#LiberatingWebinars: Abolition, Deinstitutionalization, and Decarceration in the Pandemic

Transcript of Autistic Women & Nonbinary Network webinar with Dustin P. Gibson and Shain Neumeier, 25 January 2021

LYDIA X. Z. BROWN: My name is Lydia X. Z. Brown, and on behalf of the Autistic Women and Nonbinary Network, I’d like to welcome you to the next webinar in our #LiberatingWebinars series.

LYDIA: Tonight, we have two incredible advocates and organizers who will be speaking about abolition, deinstitutionalization, and decarceration in the pandemic.

LYDIA: First, I’m excited to introduce Dustin Gibson. Dustin works in the tradition of deinstitutionalization and has worked with Centers for Independent Living in Pittsburgh, Pennsylvania, and both of the national independent living organizations. He is currently Access, Disability, and Language Justice Coordinator at People’s Hub; a peer support trainer with Disability Link in Atlanta, Georgia; and a founding member of the Harriet Tubman Collective.

LYDIA: Next, I’d like to introduce Shain Neumeier, who is a lawyer, activist, and community organizer, and an out and proud member of the disabled trans, queer, and asexual communities. They focus on ending abuse and neglect of disabled youth in schools and treatment facilities. Shain has worked with the Intersex and Genderqueer Recognition project, the Autistic Women & Nonbinary Network, and the Community Alliance for the Ethical Treatment of Youth.

LYDIA: We chose this topic to address this month because the pandemic has hit hardest and deadliest in institutions like jails and prisons, psych hospitals, nursing homes, group homes, and large-scale developmental disabilities. I’m excited to hear from Dustin and Shain tonight, discussing connections between disability justice and abolition, explaining what deinstitutionalization and decarceration are, and exploring strategies that advocates and organizers are using to challenge ableism, racism, and other forms of violence during the pandemic.

LYDIA: So first I’d like to hear from each of you, starting with Dustin, about how the pandemic is affected disabled people in institutions of all kinds. Like, what is happening right now?

DUSTIN GIBSON: Hey, this is Dustin. First, I want to say that I’m grateful to be here and that this conversation is happening. I feel like we need to continuously have these types of conversations, especially when we’re talking about groups of people that have been disappeared into institutions, all forms of institutions, and their voices being intentionally suppressed.

DUSTIN: So I think about prisons and the barriers that exist between – the communication barriers that exist. During the pandemic, what a lot of people have experienced is 23-hour lockdown, meaning that people are relegated to their cells for 23 hours per day and forced to either have shower time or phone time, which just reduces the amount of communication that can happen on the outside. A lot of different mail policies have been put into place under the guise of
protecting against COVID. That has just reduced the amount that we have been able to communicate with our people inside. So I’d say that’s probably one of the biggest things, and understanding what’s happening, the visits have stopped. And those are the traditional ways to understand what’s happening on the inside.

DUSTIN: Another thing that has happened in the congregate settings largely is the spread of COVID. The majority of deaths of COVID in the U.S. are people that are in congregate settings. A lot of states haven’t tracked the numbers for everybody, and they also haven’t tracked the rate at which staff has spread it once they’ve gone back into community either. So we could probably be safe in saying that like 75% of the deaths are somehow related to congregate settings, prisons, institutions, nursing facilities. And this is something that we have not seen before. Viral infections spread through nursing facilities all of the time. But right now, there’s just a magnifying glass on it because the entire country is dealing with the pandemic, or the world, really.

LYDIA: Thank you so much for sharing. It’s horrific, awful, and, unfortunately, none of it is surprising. Shain, could you talk about this as well?

SHAIN NEUMEIER: I’ll wait a few seconds.

SHAIN: Mostly what I would say is to add onto what Dustin is saying about the context here, is this is happening in the context of the broader pandemic in which even to this day, certain policies are being followed or made that deprioritize people with disabilities. Such as, early in the pandemic, there were attempts, whether put in place or proposed, to deprioritize people with health conditions or people who were already at higher risk of health problems and people with disabilities from COVID treatment and placed into hospitals when there was a shortage. And there was loud – widespread outcry against this, which at least publicly made some states and regions and hospitals back down from such a policy. But in recent days, news has come out as we’re recording this in early January of 2021, that Los Angeles is once again dealing with its hospital shortage, or shortage of beds in hospitals, by triaging, as it were, based on a person’s health status. Basically, weeding out people who are thought to be unlikely to survive. Which will disproporatly impact people with disabilities.

SHAIN: More broadly, the rhetoric around COVID, especially on the parts of people who don’t disbelieve that a pandemic is happening, but downplay its significance, is the idea that, well, some people are gonna die anyway. That’s how it goes. Grandma is old. This person already has health conditions. What are you going to do? So this is the context, societally, in which people with disabilities are being left to die even in community. And once somebody has been warehoused in a facility, so much the worse. And not surprisingly, also at the same time, even to the extent that the two populations don’t overlap, there’s a disproportionate amount of people in the – like overall who are people of color who have been suffering because of the pandemic, which is going to affect people with disabilities, people of color, in these carceral settings, at the margins of those two – at the intersections of those two identities.

SHAIN: And lastly, I say (and this is a relatively minor point in – as far as its – the scope of it), but, for those of you who have been following the story of the Judge Rotenberg Center, which is
the only facility in the United States known to use electric shock as a form of punishment on people with intellectual disabilities, developmental disabilities, and psychosocial disabilities, has been allowed to continue using this device despite a recently adopted Food and Drug Administration ban on the basis of the COVID pandemic. So torture is ongoing of yet another sort in the form of electric shock as punishment because the FDA has decided not to enforce its rule during the pandemic.

DUSTIN: This is Dustin. And I have just kind of want to add onto what Shain is saying to provide some scope of how many people we’re talking about and who they are that are in nursing facilities and other forms of institutions. When we’re thinking about Pennsylvania specifically, only because I do a lot of work there, a lot of my work lives there, nursing facilities would be the third largest city if we were to count them all together. So there’s service providers that are set up to provide services for 30 different counties. They have staffs of like 22 people – and we’re talking about 22,000 people that are in nursing facilities across 178 different facilities. So on average across the U.S., people that are purportedly getting care in these institutions have an average of 48 minutes per day with RN’s. So we should talk about it in the context of these being places that one, are for profit. And they’re just not holding people that we might traditionally think that are in nursing facilities, as elders, or people that are transitioning – but more so disabled people, and elders, and people that have deemed to not be valuable in society for some reason.

LYDIA: And this is Lydia. You spoke a little bit about this in talking about how the pandemic is ravaging people who are institutionalized and incarcerated. And I think most of our community here understands and knows that institutions are violent and wrong, but may not fully understand what different types of institutions are, and what it is that makes institutions violent in the first place. So could you, starting with Shain, talk about what it is that makes institutions violent?

SHAIN: So first of all, when we talk about institutions, there’s different kinds of institutions, some more harmful than others, especially as they exist now. We can say that institutions extend from regular schools, K through 12 day schools, to prisons. And, unfortunately, especially depending on the school, those might not be too different. But prisons and similarly residential locked facilities, like psychiatric wards, like nursing homes are often enough, like residential schools for people with psychiatric or learning or intellectual disabilities, like large-scale developmental centers, these are what some people have called total institutions. They’re closed systems which people can’t leave. That’s their entire world. And these are much more dangerous in a certain way than, say, a school in which somebody goes home to an outside part of the community at the end of the day or a partial hospitalization program where somebody goes there for eight hours a day and then goes home somewhere in the community. It means that somebody is separated from their community. They may or may not have any communication access. But their entire world is around staff and other people in the institution, which can not only lead to staff abuse but often facilitates bullying and peer-on-peer abuse as well, because of the separate, insular nature of the program or institution where it’s happening out of sight and out of mind for the general population. And there’s a big power differential, especially between staff and residents or inmates.

SHAIN: Could you repeat the rest of the question? Because I feel like I missed part of it.
LYDIA: This is Lydia. So what is it that makes institutions so violent? And what are these different types of institutions that maybe some folks in our community might not know about?

SHAIN: Okay, I think I did give my answer to that. So I will pass it off to Dustin.

DUSTIN: This is Dustin. In thinking about the violence of the institution, it’s not only the logic in which it’s deployed, but oftentimes, the physical structure, where it’s located. Thinking about prisons, Louisiana State Prison, Angola, situated in between 13 nuclear waste sites, a place where a lot of the food as well as the water is harvested there. So what we see is disability being exacerbated. If you don’t have a disability prior to going to prison, you are likely to develop disabilities or some type of long-term medical condition. We see that in Kentucky, they’re attempting to build prisons next to coal waste dumping sites. Military waste sites are often located next to prisons. Thinking specifically about Arizona, and the toxicity of the water that is within the prison system. And what I’m saying, the logic in and of itself is violent. A lot of the institutions, prisons like asylums, or what we would refer to state hospitals or state schools, they operate off of the idea that a person needs to be fixed.

DUSTIN: So Ervin Goffman, sociologist compared this to the TV repair model. Thinking about how we would drop a TV in the 60’s to be repaired and pick it up three days later. That’s what we’re doing to other people. So when we drop them off, we’re locating the problem with whatever is happening inside the person. And we’re not taking into account trauma, violence, poverty, deprivation, oppression, all being causes and consequences of disability. So we’re attempting to fix something that is not located inside of a person. That is a – that is a continuous cycle, right? So we’ll get people that cycle in and out of different institutions, because we’re not actually attempting to repair the harms that exist in the world. Rather, we’re blaming the people for those harms existing within them. And that’s not for every person, right? Like this is not a monolithic journey where everybody has a violent experience when they go to an institution, but we have enough history at this point to understand completely that they don’t work for what they’re purported to work for.

DUSTIN: And one of the biggest things, I’ll say the deprivation aspect of, especially prisons. You’re deprived of touch. People are deprived of sexual desires and intimacy. People are deprived of communication, especially for deaf, deafblind prisoners often time put into solitary, solitary confinement, which is a form of torture, under the guise of protection for themselves. Not having any type of visual stimulant. Deprived of language. Not being able to communicate with other prisoners. The prisons often ban sign language because they say it’s a part of gang culture and promoting that. People are deprived of recourse. Thinking about the PREA hotline numbers, which is the Prison Rape Elimination Act. For people that can’t use the phone, they’re not able to actually have any type of recourse if things – if something does happen, which it often does to disabled prisoners. The deprivation of being with family, the deprivation of being able to, like, move freely and navigate the world. So I would say that that is what makes these institutions violent. And that’s a common thread amongst them.

DUSTIN: Also when we’re thinking about institutions, it’s not just the traditional ones that have a water tower, that are self-sufficient, and that are the total institution that Shain referred to. But
it’s also the mini institutions that operate in plain sight within our communities, right? So it’s the group homes that when you go into them, they have six locks on the door. They have plexiglass on all of the electronics. They have limited furniture. They have no way to get in and out. Lydia talks about this, by saying, can you get a burrito at 3am if you want to, and if you can’t, then you’re in an institution. And those sometimes look just like houses on what would be on That on a typical street or an apartment complex. But they’re places that are segregated. Only disabled can be there. They can’t choose who they live with. And they have 24-hour surveillance. So those are also institutions that a lot of us interact with on a daily basis but are unaware of. And then the last thing I’ll say is institutions that operate in a way that force coercive medication on people. So sometimes those are recovery centers, methane clinics that are punishing people because they missed an appointment at 6am so they don’t get another dosage until the next day. And places that if you don’t have contact with them for some reason, then you’re relegated back to the criminal legal system. So it’s places where people are being mandated to be at.

LYDIA: This is Lydia. The burrito thing actually comes from Shain.

SHAIN: Which comes separately from a friend of mine, who heard it from a different friend of hers, who actually worked in such an institution so it’s passed through a number of sources now.

DUSTIN: So this is Dustin. Going forward, I’ll say that comes from community.

LYDIA: This is Lydia. Disabled oral tradition is awesome. And we get a lot of really good – really good ways of thinking about and explaining things. So the next thing I want to talk about with both of you is like what abolition is. And I know this is a lot to kind of unpack and pull apart. But can you explain, you know, what is deinstitutionalization? What is decarceration? For a lot of people, these words might be new. Maybe more folks in our community know deinstitutionalization, but might not know decarceration, and might not really know what abolition is. So can you explain, what are those ideas for people that are new, and how are they, and specifically how is abolition connected to disability justice? And I’m going to start with Dustin.

DUSTIN: This is Dustin. So I rely a lot on the teachings of people like Mariame Kaba. That’s M-A-R-I-A-M-E and K-A-B-A. And Ruth Wilson Gilmore. A lot of black feminists that have taught us about what abolition is and what the possibilities for our futures could be. And as Ruth Wilson Gilmore talks about, abolition is not a project of absence, you know, the absence of jails and prisons, but it’s more of a project of the presence of the future that we want. The idea is to end systemic violence. And it’s to put the planet before people, and profit before people, and change the way in which we interact with the planet and each other. And how that correlates with disability justice is the understanding that we need different models of care than what we have now. Understanding that the disabled bodymind, under capitalism, is always going to be devalued. And abolition gives us an opportunity to have a different system that is not racialized capitalism. That is not something that gives people their value based on how much they can produce profit.

DUSTIN: So when we think about changing the way we interact with each other, that could change the structure of how we do labor. What labor is, right, like right now care work outside of
what has been professionalized is not viewed as labor, is not viewed as work oftentimes. The people that do that work are oftentimes people that are not men. So there’s also these other systems of oppression that are informing that, right? There is the patriarchy that is informing what we view to belabor, what we view to be work, how much time we allot for that, how much pay we give to that. So I view abolition as a possibility for these things, right? It’s oftentimes thought about in terms of, well, if we don’t have prisons or police, then what could we do? What is the solution? Abolition is not one solution. It is a set of things that we must do. And a lot of things that we don’t know yet. For hundreds of years, we have tried the prisons and the police, and we put money and resources and time and energy into it to no avail, and we know the outcome to that. Abolition calls on us to try something new, and with the understanding that some things will fail, right? That’s how we will learn. But it’s the building of different things. And I can stop there and I can add after Shain.

SHAIN: I would start with pointing out two of the, I guess, tenets you could say, of disability justice that I think are relevant here. One is that nobody is disposable. And the other is that autonomy and support don’t have to be in opposition to one another. We don’t have to have a society that is, on a large-scale, of my house, my rules. Where, if you get support, you need to give up and follow somebody else’s way of living or give up your control over basic parts of your life just because you need support in some areas. Institutions violate both of those beliefs. One, by saying that certain people are beyond hope. That we just need to excise them from our society, whether because they are dangerous, because it’s for their own good, or both. And done especially under the current legal framework doesn’t really give them a meaningful chance to reintegrate, even if it were – even once they leave such an institution. Whether because they’re not prepared or because laws explicitly make it more difficult for somebody to reintegrate, such as laws preventing people returning from incarceration from accessing public services or job opportunities within the system that says that we need to work, for the most part, to earn a living, rather than it being a matter of right, which is its own problem.

SHAIN: The other aspect, though, is that a lot of institutionalization of people with disabilities outside the criminal legal system is done explicitly for a person’s own good, under the idea that because they have certain limitations within our current system or generally, because they, for instance, don’t know how to navigate a city without difficulty in crossing the street safely, for instance, or because they don’t know how to go about their daily routine and go to a job, they can’t do anything independently and they have to be controlled within these systems. Rather than saying, what does this person actually need? How can we support them to live the life that they want to lead? And what do we need to provide to the people who will provide these supports to make it possible?

SHAIN: I mean, one argument within our current system for institutions is that either, one, the parents or other caregivers of a person with severe or high support needs, they’re not always going to be around, what will happen when they’re gone, who will take care of them? So putting a person in the institution takes away that responsibility, before it has to be transitioned to somebody else, and/or the parents or the caregivers in the community do not have resources to support the person and meet their needs on their own. And that’s not a question of how do we, free up the parents or other caregivers from this concern or these barriers, so much as it is how should society be reordered so that parents, caregivers of different kinds, support systems have
the resources they need to serve a person in the setting, in the kind of life they want to lead? Whether that is living with five other people in single house or apartment unit, or whether that’s living on their own in a house or an apartment. Or whether it’s living at home with their either natal or chosen family, working or not, that they grew up in. How do we make that work for everybody involved? Or if it can’t work, then how do we get the closest thing to that that can be an acceptable compromise for everybody without sacrificing anybody’s basic wants or needs? How do we eliminate the needs for an institution rather than like – in taking all the justifications of an institution basically and turning them on their head, how can we make this unnecessary? And I talk a lot about how do you deal basically with health care or healthcare settings or the developmental centers, the state schools, that kind of thing, residential programs. Dustin, you might be better equipped to talk about prison abolition because I could talk about that, but it’s not as much in my lane as. You should have more knowledge.

DUSTIN: This is Dustin. And Shain, as you were talking, I’m thinking about all of the ways in which what you’re talking about, as far as restructuring how we do care, is a part of abolition. Like the person, one of the people I mentioned earlier, Mariame Kaba, talks about working toward abolition as creating the conditions necessary in order to render prisons obsolete, right. So care is at the core of that, right. So when I’m thinking about the incarceration system we have now, the crux of it to me is ableism. It’s to think of people, one, as disposable, based on a lot of things, oftentimes disability, right. Thinking about how disability is oftentimes criminalized. So although it may seem very esoteric. It may seem just like something that is not necessarily grounded in the way in which we talk about abolition. Abolition is something that we practice on a daily basis, especially within disability communities. To understand that disability is often criminalized and to know other people that have disabilities and to care for them so they’re not to get to a point of crisis, where oftentimes they will deal with the carceral system, right. A lot of people go into the carceral system through involuntary commitment. When they’re stripped from communities, the cops are making the decision to do that, and we know what happens when the cops interact with people on a daily basis. Lots of forms of violence can come from that interaction. So that actual care to not get people to crisis, that is a project of abolition. Last year, there was a bunch of fireworks in my neighborhood every night – it was like 12 year olds doing it, 11 year olds. Me going out to talk to them to come to a compromise that they’re not going to pop fireworks after 11pm, is practicing abolition, rather than calling the police.

[Dog barking]

DUSTIN: I’m sorry, my dog has now joined the conversation and so I’ll pass back to Lydia.

SHAIN: I would just add a few things. Maybe implicit in this, but for it to be explicit if it was meant and not clearly conveyed to anybody is a part of – like I would say two aspects that we could do is decriminalization of a lot of things. For instance, end the drug war. Straight up. Just let people do what they want to their own bodies. Good or bad. They know better than anybody else. They live in that body. I mean, yes, prevent people from driving under the influence. Whether, whatever that looks like. And I know that there are resources out there about how to have alternatives for actual harmful conduct. The one I’m thinking of, and this can maybe be put in any show notes, is called “What about the rapists?” by CrimeThinc. That’s spelled C-R-I-M-E-T-H-I-N-C. It’s with a c instead of a k. And it’s all one word. It’s C-R-I-M-E-T-H-I-N-C. And
all one word. And I’ll wait for a sec. And the other thing is to – and this is I think what Dustin was really getting at and some of what I was getting at too earlier but didn’t spell it out is to eliminate poverty. If you – if people are not homeless and food insecure they’re not going to get arrested, nearly as much as some people will still get targeted while we have anything like our current system, for say, loitering in a public place. We’re not going to have people stealing or shoplifting as much. We’re not going to have people participating in harmful illegal conduct, in harmful illegal conduct. We’re also going to have fewer people with trauma who will repeat those cycles of abuse and trauma onto other people for reasons that are often related to PTSD, post-traumatic stress disorder, and other forms of psychosocial disabilities that result from traumatic experiences, which are often tied to poverty.

LYDIA: This is Lydia. Dustin, could your dog come say hello to everybody?

DUSTIN: This is Dustin. He’s in the other room now.

LYDIA: Alas. We only have a bit of time left. We have two questions to get to. I want to move next to talking about what the top priorities for advocates and organizers need to be during the pandemic. So advocates and organizers are having to respond and have been for decades and longer to the ableism and the racism of carceral systems. What do you both think should be our top priorities in doing that, for folks especially who have been committed to work for social justice but maybe have not engaged as much in this space. And since Shain was just talking, I’ll go back to Dustin.

DUSTIN: This is Dustin. I think right now is a time in which we need to push to get as many people as we can released from the institutions that we referenced today and the prisons and jails. Prisons and jails, as we’ve talked about, they’re violent prior to a pandemic. They’ll be violent after a pandemic. People routinely die in them from all sorts of reasons. Disabilities are exacerbated while they’re there. There’s enough reason to get people released before a pandemic, but during the pandemic we’ve seen that it just kills more and more people. Not only people that are in the prisons, jails, and institutions, but also people that are in communities as well. So I think our project right now needs to be to release as many people as possible. For the prisons, there is, I mean depending on what states we’re in, there’s a lot of different inroads that we could take. There’s compassionate release that the governors could enact in a lot of places, commutations.

DUSTIN: Right now, in Pennsylvania, people are pushing for the release of Russell, Russell Maroon Shoatz. That’s S-H-O-A-T-Z, who has been in prison since the 1970’s. A Black political prisoner who has cancer as well as COVID. So we’re releasing medically vulnerable people, is one inroad. Another one is to not put more people in prisons and jails. So to decriminalize some of the things that are getting people put in jail in the first place. I think we’ve seen it’s possible. There are some places that have reduced the population of their jails rapidly, in just a short time. Whereas decades before that they said it was impossible. They said it would be a threat to public safety, and we’ve seen that it hasn’t been.

DUSTIN: For people in nursing facilities, disability rights organizations especially need to be pushing for the relocation of people. Traditionally we’ve done nursing home transitioning, which
is a very long and tedious process of finding a long-term home-based setting, working with insurance companies to do so or the state to do so. Sometimes that takes years. And that is with funding. Right now, we have a situation where we don’t have a lot of funds. But there are ways we can be creative about it. By getting money from FEMA to say that this needs to be an emergency relocation, where people go from nursing facilities directly into hotels or directly into whatever place will be able to take people until they quarantine, while they’re quarantining. Building up skills that folks might need. Learning to use smartphones, tablets, learning how to do online grocery shopping. And then getting people placed in the community rather back into facilities. This is happening. There’s a center for independent living in Williamsport, Pennsylvania that’s doing this. There’s a center that is in Denver, Colorado, Atlanta’s community is doing this. But we need a widespread push for the release of people. Not just to find out ways to make the facilities themselves safer, which we also need to do. But we need to release as many people as possible and be creative about that and have a united message in doing so.

LYDIA: And, Shain, would you like to add to that?

SHAIN: I would say that there are a lot of ways as we’ve kind of suggested over the course of this program to attack the problems that lead to institutionalization and to the extent that you know and are interested in those issues, whether it’s institutionalization and abuse in these facilities directly or it’s a related issue, I would focus on those things that interest you. If, for instance, you are interested in Housing First, which is a proven successful way to reduce homelessness, with homeless people being both criminalized and pathologized and put in various institutions accordingly, you can find organizations or resources and look more into that, and support initiatives or propose them possibly for Housing First policies. If you are one of the very skilled people who can read Medicaid policy and not feel their brains melting, which is me on my good days. Not always my best, not always, unfortunately. Home and community-based services plans and regulations, federal level and the state level, may be an area that you can push for changes in. There was movement towards better regulations supporting community-based settings in 2014 or thereabouts. And obviously in the last several years, those changes haven’t been as emphasized. And some of the state plans have even been falling by the waysides. But as the name suggests, Home and Community-Based Services seeks to move people who receive Medicaid out of institutional settings and into community-based settings where they will likely have more autonomy. And for instance, proposed measures that would exclude restrictive group homes from the definitions of Home and Community-Based Services for the reasons that Dustin discussed. So there’s a lot of avenues to challenge institutionalization and the conditions that create it. And especially as autistic people who have various passions and find one thing that we can learn everything about. If you are a member of the autistic community or the ADHD communities, which is just as likewise as often, I would suggest a follow your passions approach in tackling this issue.

LYDIA: And lastly, when we’re thinking about not just what we can do and should be doing next, can you talk about what some of the things are that we’ve learned coming out of the pandemic? Or, you know, hopefully soon, in the next, I don’t know, couple years, actually being able to come out of the pandemic. And Dustin, I’ll turn it back to you.
DUSTIN: So I think one of the biggest things that we’ve learned in the pandemic is that we don’t have a system of care that is equipped to handle a pandemic. And one of the big reasons that we don’t have that is because of our investment in the military, our investment in police, our investment in surveillance and security rather than an investment in care. So broadly, thinking about our commitment to imperialism as the United States rather than our commitment to each other and our care. So one thing we’ve learned is if we don’t have enough systems of care within our local communities, then we probably have a budget of – a lot of our budget is going to police. So the thing that we can do is push for that right now, right. To push for the police to be divested from and us to invest in the things that we actually need, which are some of the things that have been lifted today. Whether it be personal care attendants, whether it be housing that is free from any type of court mandated systems. So thinking about recovery centers. Thinking about places, respite care. We know that the police are people that are being a conduit for COVID and more people catching it. So this is also a time where we can push to remove the police from the fabric of our lives. They’re intertwined within the family regulation system, as Dorothy Roberts calls the child welfare system. They’re intertwined within our school systems. So we can push for them to be removed from those places right now.

DUSTIN: And those are just – and then I guess another thing, something that has painted the entire pandemic is the amount of access that has been provided to nondisabled people, essentially with the snap of a finger. Things that disabled people fought for and died behind for decades now, nondisabled people have gotten them. In many cases, they’ve gotten those accommodations or they’ve been granted access so they can continue producing for corporations or companies or organizations. But we’ve learned that it’s possible, right. We’ve learned that it’s a new reality in the way that we do work. It’s a new reality in the way that we can provide telehealth or receive care. So it is to know that that’s possible and we can continue to push for other things. But I think the fight then becomes that those accommodations and the access that has been provided doesn’t be taken away when people feel as though, as if it’s safe to go outside.

SHAIN: One of the things that we have hopefully learned or are starting to learn, and people in power likely know or have reason to know what I’m pushing back against every step of the way, is that our current system that assumes that your health and your financial well-being, your life in general, is all in your control – that’s a myth. That’s a comforting thing we tell ourselves in order to feel safe and to justify the system of capitalism that we’re in. The pull yourself up by your bootstraps kind of thing. But hundreds of thousands of people have died of a pandemic that a few people saw coming – at the top. But the rest of the world was just hit all of a sudden with. Many people who didn’t die but who had COVID are permanently impaired by and disabled by its effects. Millions of people have lost their jobs because of the pandemic out of nowhere. They could have been the best employees. They could have at least been sliding by. Suddenly they’re out of work for reasons beyond of their control. And what should be taken from this is that people are, people deserve support for being people rather than, well, you didn’t do enough, you didn’t do a good enough job taking care of yourself or your body, your finances, your job, or what have you. Because all of that is contingent not just or even at all on conduct but just on your circumstances.

SHAIN: And if we’re lucky, this will lead to things like basic income, to healthcare as a right, to housing first policies, to the things that will make safety, health, security, what have you, a
matter of right rather than alleged merit. And this will, of course, help disabled people a lot, including in avoiding institutionalization because it would provide a base level of support in a community. You would take the argument out of, how will this person going to support themselves? How are they going to keep themselves safe and sheltered, if no matter what, they have that shelter available to them. They have the resources and the support to access them, hopefully, that they would need in order to survive in the community – maybe not on their own, but at least regardless of whether they or their immediate social circle could provide for them. It would also allow people to receive healthcare before it becomes a crisis that would lead under our current system to institutionalization. And prevent many people from entering the carceral system based on any of the poverty, any of the poverty-related reasons that we’ve already discussed.

LYDIA: And that’s what, at the end of the day, I think what a lot of us are fighting for, right. Is to make receiving care and being able to define safety by your own community’s terms, not contingent on the ability to be seen as productive or contributing or to have certain cognitive or physical capabilities or not.

LYDIA: Well, I want to thank both of you for taking time out of your day for this conversation. For those who are interested, you can follow Dustin and Shain’s work online. Both of them are very prolific writers and speakers and organizers. And I hope that you’ll stick around for a few minutes of questions and answers.