



#LiberatingWebinars: Before You Go: Enabling Access for Autistic Trans People in Healthcare

Transcript of Autistic Women & Nonbinary Network & National LGBTQ Task Force webinar with Victoria Rodríguez-Roldán, Finn Gardiner, Noor Pervez, and Kayley Whalen
28 October 2020

(Opening remarks from Victoria Kirby-York and Lydia X. Z. Brown not included)

SHARON DAVANPORT: Hello everyone and welcome. I'm Sharon daVanport, the founding ED of AWN. We are the Autistic Women & Nonbinary Network. I wanted to start today's webinar by saying thank you to everyone who's joining us today, and especially to our panelists for taking time to have already reviewed the resource and prepared to share their thoughts with everyone today.

SHARON: The resource is titled, "Before You Go: Know Your Rights & What to Expect at the Doctor and in the Hospital." It's a guide that basically has tips and advice—life hacks—for autistic, trans people about finding and going to doctors.

SHARON: I want to send a shoutout and thank you to Victoria for hosting today's webinar. And, most especially, for all the work you did, Victoria, on co-authoring the guide along with myself and Lydia Brown. Thank you too, Lydia, for all of your work on the project and for organizing the webinar today.

SHARON: I especially want to say how much AWN has appreciated partnering with the National LGBTQ Task Force. We are really excited about the rollout for our organizations to offer this to our autistic, trans community. We know how helpful it's going to be. We've had a lot of input and guidance along the way.

SHARON: So we really appreciate that. And I don't want to miss out by saying thank you to Erin Casey. Erin is AWN's Art Director and Aaron is the one who actually did all the illustrations and designed this guide. And I don't want to say too much about the guide itself because that's what the panelists are here to do today. So I'll let all of you take it from here. Thanks so much, everyone.

VICTORIA RODRÍGUEZ-ROLDÁN: Hello everyone. I'm Victoria Rodríguez-Roldán. Welcome to today. Thank you Sharon for your comments and—personally, my day job—I'm the Director, Senior Policy Manager at AIDS United. I used to be a Senior Policy Counsel at the National LGBTQ Task Force when we first started writing this. And I'm one of the co-authors of the "Before You Go" guide, alongside Lydia. It's been a really interesting journey.

VICTORIA: And with that, I will introduce our panelists. First off is Kayley Whalen. Thank you Kayley for coming. Kayley Whalen is an independent communications consultant who works with organizations dedicated to social justice. She has led digital campaigns for numerous organizations including Sins Invalid, the Alliance for Citizen Directed Supports, Trans United Fund, Greenpeace USA, Casa Ruby, and the National LGBTQ Task Force. She is a



neurodivergent, transgender, Latinx advocate and writer, and was Miss USA in the 2020 Miss International Queen Transgender pageant in Thailand. Her blog, TransWorldView, records her experiences interviewing members of the transgender community in Southeast Asia and around the world.

VICTORIA: There's also Finn Gardiner, who I've had the opportunity to know for a very, very long time—longer than I care to admit, as it's almost admitting my age. Finn is the Lurie Institute's Communications Specialist. He is a disability rights advocate who is primarily interested in accessible communications, intersectional disability justice, inclusive technology, and equitable access to community resources including education, employment, and healthcare.

VICTORIA: Throughout his work, Finn combines disability, advocacy, policy analysis and research, and written and visual communications through policy briefs, original reports and white papers, and contributions to research projects. His research and advocacy interests include education and employment for autistic adults; comparative disability policy; inclusive technology; LGBTQ and cultural competency; and policy that takes into account the intersections between disability, race, LGBTQ identities, class, and other experiences. He holds a Master's of Public Policy degree from the Heller School and a Bachelor's degree in Sociology from Tufts University. Finn also serves as a member of the Board of Directors at the Human Services Research Institute, a nonprofit dedicated to research and policy advocacy benefiting people with disabilities and seniors.

VICTORIA: Then, finally—but not least—we have Noor Pervez, who is a community organizer who works at the intersection of race, religion, LGBT+ issues and disability. He is the Community Engagement Coordinator at the Autistic Self Advocacy Network and Access Director at Masjid al-Rabia. He previously led his campus LGBT+ advocacy group, Rainbow Guard, and gave a number of talks regarding intersectionality. His previous work centered on exploring the intersections of disability, LGBT+ and religious issues. He is a graduate of the University of Texas at Dallas—the same alma mater of my wife—with a degree in Emerging Media and Communications.

VICTORIA: So with that, is everyone ready? Is everyone in here? Feel free to put your cameras on if you're there. If not, that's okay. So I guess a few questions that I would have is what issues—for whoever wants to go first—since the topic is healthcare, going to the doctor's office, et cetera, what issues do you feel trans and autistic people face in accessing healthcare?

FINN: I think that there are several barriers, including communication. So a lot of autistic folks may struggle to communicate in ways that neurotypical people may understand easily. For example, a lot of autistic people might be nonverbal, they may use augmentative or assistive communication or AAC. So they might use an iPad that is programmed with phrases that the iPad will read out as they press a button.

FINN: Or they will use a text-to-speech device that they can use to talk. And if a doctor or another clinician is not familiar with AAC, they may not know what's going on when somebody comes in with an iPad or phone or some other device that they use to communicate. Some other autistic people may struggle to talk about their feelings or may perceive pain differently from



non-autistic people and it might be important for clinicians to ask further questions to see—to understand exactly how they are feeling.

FINN: And then trans people also encounter barriers when accessing healthcare. For example, some insurance companies may not be able to reflect a trans person's gender identity on their paperwork. And if a provider's office isn't set up to acknowledge trans people's identities, there runs a risk that the trans person in question might be misgendered or otherwise treated the wrong way because there is no method for them to indicate how they'd like to be addressed before the appointment starts.

FINN: Now, some clinics—especially LGBTQ-friendly ones—will have a space for pronouns and names, but that's not the case for all clinicians. But that's not the case for all offices. And so a lot of these problems arise through ignorance. And I don't mean ignorance in a condemnatory sense, I mean ignorance in the sense that they just don't know better: they don't have the training, they don't have the experience, and they did not cover these issues in medical school or nursing school or wherever they studied.

FINN: So you have these systems in place that are designed for an “ideal default person” who doesn't actually exist, and trans people and autistic people encounter barriers in accessing these services because it's not set up for us. It's set up for other people. It's set up for cis people—that is people who are not trans—and it's set up for non-autistic people. Another difficulty that arises, at least for autistic people, might be sensory issues. Fluorescent lights might be too intense. There may be too many stimuli in one place.

FINN: That's especially the case in a large hospital. You have staff going back and forth, you have patients going back and forth... it's chaotic. And that sensory overload can exacerbate the stress that an autistic person already feels when they are going to the doctor's office. And then if they're also trans on top of that, you're combining the sensory overload with a potential ignorance of how to handle trans identity, and possible communications issues—possible *communication* issues, sorry.

FINN: So all these difficulties combined, you know, you're going to get a tempest in a teapot. It's going to be difficult to get the care that you need if there are all of these potential microaggressions, if there are all these potential sources of sensory or emotional overload. I feel stressed out every time I go to the doctor's office because I'm always worried that somebody is going to screw something up. Because I've had so many people screw things up.

FINN: Or people are going to focus on the wrong things. And I think if you throw race in there as well then, ooh, that makes things even more complicated. Because people of color, regardless of gender identity or neurotype, are likely to be discriminated against at doctors' offices. A lot of times, people of color—especially Black people—will be perceived as feeling pain less strongly than white people.

FINN: There will be a lot of assumptions made about our health, what we do, a lot of victim-blaming. Some providers will zero in on, say, weight, as opposed to overall health. And there is some racist history behind weight stigma as well but I'm not going to go into that right now. But



there are so many different ways in which a multiply marginalized person can feel that oppression, can feel that marginalization, in the doctor's office.

[Pause]

NOOR PERVEZ: I definitely agree with Finn in that a lot of structures of oppression get kind of baked into the way that hospitals and major medical systems work.

NOOR: I would say that that can surface in terms of microaggressions. That can also surface in terms of a complete inability to understand how trans people might be medically different. So for example, if you have a trans person who has gone through hormone replacement therapy, if your doctor perceives you as, say, the gender you were assigned at birth, they might be missing out on key risk factors that can change when you're changing hormonally.

NOOR: For example, if someone has been on testosterone for several years, they might have an increased risk of certain types of cancers or certain types of liver conditions. But doctors who have no experience with patients who have been on hormone replacement therapy might have no frame of reference for that or might be working from the assumption that someone on testosterone is "just the gender that they were assigned at birth."

NOOR: And that can be extremely, extremely dangerous, particularly when you take into account the fact that people who are autistic will frequently have co-occurring medical conditions, so there is that level of things. I would also say that autistic and trans people face a lot of barriers to accessing healthcare that is related to gender identity.

NOOR: Very frequently, I have run into providers that have asked, "Isn't an autistic, trans person just experiencing a special interest in gender?" which is ignorance on many levels, but is also kind of a way of coming to a head—this system of oppression of ableism and transphobia kind of coming together to assume that autistic people can't have agency over their own gender identity.

NOOR: And it is a challenge when you're in a patient position to advocate for yourself while simultaneously getting the care that you need, because it's very overwhelming. It can be exhausting. And it can put you in a position where you feel like there is no point, almost.

NOOR: Or there is just so much going on, and it can make people feel like giving up. And that's where you get people who refuse to seek medical care. Or people who choose to not seek treatment for certain types of medical conditions because these types of situations where doctors flat out refuse to acknowledge their own shortcomings and knowledge.

NOOR: Or when doctors are refusing to kind of bridge those gaps in knowledge for themselves, patients can feel as though they have to do these things for themselves, and it can make it very challenging to feel that you're deserving of healthcare. And it can make it very challenging to feel that if you seek healthcare, that you will end up better off than you were before.

[pause]



KAYLEY WHALEN: So I think healthcare access is a huge issue. I think even getting a competent provider that is covered by your insurance can be quite a long search. And I found it hard to get a therapist who kind of fully understands both the trans part and what I would say is my neurodivergent identity—so bipolar, ADHD, some combination of autism spectrum disorder which still is a puzzle to figure out for me.

KAYLEY: But, you know, I have my therapist, who I've been seeing for years, as I am learning more about autistic identity being like, "You're not autistic. I've known you seven years. You have tons of empathy. I don't think so. You can believe that. But I don't think so." I think even though he is wonderfully, well-meaning, gay man who I trust and has been very accepting and positive—just not having that level of awareness, maybe, of how autism exhibits differently in femme and women, as opposed to the stereotypical cis male or at least masculine model of autism.

KAYLEY: And I have also had issues with educating providers about my transgender identity and health needs especially because it's non-traditional. Because as a queer woman, I think a lot of trans health providers are less aware of the difference between gender identity and sexual orientation—that you can be attracted to women and identify as a woman.

KAYLEY: It seems pretty straightforward but I think it's still a concept a lot of trans providers are getting their head around. And one other thing is that when we talk about hormone replacement therapy, everyone has different hormone levels. And when you think about hormone replacement therapy for women, most people just assume it may be progesterone or estrogen, maybe testosterone blockers if you've not had a form of gender-confirming surgery that reduces your testosterone level significantly.

KAYLEY: And then as someone who's had gender-confirming surgery that dropped my testosterone levels to below what a cisgender female would usually experience, I had to spend months educating my doctor and asking them to be like, "Look, I don't feel like myself because my testosterone levels are way too low." And I think some trans women don't pay attention to that or don't care. They have this kind of ick factor: "I don't want any testosterone at all."

KAYLEY: But if you look at normal variation within cisgender women, a lot of cisgender women have pretty moderately high testosterone levels normally. And I just felt more at peace with myself when I had more testosterone in my system. So this may be true for a nonbinary person or a femme trans woman like myself. Even though I go to an LGBTQ healthcare clinic—Whitman Walker Health—even though I have been seeing their transgender specialist, it took a lot of education to be like, "You know, I actually want to take testosterone as well as estrogen." And that was a tough process.

KAYLEY: So, you know, there has to be a lot of self advocacy and unfortunately we're constantly in a position having to educate people about what "neurodivergent" means, about what "transgender" means and about what "autism" means.



KAYLEY: There is the common phrase that “if you met one autistic person, you have met one autistic person.” We all have unique needs. And I would say the same thing about trans people; you meet one trans person, they're not representative of the entire trans community.

[Pause]

VICTORIA: Thank you, Kayley. And I would add my personal experience with trans. For example, one time I had to have emergency surgery in Texas and Kayley probably remembers the great Texas gallbladder affair—as I call that—and having to take care of my cat during the meantime. I remember very distinctly in the prep for the surgery where they are going to slice me open and extract an internal organ from me, one of the nurses asked me, “Are you pregnant?”

VICTORIA: Not wanting to do a massive education on what is trans, I said no. She asked, “When did you last have your period?” Okay—it’s inevitable—and I told her I’m trans. And she just said, “Oh, okay, but what does that have to do with anything?” And at that point, I was pretty much just like, “Okay, just put me under. I don't want to have this conversation. Just put me under and slice my belly open.”

VICTORIA: This is an example where even the “well-meaning, not being transphobic, et cetera” can come with transphobia, with misunderstanding. And a large amount of trans people do avoid seeking medical care precisely because they feel unsafe in seeking care.

VICTORIA: Which brings me—let's see the other questions we have prepared. In the sense—when you go get advice, because the guide we’re announcing is precisely about advice for autistic people around how to access healthcare—what do you think is most important for trans and autistic people to know about accessing healthcare?

VICTORIA: Basically I'm thinking if you have to give advice to someone who was somehow born yesterday and has never accessed healthcare, has never gone to the doctor ever, but yeah.

[Pause]

NOOR: So in terms of what would be really important to talk to trans and autistic people about in terms of accessing healthcare, I would say before anything else, to know that there is community. There are people that have gone through it before. And that while it can be a challenge to connect with those people, that it's really important if it's even remotely possible for you to connect with the larger community and to get an idea of some of the challenges and some of the problems that we face in healthcare, and to get an idea of the different ways and different approaches that people have taken to this historically.

NOOR: I would definitely say that learning how to be your own advocate in terms of understanding your rights in a medical setting—and this can vary by state because unfortunately, particularly in the U.S., anti-discrimination laws around transgender identity tend to vary depending on where you are.



NOOR: But know what the rules are in terms of what providers have to do, where you are. And understand what rights you have in terms of, as a person with a disability—in terms of what anti-discrimination protections there are for you as well as what standard issue kind of problems are that you're going to run into for your particular condition.

NOOR: For example, as someone who uses a power chair, I will very frequently run into hospitals that are inaccessible or that have treatment rooms that don't have enough room for me. So I have gotten used to that idea. For me, what ended up working was getting a travel chair. It was obtained for other purposes but ended up being useful for medical settings because it's smaller and can fit into smaller rooms.

NOOR: That's one example of an accommodation. It's a very literal one. But other examples might be talking about if you have, say, a sensory reaction to certain types of products—like I know, for example, that there are people who have either allergic reactions or sensory reactions to latex.

NOOR: It might make sense to advocate for yourself and say, “Hey, latex causes negative reactions for me. Can you please use a different type of glove?” Or, if you are really proactive, you can bring a box of gloves yourself. Things like that, in terms of understanding what you are going to be up against and understanding the different tactics and different approaches you can take.

NOOR: You shouldn't have to argue constantly to get what you need in the medical setting. Unfortunately, in a lot of cases, you're going to have to, and that sucks. I would also say that in non-COVID times when it's a lot easier to bring an advocate with you—so for example a partner, a family member, friend, or a direct supporter—that can make a big difference in terms of having someone to help you if you are overstimulated or if you are having communication difficulties that you don't understand how to solve in the moment.

NOOR: There are procedures during COVID for people to bring support people in with them to the hospital if you have a disability. However, people run into a lot of difficulty with that unfortunately, with providers who either don't know about the fact that that's legally allowed or flat out refuse to deal with the legislation, which is a whole ‘nother can of worms to deal with from a legal perspective.

NOOR: So basically what I would say, just to kind of boil it down: learn how to self-advocate; learn different approaches to self-advocacy; and learn about your rights and your ability to bring in direct support people.

[Pause]

VICTORIA: So, Finn or Kayley, what do you think is the most important thing or advice or whatnot that you would give to trans or autistic people who are seeking medical care? What is the most important thing they need to know?

[Pause]



FINN: I think that it's important to be straightforward with trans and autistic people. Let them know there are issues with the system and that they may need to fight, that they may need to be prepared before they go to the doctor.

For example, they can have a list of all their needs: like access needs, information about their condition, information about their gender identity, et cetera. You can just condense that all into a list and give it to your provider. Or even keep it for yourself so you have a script of what to say when you go to the doctor. While I haven't used a script like this in a while, I have created similar documents before.

FINN: So I remember... oh, if somebody said something like, if somebody said something asinine about my gender, then this is how I react. And I think it's also important to know where you can complain, where you can report issues. Whether that's to somebody at the hospital like a director or a manager, or your state's—or a committee in your state that oversees healthcare. Knowing where to report is helpful. So if something really bad happens, you should know where to take the complaint.

FINN: I agree with what Noor said about bringing someone else along. I have never done that myself but I know other people who have. I also think that having a self-care routine both before and after the appointment can also help. Maybe making sure that you are not doing other things that day if it's possible. Now, if you have to work, you have to work. But if you don't have to work, if you don't have to do other things, then just take the time off after the appointments so you can decompress.

[Pause]

KAYLEY: So I find difficulty going to a doctor. And unfortunately, as someone with a marginalized identity, we can get really angry and get really pissed off that we feel like someone doesn't understand our needs. And that's great as an activist and to have someone in your community you can talk to about that. But it's not going to get you very far with healthcare.

I remember getting so frustrated that one day I was in line at the LGBTQ health clinic and I had been fighting so long to get my hormones and they didn't have them that day after such a long fight. And I was so mad, I threw my smartphone and it smashed. And I think that's because I—we talk about spoon theory or running out of the ability to cope and deal with stressors and microaggressions that add up and up and up.

I think it's good to have a person there with you to help calm you or be on the phone with someone. Because it's a very stressful experience. And just knowing your limits. I think it's great if you know you can take time off and then focus on going to the doctor. Unfortunately, that's not true for a lot of us. But just knowing what you need to get, treating it, unfortunately, as transactional. And an emotional plea won't often get you as far as just coming there with data and facts and concrete needs, so.

[Pause]



VICTORIA: Thank you, Kayley. I would also add that when it comes to what people should know and understand, I always try to say that we need to have a mindset that the doctor works at your pleasure basically. Like they work for you. Like if you had a car and you don't like the mechanic or they did a shitty job of repairing your car, you wouldn't go back there. You would change them.

VICTORIA: It is more difficult with doctors. At times they have a lot of power over you, especially when you're inpatient in a hospital or when you have crappy coverage from your insurance. But at the same time, you should try to see the doctor as not some know-it-all, but as... you know your own life experience and they are there to work for you, basically.

VICTORIA: And in that sense, you should always try to have that attitude towards it. But yeah. With that, I think one of our last questions is basically what can policy makers do to change circumstances for trans and autistic people accessing healthcare? And what do you think about that, as far as how would you go about doing that?

VICTORIA: As far as what should be—I'm a policy attorney, basically—what would you suggest as a policy solution to fix this? To make healthcare more accessible for trans and autistic people? To make them less afraid of the doctor? And I myself can come up with a few that we're litigating right now: the discriminatory regulations at HHS that would make it easier to discriminate against trans people, despite the Supreme Court decision in *Bostock*. But you all go for it. You're the panelists. I'm just a moderator.

FINN: So I think that there are a number of solutions that policy makers can implement to help protect both trans and autistic people in healthcare. For example, as Victoria mentioned, fighting rules and regulations that would allow providers more leeway to discriminate.

[Brief pause]

FINN: Sorry about that. All right. So one method that policy makers could use is making sure that regulations actually protect trans and autistic people. Making sure that HHS or other government agencies put into place rules that ensure that the kind of discrimination that people often count under “religious freedom” is not allowed. And there are some pretty good constitutional arguments against this kind of discrimination. Now, note, I am not a Constitutional lawyer—I did study public policy—but anybody else can jump in if I am totally off base here.

FINN: So everybody has the right to equal protection under the law, the 14th Amendment. And, the *Bostock* ruling suggests that trans discrimination is a form of sex discrimination. So based on the Constitution and based on the recent Supreme Court ruling, it is—or it should be—illegal for medical providers to discriminate against people based on their gender identity. I also think that it might be wise to pass legislation that explicitly protects trans people.

FINN: For example, Massachusetts and California and several other states have laws that protect trans people in public accommodations, and in medical settings, and in the workplace. And if



other states adopted these measures, then it would be much easier to bring a suit against providers that discriminated, or make it easier to make the formal complaint process.

FINN: I also think that possibly having an Ombuds officer or somebody similar to address these complaints, and possibly adjudicate if something goes wrong, would be a good idea. Just to have some independent oversight.

FINN: I think that there's a lot that can be done on the state level, especially if the federal government is being difficult. Especially when we have—especially when we have federal agencies that are run by people with particular ideological dispositions that tend to be hostile towards LGBTQ people, in general.

FINN: As for autistic people, I think that enforcing the ADA and educating people about the ADA is probably the best choice, probably the best course. Unlike with trans people, the law is much clearer with disability; though, admittedly, the ADA is more difficult to enforce than some other laws because you have to sue.

FINN: And there are quite a few steps you have to take before you sue whoever violated your rights as a person with a disability. But emphasizing that it is the law and having more oversight of hospitals who are treating people with disabilities—which they all do—would probably help to mitigate a lot of these problems that autistic folks and trans folks encounter when dealing with the healthcare system.

[Pause]

VICTORIA: Thank you. Who else wants to answer that? Just basically what are policy solutions that can be made?

[Pause]

KAYLEY: So this is Kayley and in 2014 I was part of the National LGBTQ Task Force and a bunch of other groups that were opposing legislation known sometimes as the Murphy Bill after U.S. Representative Tim Murphy—officially called the Helping Families in Mental Health Crisis Act. And this is an example of bad legislation, bad policy that's couched in, “Oh, it's helping people.” But these are the kind of policies that we need to be uniting to fight against.

KAYLEY: And it's great being part of an LGBTQ organization that realized the harm this would do to all disabled people such as increased ability of families, caretakers and others to involuntarily commit someone to a mental institution—which is another form of prison, in my beliefs. And, so the other thing was it would have done away with a lot of the privacy protections and disclose someone's mental illness, possibly also their transgender or LGBTQ identity to their family members or caretakers, which is very dangerous—you know, in a homophobic or transphobic setting. And these were the kind of policies that it was great to have a coalition to fight against.



KAYLEY: But we should be fighting for policies—you know, I work with three different non-profit organizations: Values Into Action, Alliance for Citizen Directed Supports, and the National Leadership Consortium on Developmental Disabilities. And all three have the stated goal of getting people out of these institutions, big programs, congregate care settings. Basically settings that isolate, often autistic people, but people with intellectual, developmental disabilities and other severe mental health disabilities that put them in these segregated facilities. They have to be away from their friends, their family. It makes it hard for them to make friends. And then they become dependent on the system of an institution that takes away their freedom and their rights and then says, “Oh, we’re helping them and providing them support for their health needs.”

KAYLEY: Well, if they were able to live at home, maybe they’d have friends, you know, maybe they’d have community. Maybe they wouldn’t need nurses and caretakers to meet all their needs. We should be supporting policies that move people out of institutions and move them towards what’s known as person-centered planning and self-directed supports. These can be provided under the Home and Community-Based Settings waiver, which can be funded through Medicaid.

KAYLEY: And these programs let people choose how they want to be supported. They let them hire the staff. They emphasize in person-centered planning. Figuring out how you want to be supported is paramount to how you receive care. What are your employment goals? What are your life goals? You know?

KAYLEY: I have interviewed an artist Mara Clawson, who runs a very successful art business, and gets shown in art shows around the nation, teaches art, and also has been the subject of an award-winning film documentary. And she’s able to run her own business and do art because she’s able to self-direct her supports and not be in a day program where she would be beholden to staff: “Oh, what’s today’s activity? Let’s all throw you in a van and take you to a bowling alley.” Like, she’s able to choose her own path.

KAYLEY: So supporting self-direction—supporting the idea that people should not be locked up in these institutions, the policies that involuntarily commit people. And, furthermore, when we talk about these institutions and people being involuntarily committed, this is also tied into, you know: our government and cultural dependence on police and the regulation of people with mental illness, autism, intellectual and developmental disabilities that are seen as not being full members of society. Not being deserving of the same rights as other people. Not being seen as able to make decisions about their own lives.

KAYLEY: And these are people that, you know, someone can call the cops and be like, “Oh, they’re having a mental—they’re having a breakdown.” And then that person can be committed against their will, often by caretakers, family members.

KAYLEY: I just have to say, I find it extremely ironic that I am doing this webinar for the National LGBTQ Task Force because I am still a little bitter that a few years ago at their Creating Change conference, I was violently assaulted by protesters and I was traumatized by this experience. This was in 2016. And the next morning I get woken up early by my roommate and then all of these phone messages and calls. And I was the Social Media Director for the conference. And between the trauma I’d experienced from being assaulted the night before, the



being woken up early, these really kind of harassing text messages I was getting from my mom, I just had what you can refer to as a meltdown or a breakdown. You know, I didn't have any spoons. I woke up feeling traumatized. And I got so mad, I threw my phone against the wall. I was the Social Media Director for the conference and my phone shattered. And now I didn't have a phone and I started screaming, and the National LGBTQ Task Force decided to send paramedics to my room that then involuntarily committed me to a psych ward that day. So that was not cool.

KAYLEY: We shouldn't be involuntarily committing people who are traumatized just to traumatize them further by putting them in a psych ward. Literally, they were trying to take my computer laptop cord away from me, which I needed to work, because they thought I was a suicide risk. And, I had made the mistake when I was having a panic, and the paramedics were like, "Are you going to harm anybody?"

KAYLEY: I'm like, "No, I'm not going to harm anybody." And I was so upset and they said, "Are you going to harm yourself?" And I'm like, "I don't know." And they're like, "Ok, you're committed to this psych ward all day long." And I had to fight with psychiatrists all day to get released. It took like 8, 10, 12 hours to get released.

KAYLEY: So I think police and paramedics, someone being involuntarily committed—when all I needed was someone to talk to me and calm me down and drink some tea, you know, and curl back up in bed and just chill—I think this is a form of state violence or a form of violence that we need to stop.

VICTORIA: Thank you, Kayley. And I would agree, we need to put an end to coercion in mental healthcare. I am currently writing a piece of research for the Drexel Law Review around coercion and involuntary commitment and mental healthcare and how it disproportionately impacts marginalized identities. So with that, I encourage people to read it when it comes out next year.

NOOR: One thing that I think is important to address with policymakers when it comes to changing circumstances for trans and autistic people in healthcare, is thinking about really how to change things at a structural level to kind of put decision-making power back in the hands of autistic people in particular. I'm thinking particularly here in terms of, like, the current structures we have around, for example, guardianship... which kind of puts power over how people are allowed to dress, who they are allowed to date, who is allowed to go where, who has power in a relationship.

NOOR: When we think about changing that structure and we look at different formats as self-directed support, such as supported decision making, I think it would go a long way in terms of making sure that people who are autistic—and people who are trans and autistic, in particular—would have the power to make decisions about how we present ourselves to the world.

NOOR: But also it would really give autistic people the chance—who, under the current system would be under guardianship—the chance to have control over how we access our supports, and who has power over certain aspects of our care.



NOOR: So for example, in terms of a medical setting, someone under guardianship might not have all of the same rights in terms of accessing, for example, hormonal replacement therapy if their care provider does not agree with their decision to want to go on hormone replacement therapy. This is just one example of a major medical decision where the power is taken out of that person's hands, but there are a lot more.

NOOR: That can range from minor things like, “You need to take medicine,” all the way up to surgical decisions. That's a really big deal. And when we look at supported decision making, where the person in question gets to choose the way that they get their supports and at what point they are able to shift that power and regain it for themselves, that's really important.

NOOR: I would also say when we're talking about autistic and trans people in healthcare, policy makers could do a really good job in terms of promoting non-carceral solutions when it comes to accessing mental healthcare, particularly in crisis situations. Because very frequently that is used against autistic and trans people in crisis.

NOOR: And, very frequently, the positions that people are placed in, whether that's involuntary commitment or psych wards—depending on what state you're in, what your health records look like or if they are listening to you—you might be treated very, very poorly, or be misgendered, or have a variety of micro- and macro-aggressions put against you as a result of your identities. And that's really, really harmful.

NOOR: So I would say: definitely working on promoting self-directed supports like supported decision making for people who are asking for additional help. I would say supporting home and community-based services. And I would say promoting non-carceral solutions to mental healthcare are all really important.

[Pause]

VICTORIA: Thank you for having us. Thank you for being here. Thank you for your responses. I would love to keep going but we are eventually going to run out of time. And with that, I will pass it on to Lydia.

[Pause]

LYDIA X. Z. BROWN: Thank you, Victoria, for your skillful moderation of this panel. And thank you so much to Kayley, Finn, and Noor for each of the things that you have shared. You are all friends of mine and colleagues whom I deeply respect and admire.

LYDIA: I have learned a lot from each of you in the time and opportunity that I've had to get to know you. And I am so glad that you are at the forefront of the fights for justice for autistic and other disabled people, and for trans people. I know that our movement has a great future because you are part of it and I am glad to be in the trenches with you and call you my friends, my comrades and colleagues.



LYDIA: For those of us who are joining us and learning about this for the first time, we are so glad that you have taken time out of your evening to be with us tonight.

LYDIA: We did record this in advance by the time you are watching this. Today is, in fact, my partner's birthday; and I could not be happier that this evening will be spent talking about what trans and autistic people need and will be still advocating for in years to come. Because that is work that is at the core of who both of us are.

LYDIA: I will direct each of you to the websites of both AWN and the Task Force where you can download a copy of Before You Go. And please share that with your friends, with your communities.

LYDIA: We hope this guide will prove useful and helpful for many trans and autistic people out there and that it will in turn spur further conversation among policy makers, among advocates, and among healthcare providers about what we can do better so that nobody will ever have to experience the things that Kayley, Noor, and Finn have talked about ever again.

LYDIA: And so that healthcare no longer has to be confusing, overwhelming, or traumatizing, but instead can be about what it is supposed to be: about care, about well-being, about making sure that each of us is still alive to fight another day, and—more than that—to be able to experience joy and pleasure, things that we are so often denied but absolutely deserve.

LYDIA: So thank you again to each of you for sharing. Thank you to our interpreters, Victoria and Jaron, thank you to the Task Force and to AWN for collaborating to put this booklet out into the world, and thank you to our editorial and captioning team and to all others who make this work possible—and much more to come. Thank you and good night.

[End of Panel.]

