## Audio link:

https://soundcloud.com/cdt-tech-talk/tech-talk-disability-benefits-algorithms-talking-tech-w-lydia-x-z-brown-alexandra-givens

Automated Transcript:

Welcome to Tech Talk

by Cp T. Happy New Year and welcome to CDTs Tech Talk where we dish on tech and internet policy while also explaining what these policies mean to our daily lives. I'm Jamal Magby. And it's time to talk tech.

Elections have dominated the headlines. And as our listeners likely no CDT has been busy on that front, check out our most recent episode for more. But that's just one of our many issues our experts have been working on. Today we're talking with one of the newest faces at CDT Lydia XC brown Policy Council with our privacy and data project, and well established disability advocate, in addition to our CEO, Alexandra Gibbons to discuss CDTs latest report on artificial intelligence and benefits determinations. Lydia and Alex, thank you both for being here today.

I'm excited to be here. Thank you so much for having me.

So So for our listeners who don't know, can you give us a little background about who you are and where you're coming from?

My name is Lydia, as you shared, I always introduce myself by mentioning that my pronouns are they them. My background is as an advocate and a community organizer in disability rights and disability justice, which are actually two distinct but very closely related movements, and ways of thinking about disability in the world. Before joining CDT, I worked with Alex at Georgia laws Institute for tech law and policy, where we launched the project on disability rights and algorithmic fairness. And prior to that work, I was a fellow at the Babylon Center for Mental Health Law, where I represented disabled students facing school push out and criminalization of all of that work. I've been an advocate on issues of disability, race and gender for about a decade. And I'm very excited to bring that analysis and commitment to CDT.

Wow, that's an incredible background. I mean, we're super grateful to have you and your expertise at CD at CDT, supporting with our work. So with that, I want to jump into the issues at hand. If you could tell us more about how widespread the use of algorithmic decision making is, and where specifically, you're seeing it being used.

Many people know that our lives are increasingly governed by algorithms everywhere from our social media feeds, to high level decisions about policies that may reflect how our decision makers think the population will respond to certain changes. And what many people don't realize is the impact that algorithmic decision making might have on decisions that affect our very lives or access to housing or to employment. And that's what we're seeing for disabled

people. Some of the key areas that our project has been looking at for the last couple years has been ways in which algorithm driven decision making informs which people have been determined eligible to receive benefits, what kind of benefits they're getting, which people might hired for jobs, and whether you might even be may get passed an automatic screening to be considered for a job to even get to a human reviewer. Whether you might be surveilled in school, while taking tests. Whether or not data related to your health is shared with a company that you might know nothing about their intentions, or whether your data might end up in the hands of police, and what that data might even look like.

So switching gears here a bit. Alex, you brought this project with you when you became CEO of CDT why was it important to you to have this work happiness.

So as Lydia described, algorithmic decision systems are being used an increasing array of walks of lives with real effects on consumers on job applicants and others. And for the past couple years, there's been a really important conversation happening around the potential for discrimination. So just for an example, right when people are applying for a job, one of the ways that an algorithm that is being used in the hiring process will help sort resumes for applicants is by analyzing those resumes and comparing how an individual candidate compares to existing employees at the company. If you pause for just a minute, you can think about some of the structural flaws and that approach, right? We already know that there are systemic inequities and how people are represented in the workforce. And if you're using the status quo to train the future, there's a good chance that the future is going to perpetuate that exclusion as well. So that's one area where there's been an increasing focus and awareness about the region, risks of these tools. And we can talk about some other examples as well. What we notice is that there had been a really good conversation about the potential for racial discrimination and gender discrimination along these lines. But the conversation about disability was really being excluded. And so a couple years ago, I started doing work and was able to find really thoughtful partners at the Ford Foundation that were willing to support us to start integrating the disability conversation far more squarely into these mainstream conversations around algorithmic bias and algorithmic fairness. Lydia came on as a very early partner, they were one of my best hires and have helped lead this work ever since. And so when I got the opportunity to come over to CDT, we faced a decision, which was do we keep this at Georgetown where the work was going well? Or is there a real opportunity here? And to me, the opportunity was this CDT has been around for 25 years, it's a really well known organization. It has a wonderful foothold. And really a platform in tech policy conversations, right? We have access on the hill, we have partnerships with companies that we hope most of the time, listen to what we'd say, we have these great collaborations with other civil society organizations. This is a place where if we can start to center disability questions in these broader conversations around tech and civil rights, it can have an enormous difference. And so to me, it was a wonderful opportunity for such a well established organization to really embrace this cause and begin using our platform and an effective way to continue focus on these issues.

Now, Lydia, you've recently released a report on the use of AI benefits and determinations. What did this report analyze? How was aI being used in these settings? And why is it important for people to know to know about these,

our report examined the last several years of litigation brought by advocates challenging the harmful use of algorithm driven decision making in benefits. More specifically, we looked at ways in which advocates have challenged algorithms under three main theories under constitutional and procedural due process violations. Under violations of notice and comment rulemaking requirements, how states are required to change policy, and solicit feedback from the public before they're allowed to do so. And potential violations of the community integration mandate in disability rights law under the Americans with Disabilities Act and the Olmstead Supreme Court decision. You know, what we looked at in this paper were ways in which different states adopted algorithmic decision making at one or two levels of the process, largely around benefits for people who receive care through Medicaid, home and community based services or other long term supports and services programs. And the way that most of those programs work, or that people might be allocated either a certain number of hours of care or services in a particular week, or they may be allocated a particular dollar amount to budget, the cost of their care during a particular timeframe, like a week or so. And algorithms can enter the process at one of two places, they can enter the process in the assessment stage where someone's needs, what type of care or services they might need in order to live in their community and to be healthy and to have a fulfilling and meaningful life, what that might look like. And the other way where algorithms can enter the process as in the allocation determination, which is in determining how much care or how many hours the person will actually be approved for. And that can get a little bit muddy, especially for folks who aren't necessarily up to their eyeballs in thinking about the intricacies of Medicaid policy. But what it functionally can look like is what happened to two of the plaintiffs in Arkansas, Bradley Ledgerwood and Tammy Dobbs, both of whom have significant disabilities, that mean that they need help with everything with dressing with eating, taking medication, even assistants to move and reposition their bodies so that they can be comfortable and not get bed sores. And both Tammy and Bradley had previously been approved for 57 hours of care each week. And that approval came because a nurse had done an assessment and decided based on what I've observed about your level of care needs, like what kind of support you need to live in the community and to be healthy and to feel good about your life. You will need about 37 hours of care and the nurse made a discretionary decision sent in that paperwork and that is what the state paid for. But after Arkansas introduced a new algorithm to decide what type of care so would need and then automatically determine how many hours that the assessment would then translate into both of their care hours were slashed nearly in half. And for Bradley, that meant that he and his family even started talking about whether he would have to go into a nursing home, just to make sure he could get necessary medication and be moved and repositioned at the right times, because they wouldn't be able to afford the cost of care without this help from the state. And all of this happened because a computer decision made a computer program made a decision based on assumptions about what type of care somebody should need, that took the decision completely out of the individual nurses hands.

So the paper centers on disabled people stories in cases, and you talk specifically about cases where people have successfully challenged AI systems in court, can you give us some more examples?

Sure. In the state of Idaho, which similarly adopted a new algorithmic tool for assessment of people's needs, the state started to use an assessment that would automatically determine what level or range of care somebody would be in based on a series of predetermined categories. And the assessment itself simply forced people to input answers about their needs and what tasks they needed help with, and then would spit out discrimination automatically to decide what range of care they should be placed in. And once that range of care had been determined, or that level, then that would determine later how much hours of care they would be approved to receive. But Idaho devised its algorithm to produce those determinations, based on deeply flawed and incomplete data. In the court case brought by advocates at the ACLU of Idaho, the judge found that the data used to create this algorithm had been so riddled with inaccuracies, that up to 66% of all the data ultimately had to be discarded as not fully usable, or not usable for the purpose of of calibrating the algorithm. And that was because some of the data was incomplete, some of the data was inaccurate, and some of the data was simply unreliable. And it was all based on a relatively small pool of data as well, from a few years before it was used for calibration. And that small pool of data was not necessarily genuinely representative of or meaningfully, responsive to the needs of the entire population of people in Idaho, whose disabilities might mean that they would need support through this program. And so the result was that across the board, large percentages of people who had not faced significant cuts to their approved hours, suddenly were facing drastic and noticeable cuts to their hours comparable to the ones faced by the plaintiffs in Arkansas. And the case brought against Idaho centered around Idaho's adoption of an algorithm that was not sufficiently explainable to the people whose lives were affected by it to an algorithm that did not allow for a sufficient process to be able to challenge the determinations that it made that then affected people's lives, and to whether or not it could in fact, fulfill requirements were due process under the Constitution, or the enabling statutes for the program for which it was used, in this case, Medicaid to actually to actually protect people's rights to receive the type of the type of benefits that they had been receiving previously under law, and to which previous court decisions in our history of jurisprudence have established that when you are receiving benefits, that you have certain rights associated with them, because you become dependent in some ways on your survival in your health, requiring access to certain types of government provided benefits.

Now, Alex, why are cases like these important to highlight? What are some of the bigger policy lessons we can take from them?

Well, I think one big takeaway from what Lydia is describing is that there is a huge need to educate state decision makers about the trade offs that come with the adoption of some of these systems. Lydia described some of the data entry issues, some of the programming errors that lead to generalizable rules that don't actually work for people in their individual circumstances. And there is an uphill battle educating the people that design and deploy these systems about what the real human cost is. So there's work to do there. There's also work empowering legal

aid lawyers, self advocates, you know, others that are experiencing these cuts and maybe as the result of a flawed system, as to how to advocate for themselves and how to fight for their rights. The bigger piece about this is the for folks that are interested in algorithmic fairness, more general more generally, these are some of the first cases that are actually being litigated, where courts are deciding what does an explainable algorithm actually mean? What does auditing mean? How frequently the states need to be checking the results of these programs and seeing whether or not they're working as intended. So there's really interesting case law being developed from from these from these litigations, where we are starting to really grapple with these questions of when you deploy a tool to assist in decision making, what is the responsibility of the human that is using that tool? And how can we think about better strategies to educate people about their effects?

And Alex, you mentioned earlier about how important it was for you to bring a disability focus project into a mainstream tech organization like CDC, what does it mean for an organization to center disability issues? And how with CDC trying to do this?

Yeah. So you know, first of all, I will not purport to have all of the answers on this. I think it's an ongoing project for us. But I will say that it is a really important goal for us to think through in the broader conversation around technology and civil rights. How do we make sure that disability rights have a seat at the table? And that there's a focus on the intersectional nature of these questions, right? When you think about people that face, marginalization on multiple fronts, if they are people of color, who are also disabled, who we know historically, are excluded from the workforce tend to be at the receiving end of the most extreme forms of discrimination. So we're trying to think of a couple different things. One is that it really matters to us to partner with disability first organizations in particular organizations that are led by people with disabilities themselves, to think through how can we be a resource, CDT has been around for a long time, our bread and butter is integrating technologists into policy conversations to help make for more informed and, frankly, more effective advocacy? How can we use our skills and our platforms to help the organizations that are really on the frontlines grappling with these questions. So on this benefits paper, for example, we held a workshop that brought together the legal aid organizations that are on the frontlines, actually litigating these cases, the self advocates that have had the guts to go out there and talk about their own cases and mobilize other people to help them. And then major national disability organizations that we hope will help engage on these issues in a better, more forceful way. So our goal is really to think through how can we help that effort? What is our role? When do we make sure that we are stepping aside to give the platform to others that really can carry this fight forward? But really, how can we be good allies to help them that work? There are a couple of technical ways that we do that. So in addition to our own staff, we also partner with consultants, several of whom have disabilities themselves and have been involved in this work for a long time to try and carry forward the advocacy and bring them in to the work that we are doing. We also formed an advisory council, which has a range of experts from disability groups, from a legal background, a couple of people with enforcement experience at the Justice Department and the Equal Employment Opportunity Commission, and then some technical expertise as well, to make sure that we're grounding our

work in the efforts of the broader community and have ties to other to other initiatives that are happening so that we can make sure that we're doing this in ally ship with others.

And Lydia, in addition to this report, what are other things you're working on as CDT what other projects are on the horizon?

We just released another report, which is pretty awesome, right? That report came out a couple weeks ago on the use of AI hiring tools. And Alex mentioned this a little bit earlier in our conversation today. But I just find it fascinating and horrifying. To think back to even you know, my own time in high school when I was applying for job after job mostly in retail. Sometimes for Office Administration type jobs, you know, the kind of things that the average high schooler about to go to college age range might be looking at applying to. And I just remember time after time, it opening on the screen, some kind of personality test. And at the time, I just thought this is weird. I have no idea why I have to fill this out. But okay, sure. Here goes I guess. And I would fill this out. And in four years, I never got a callback for a single job. I have no idea. You know, what happened and what factors went into me not being able to get hired anywhere. And so I can't say was this all because of those tests or not? But it does leave you wondering, to what extent did those automatic personality tests, if any, play a role in ensuring that my resume might not have been seen by any of the hiring managers in you know, every single store in the mall still bitter about it as an adult. We are building out work to address what does this actually look like at scale? How many employers and in what fields are using not just personality tests, but other automated hiring tools? What kind of information are they collecting on people who are applying for jobs? And how is that used to determine who can even be fairly considered? And in what ways might this harm most disabled people at the intersections of race of gender of class, and other axes of marginalization. And beyond that, we're looking at what we might have to say about the way that AI is intruding into our lives in schools surveillance, in police surveillance, and collection of health related data, whether specifically of people with disabilities through apps or programs that are designed specifically to respond to disabled people's needs, or whether in devices that are made available to everybody that monitor your health. And, you know, I think we all know, just how vigorous those kinds of technologies have become. And I don't think that enough, people are talking about what the ubiquity of health monitoring and health related data collection will mean for disabled people who have always already been subjected to intense surveillance and to social policies that usually don't have our best interests in mind.

Alex and Lydia, thank you so much for joining us here today.

It was great talking to you.

Thanks for having us.

You can find the disability benefits in AI and hiring reports as well as a plain language version@cdt.org And don't forget to check us out on Twitter, Facebook and LinkedIn at said dem tech

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