they're very important in our society. But at the end of the day, we can't legislate morality and you can't legislate away ableism because it's a value system. It's not a legal system, it's a value system. Ableism shows up in our laws, it's embedded in our laws, it's embedded in our legal institutions. And so legislating against hate crimes targeting disabled people, while incredibly important symbolically in naming that disabled people's lives have value, that disabled people deserve protection, and that we should societally condemn violence against disabled people because of our disabilities, that doesn't necessarily translate into an actual decrease of violence nor to actual meaningful enforcement either in response to acts of violence or let alone proactively to prevent violence against disabled people, which goes to the second part of the question that you'd asked.

But staying on that first part of the question for just a moment here, when we think about violence against disabled people and our federal hate crimes law that now enumerates disability as a category that can be recognized as motivating in a hate related incident in an act of violence that targets disabled people. Well, we know that disabled people are continuing to be restrained and secluded in schools, punished with electric shock torture at the Judge Rotenberg Center in Massachusetts, that disabled people comprise anywhere from 50 to 80% of people who are killed by police, that disabled people, if you have a developmental disability, experience a rate of sexual assault at least seven times higher than that of non-disabled people. And I don't think that this law is materially changing those



realities, but that's also a reflection on the limitations of legal advocacy and legal reform overall.

Our laws are important tools in our fight for disability rights in particular, but the law doesn't necessarily guarantee its fulfillment, let alone the removal of the systemic barriers that necessitated passage of the law in the first place. This series is commemorating Section 504 of the Rehabilitation Act half a century after it was passed. Well, the Rehabilitation Act mandates non-discrimination, which includes provision of reasonable accommodations in federally funded services, activities and programs disabled people might be affected by or participating in. And we know that disabled people continue to be routinely denied, federally guaranteed, legally-mandated rights of access, of accommodation, of non-discrimination in court houses, in jails and prisons, in state universities and colleges. In so many different areas of our lives disabled people do not have equal access, equal opportunity, or inclusion even though the law mandates it. So you asked the question of has this hate crimes law materially helped?

I think it'd be very difficult to answer that passage of a law actually translates into a change in values because a change in values is what the crisis of ableism requires. It's a value system, it's not a legal system. But then the second part of your question was, well, regardless of the state of this law and its impact, what can we do to prevent violence against disabled people? And I want to encourage us to be expansive and imaginative in our thinking. Violence against disabled people does not occur in a vacuum. In an individual, in a personal case, it may be because somebody realizes that they're in a position where they can exercise power over somebody else, where they believe that nobody will fight for the person they are targeting or that the person they're targeting won't or can't fight back, or it may be, has been in the case in a number of horrifying incidents that have hit the news over the last several years that some non-disabled people really just hated disabled people, really just hated us.

I'm thinking, for example, about the mass murder in Sagami-hara, Japan a few years ago, in which a former employee of a large-scale institution for disabled people broke into the institution to murder as many of the disabled people institutionalized there as possible. And this former employee, the attacker deliberately chose first to attack the disabled people who he knew were non-speaking and thus not able to call for help in a way that people who might use verbal speech would've been able to. And when asked about what his motivating factors were and when he produced a manifesto he'd written explaining those



motivations, he made it very clear that he found disabled people's existence disgusting, abominable, grotesque, horrible, and a blight not just upon the government invoking age's old eugenicist rhetoric of burden, but on society. The disabled people's existence was a blight on society, and he hoped that his attack, this mass murder of institutionalized disabled people would be just the beginning, that the government of Japan would be spurred on to enact a national euthanasia program to permanently eradicate disabled people.

That incident stood out for many disabled activists as particularly horrific and appalling, but at the same time, the sentiments that that attacker expressed are not remotely uncommon. They're encouraged from a very early age, but often disguised with pity and with charity so that they don't seem as abhorrent or as objectionable as they do when spelled out explicitly and without any qualification at all. So if you ask what we should do to prevent violence against disabled people, we need a value shift. And we need a value shift now because we are teaching people, disabled people and non-disabled people from a very young age that disabled life is not worth living. That disabled life is disgusting, that disabled life is burdensome, that disabled life should make you feel uncomfortable at best and afraid at worst.

And that is setting up an environment where not only can any number of abuses be heaped upon disabled people, so long as people say it's for our own good, but where over extreme violence, like that massacre can also take place and will still somehow be excused as, at worst, simply an unfortunate tragedy. And then the disabled victims will still be talked about as "Well, they're probably in a better place by now." The implication being if there is some kind of afterlife or some kind of return back in a different body, different world in the future, that maybe they will have the blessing of not being disabled again, which again just reinforces those very same ableist ideas and values about disabled people that enable that kind of violence in the first place.

Jonathan Martinis:

Thank you so much for that Lydia. Among the incredibly powerful things you just said is something I believe in my marrow is that laws don't change values, they don't change culture. Only advocacy and openness and conversation can change values and culture. I like to tell people that the Americans' Disabilities Act was passed in 1990, 32 years ago, and it said that people with disabilities are people. That's all it really says, that they're people with the same rights as everyone else, and it hasn't fixed the problem any more than the Civil Rights Act passed almost 60



years ago has cured discrimination. If laws changed beliefs and culture, nobody would speed. So thank you for making that incredibly powerful and cogent point. Let's shift gears to some of the work that you are doing. You are the founder and co-director of the Fund for Community Reparations for Autistic People of Color's Interdependent Survival and Empowerment. Would you please tell me how you came to found that fund and about the work you do?

Lydia X.Z. Brown:

This is Lydia again. The Autistic People of Color Fund, which is the shorter name, a little bit easier to say, rolls off the tongue better, it was an idea that I'd had for many years, and I think an idea that many people in the autistic people of color community had had in various forms. We all, when we're in marginalized communities have had the experience of not having our needs met, of not being able to easily access support or not being able to access support at all, of not being believed if we ask for support and of knowing that most resources that exist are not targeted toward or really designed for our communities and therefore that we run the risk of not receiving the support or the resources that we need even if we were to attempt to reach out and we want to be able to support each other.

We want our community members to be able to thrive and to be supported and to be cared for. And so the opportunity to create the Autistic People of Color Fund came through a confluence of circumstances. Proceeds from the publication of the first edition of *All the Weight of our Dreams*, the anthology on autism and race and receipt of an award from the American Association of People with Disabilities, AAPD, in recognition of my advocacy work allowed me and a few other community members to create a seed fund to be able to start returning money like literal material resources to autistic people of color who have disproportionately experienced the brunt of economic deprivation, exploitation, and neglect because of the nexus of racism and ableism. And that initial pool of funding was slightly less than \$10,000 and it was gone within 60 days because that is how urgent our community's needs have been as a result of systematic resource theft and exploitation.

And over the last four-and-a-half years since the Autistic People of Color Fund began, we've been able to build out the pool of money available primarily through small contributions from directly impacted community members who understand the importance and the necessity of this type of work. We've also been fortunate enough now in the last couple of years to have received some grant funding as well,



which has allowed us to stabilize our operations, to grow the fund as its own organization and to expand the fund's tactics out of solely resource redistribution and returning funds to the community and also into systemic advocacy for policy change and for values change in society. So now we have a small staff with a research coordinator, a policy director, a program coordinator, and usually a return we have between one to three interns and fellows who want to gain experience working in movement for social change and social justice. And I think that that work is incredibly exciting, and I'm personally really thrilled to see where the Fund's work will go over the next year.

Jonathan Martinis:

Lydia, you're also the policy council with the Privacy and Data Project at the Center for Democracy and Technology. The CDT works to promote democratic values by shaping technology policy and architecture with a focus on the rights of the individual. For those who don't know, could you please tell us how technology is often exclusionary particularly to people with disabilities and other marginalized groups, and what can be done about it and what the CDT is doing about it?

Lydia X.Z. Brown:

This is Lydia. I would actually reframe the question that you asked because exclusion is only one piece of the puzzle. Disabled people are excluded all the time in all facets of life and in interactions with technology and ways in which technology mediates our lives, that reality is no different. Many technologies remain inaccessible and fail to meet the WCAG 3.0 guidelines that govern accessibility standards for internet- and computing-based technologies. Many websites fail to meet the standards, apps fail to meet the standards. Many disabled people don't have access to enough economic resources or educational support and training to be able to use technologies that may seem ubiquitous in modern life today in the United States. At the same time, technology affects our lives in so many more ways than whether or not someone has access to a cell phone or whether a particular website is accessible.

While those issues are vitally important, especially where your access to education, to employment opportunities, or even to basic public services, whether they're specifically services for disability or whether they're services that all people, disabled or not, should have access to, depends upon your access to a cell phone or broadband connection or a computer. But technologies like algorithmic and



automated technologies, which have been a focus on my work for the last few years, are also making decisions about our lives at every turn. You are probably being judged and assessed by an algorithm anytime you apply to rent an apartment. If you ever decide to apply for a personal loan or a credit card or you are getting ready for a mortgage, if you are applying for a job, whether that's to work in the mall or to work at a consulting firm, there's a good chance that some algorithmic technology is scoring you with or without your knowledge.

If you go in front of a court and you're brought up on charges, there's a good chance that they will use an algorithmic technology to decide whether or not you should be granted bail and pretrial release. If you are living in the world as an alive human, a huge number of companies, many of which the average person doesn't even know exists are amassing an incalculably large trove of data about you, down to where you spend your time, who you communicate with, what your sexual orientation might be, what mental health disabilities you might have had in the past, as well as what mental health disabilities you might experience in the future might be. Whether you could be pregnant, if you might be married, or will have children in the future. And that is deeply intrusive, invasive levels of detail about our lives that for-profit companies, law enforcement and private actors alike all might be able to access and use to profile you, determine what opportunities you have access to and make decisions that fundamentally impact your life, your health, and your freedom. And we should all be concerned.

Jonathan Martinis:

Thank you. Finishing where we began, Barry mentioned that this interview series is designed to celebrate or create a history of the 50 years since the Rehabilitation Act has been passed. I like to say that in 50 years we've may have come a long way, but it just highlights how much farther we have to go. I mentioned to people when I speak that 50 years ago when the Rehab Act was first passed, fewer than one in five children with disabilities had access to any education in public schools. So undeniably there have been gains, but I'd like you, I if you could, to tell me in your opinion what the most significant gain has been in these 50 years, but just as importantly, if there's one thing that truly needs to be fixed, that if you were given the wand to fix a problem, the biggest problem we face, what would it be?

Lydia X.Z. Brown:



This is Lydia. Oh, come on. You can't throw that question out. One thing, there is no one thing. There are a million different problems that we face as disabled people, but it does come back to ableism as a value system being deeply embedded in our society. Our society as it is right now would not function the way it does were it not for its commitment to ableism, were it not for how pervasive and all-encompassing ableism is. And so wave this hypothetical magic wand, I would disappear ableism as a value system. If we disappeared ableism, then the structural inequities and systemic injustices that we are dealing with would not be possible. They might not even be imaginable in that world, especially because ableism is so deeply and inextricably tied up with and wrapped in other forms of marginalization and oppression as well.

It is not possible to end ableism without ending every other form of oppression that currently exists. So if we could disappear ableism, we would be in a radically different world, one that frankly would be unrecognizable, and one in which the types of laws that we've passed now wouldn't necessarily have to exist because the ways that we would regulate life and what kinds of access we might mandate might be completely different in a world that has accounted for and respected the value, the worth, the ways in which disabled people exist, all of our experiences from the beginning.

Jonathan Martinis:

Lydia, I have to tell you your answer was the one I've been hoping to hear in every interview. And given that yours is the last interview, thank you for ending us on a very high point. Ableism is the river. Everything else is a tributary from it so it's the wand would require damming of the river, and I hope to God we get to see something like that happen.

Lydia, it's been an absolute honor, as I said when I began. Thank you so much for joining us. Thank you for your time and your insights.

Lydia X.Z. Brown:

Thank you again for hosting me. It has been a pleasure to be part of this conversation.

Barry Whaley:

Thank you both. What a wonderful interview. And as Jonathan expressed, Lydia, just we're going out on a high point. Thank you so much.



Listeners can access this interview and other interviews at Section 504 at 50 website. The web address is section504at50.org. This series is produced by the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and is a collaboration with the Disability Inclusive Employment Policy Rehabilitation Research Center. Again, thank you for listening, and we look forward to seeing you at our next interview.

