

ANNE: This episode has a content warning. In this episode, we will be talking about the Judge Rotenberg Center, so this is a content warning that we will be talking about abuse in a residential setting.

[background music]

Cal Montgomery is a trans, queer, autistic, physically disabled activist and writer in the United States and a survivor of long-term institutionalization. A member of the Board at the Autistic Self Advocacy Network, Cal is at the forefront of the action against the electric shock aversives used at the Judge Rotenberg Center in Massachusetts, which we will be talking about today. Cal is probably best known in the neurodiversity community for his essay "[Critic of the Dawn](#)."

ANNE: Welcome to the show, Cal.

CAL: Thank you very much.

ANNE: I'm going to give some background before we start--about the Judge Rotenberg Center.

Children and adults are being tortured at the Judge Rotenberg Center, a residential facility in Massachusetts. The workers there apply shock torture as a so-called "aversive." The residents are forced to wear shock devices on their bodies. These are called GEDs. GEDs cause extreme pain, they leave burn marks on the skin, and other physical effects include neuropathy and many more.

One psychological impact includes that wearing a GED and living in that environment causes severe Post-Traumatic Stress Disorder. One resident at the Rotenberg Center, who was being punished for not taking his coat off fast enough, was shocked 31 times for 7 hours. Afterwards, he became catatonic for 3 days. The Center did not take him to the emergency room at any time. That case, which went to trial in 2012, seems to be the moment when the media began to notice. And now, after — six years later, the FDA, a regulator, has also noticed. And we'll get to that in a moment.

But before that, I want to ask you, Cal - you and other activists have been raising the alarm about the Rotenberg Center for years. Why do you think it took so long for media and regulators to act?

CAL: I think there are a bunch of factors. For one thing, privacy concerns mean a lot of stuff isn't available. We know what's going on, we know there's records, but we can't get them, because people have privacy rights, which are important.

Another is the Rotenberg Center takes a lot of people from out-of-state. The largest group that is there is actually from New York; it's not from Massachusetts. So many people are separated from their families by quite some distance. People don't see them regularly. They don't really know what's going on. Even the families, who have rights to find out this stuff. That's the second thing.

A third thing, particularly in past regulations, is that were actually up to the GED-IV. They had a device called the SIBIS, which delivered what was reported to be a mild electric shock. They didn't think that was strong enough, they invented the GED. We're now up to iteration 4 of the GED. The FDA looked at the first version of the GED and decided that this was an acceptable device, which I disagree with, but that's what they decided. The Rotenberg Center then went up to 4 without telling the FDA and continued to say, "This is an FDA-approved device." So many people were completely unaware, including workers, that in fact, this was not an approved device.

I think we've also got problems with public relations, because in fact 48 people are currently having this happen to them there... they are painted in the media as the worst of the worst, terribly dangerous people and so forth, and people have a lot of fears about autistic people, and I think are just imagining just these horrible, uncontrollable people out there. In reality, everyone who's got a GED has someone comparatively similar being supported in the community using other methods. Or in an institution. I don't like institutions, but there are certainly institutions that at least don't shock people. So, I think, the PR issue.

And I think a lot of people just defer to the experts. If they hear the experts say this is necessary, I guess it's pretty much it, it must be.

And then, of course, there's the belief many people have that you know, everybody loves disabled people. Everyone is nice to disabled people. Of course things are going well. And so, it's very hard to even get just that, just that anything happening in an institution could be harmful, that it isn't a complete aberration. That's a hard sell for many people. So I think there are many, many factors involved.

ANNE: Yeah. Definitely.

CAL: I think, in addition, regulatorially, this is an institution of last resort. People don't go there as their first place, their first setting. They go there after they have "failed" in other settings.

And we can be very critical of the settings that are out there. People—there's staff turnover, there's lack of training, even supports that are really necessary many not be implemented correctly or consistently. And so, but again, people think, well, this is the best we have, this is pretty good. So if this person isn't successful here...

So people end up in places like the Judge Rotenberg Center and then, I think the fear is that "if we shut down these people, there's going to be nowhere for anyone to go, because we don't have the programs." And the fact that we don't have the programs and the supports that people need where they need them, in their own communities with their loved ones around them, who can check on them and know what's going on...I think that's the real issue.

ANNE: Right, like, you said how there are people *just* like the people that are in the Judge Rotenberg Center [being supported elsewhere], and that's a huge key point. And I think—I wonder that the FDA has picked up on that. I saw that the FDA has picked up on a ban of the kind of shock tortures being used at the Rotenberg Center. Do you think that they will be taking enough action based on their statements, or how do you think that's going to go forward?

CAL: Um, well, the way this would— uh, Andre McCollin's case, which you mentioned, he was shocked 31 times, uh, initially he didn't take his coat off

was the issue. And then many of the later shocks were just because he tensed up his body, which is a technique that people in this facility use to reduce the amount of pain they're going to be in when they anticipate being shocked. So he was shocked for expecting shocks, basically. This is the justification for why this was quote, "necessary," unquote. But that happened in October of 2002.

The story broke in April 2012 when McCollin's — by his mother, because he's never recovered — his mother sued and in April 2014 the FDA held hearings. And we had some really powerful people in the community go and speak at those hearings. In April 2016 they got around to saying, "Yeah, we need to ban this thing".

So I'm really heartened by this development, that they're now saying "We're going to do it this year, we're going to ban it this year", but realistically, we know people are gonna — there are people who are really invested in this. This is a big money-making operation. There are families that feel like, "If we don't have this, what are we going to have for our kids and our loved ones?" There are, certain states that do not want to support these people and wouldn't rather ship them to Canton, Massachusetts. We've far from won. It's a major, major victory, but it's not over.

Secondly, however, I think we gotta also acknowledge that these shocks, they're happening to 48 people, but they're part of a whole system here of— to start with Level 3 aversives, which include things like pinching and slapping and food deprivation; these are in use in other places. The shock device isn't. And the FDA isn't going to do anything about this because it's not a device, it's not a medical, you know, *treatment* or whatever. We gotta fight this one out, it's gonna be a separate fight, it's gonna come next. And then I think we're going to need to move on to all the other aversives.

Sorry, let me just say: In a behavioral context, an aversive is anything that discourages someone from doing something again. So if I give you a dirty look, that's an aversive. And we're not talking about that. We're talking about these formal programs in which aversives are manipulated and applied consistently to control people. Not just the everyday social stuff. They do try to conflate these two things and it's completely different.

So I think that as activists, we've got a long way to go. But I think this real hope that we may at least get this particular, incredibly egregious device stopped this year. I really hope we can do that.

ANNE: I hope so too. And that bigger battle that you're talking about, that, I think that maybe the denial about what the Judge Rotenberg Center is doing within our society reflects a desire in part to deny all the systemic abuse. Because once you admit that this is happening and address how it's happening there, you have to look at the whole system and how it's working. The whole system, you know...

CAL: I think the structural thing is just so complex. You know, I mean, for example, I don't think this would be happening nearly to the extent that it is if we had, say, better services in New York State. And that's not the obvious place, to go to improve services in New York State, if you're trying to solve abuse happening in Massachusetts. But the connection is there.

ANNE: Right. You also know that Nancy Weiss, she's the director of the National Leadership Consortium on Developmental Disabilities, Nancy testified to the FDA that no attempt is made at the Rotenberg Center to identify the functions that the behavior may serve or to use alternatives. This is really the norm, that the GED is the norm there. And then David Coulter, who's a child neurologist, and past president of the American Association on Intellectual and Developmental Disabilities, said that in his 15,000 resident career at state schools, he said, "I have never seen anyone who in my medical opinion needed electric shock as a form of behavior management."

So you have people, people in the community really very vocally--in addition to activists--speaking out against this, but yet there's no ABA center or organization that's come forward with *any* kind of a statement, to give *any* public statement to condemn the Rotenberg Center. Not one. And I guess I'm just wondering, why do think this is?

CAL: So for one thing, ABA came out of Rotenberg. The behavioral stuff, you know, it'd already begun to operate elsewhere. But really, bringing it into the autism world, and focusing this, the Rotenberg Center was really pioneering in this area. So I think there's that history to contend with.

But also, again, the Level 3 aversives, the ones that are painful and so forth, that are considered the most severe - most of those are in use of other places. And of course there are plenty of places that are, quote, "positive only," which means they use rewards but they do not use aversives. Aversive stimuli. They're willing to take things away from people as a punishment.

But I think this really isn't that far outside of the mainstream of ABA stuff. It's not the face that gets presented, it's certainly not what the parents of three-year-olds are being shown, but it's part of the whole system. And... so I do think there's probably that discomfort there, with, you know, where could this lead? If they win on this, where are they going to go next? Are they going to go after the Level 3s? Are they going to go after the Level 2s? And so forth.

But I also think that there's probably some people working in ABA who are like, "We're the good guys, you're the bad guys, that's completely obvious, we don't have to say anything." And I think that's complete denial, abdication of responsibility, but I do think that's something people probably tell themselves.

ANNE: That's interesting. ... I want to talk about institutions for a moment. Here in Ontario, while most large residential institutions were "closed" in 1993, the institutional mindset is still here. So we still have most of the funding going towards, for example, group homes, which are like mini-institutions, unlike other autonomous programs that encourage autonomous living situations. And we have no tracking in the group homes of abuse. So. We still have also open sheltered workshops which are open, which are kind of a relic of the institutional era. In our public schools, we still have mandatory ABA, and our special education classrooms are still closed off, so no one can go in or out, so there's no transparency or accountability there. It seems like we have this huge legacy of the institutions that we haven't really deinstitutionalized ourselves of.

I was wondering: in America, how far is there still to go in terms of breaking out and changing out of that mindset?

CAL: It's enormous. It's just enormous. You've mentioned that I belong to ADAPT. ADAPT's primary goal is ending what we call the institutional bias, which is the setup that steers people who want to live in the community into institutions. And one of the key ways we do this in our country is that most people who need long term services and supports to get through the day cannot afford it. Even with a good job and good health insurance, you can't afford it. The only way to afford it is to go on Medicaid.

In Medicaid, if you meet the institutional level of care criteria, they will pay for you to go into an institution as long as it's a developmental disability institution or nursing home. They won't pay for you to go into a psych facility. So you have people in nursing homes who might otherwise be in the psych system. But they'll pay for you to go into these institutions. That's a right. You have a right to that.

You do *not* have a right, an equivalent right to services in the community. States provide these, but they do this by means of a waiver. You have to — first you have to qualify. Then you have to apply for the waiver, and there are limited labor slots in the states. So in Illinois, for example, we have something like 19,500 people with developmental disabilities alone and vastly more with physical disabilities in the nursing home system or other facilities, that don't qualify for the DD program, waiting for services in the community. Either you can hang on with your loved ones providing the care that they need — and yes, people age, and as families age, it gets harder and harder — or you go into an institution, or you die. Those are your options. That's a big part of what we do in ADAPT, is try and solve this problem.

But I think it's also important to look at the history of institutionalization. Physically disabled people have fought for their own deinstitutionalization. The visible part of the movement of the deinstitutionalization of people with developmental disabilities has involved a lot of non-disabled people.

ANNE: Mm-hm.

CAL: Although certainly the self-advocacy community has and continues to do powerful work. I'm, like, so amazed at what's coming out of People First

these days in Canada. And we're seeing similar stuff in the United States, although, well, I don't get as many flyers on the national stuff.

But these people have pretty much looked into institutions as places as, quote, "congregation and segregation." That means taking a bunch of disabled people, sticking them together, and not letting them integrate into society.

ANNE: Hmm.

CAL: So we're looking at big institutions. People honestly believe that an 8-person group home is integration into the community. And it basically never is. Because you're sharing staff. The supports that you need to go out and be in the community, you're sharing with other people. And you can't really integrate into the community if you have to take 7 friends along. You're going to have different interests. You may want to take a ceramics class but your friends may want to go to the library. So you're not going to be able to do the things regularly, meet the people, get to know people, and really participate. You get more community tourism than community integration.

And, again, and this is — because, you know— many people with physical disabilities want to get them into the room. They're fine there. But many people with cognitive disabilities, including autism, including intellectual disabilities, they need supports once they're in the room. They need help with the communication. They need help with, you know, understanding. They need help with social norms. And so what has — it may be enough for some people to just stick them in the community and say, "Take it from here," but we still see that we're not getting that kind of integration from proximity to your neighbors in the developmental disability world.

Further, we're seeing really good control of service programs for people with disabilities. That people hire, train, supervise, manage, and fire their own personal attendants. But in the DD system, you very much have other people deciding who's going to provide you with your services, where they're going to provide your services, and who's going to do it. So the control aspect is really intense.

After I was institutionalized, I worked in group homes, and it's really not hard to take a system that looks like it supports self-determination and make it all about control. It's really not hard. And we see it done every day.

So I think we've got all this stuff going on. It's not just that we still have the big institutions, although we do, we're still trying to close them down. And the intermediate care facilities, which we're still trying to close down. But even with what we consider, what we treat as "community-based," it's still largely institutional. It's still largely based on a mindset that these are people need to be controlled. And I think Roland Johnson, who's one of the great self-advocacy leaders, really, he has a wonderful keynote that's available on the internet and it's all about who's in charge. Who's in control. Who is running your life. Is it you or is it them? Because it's *supposed* to be you. It *should* be you. We need to make it so that you're running your own lives and staff are not running your lives. And I think that's who, of all the people I've read and of all the people I've studied, that's who really *got* the deepest into what institutionalization is about. It's about control.

ANNE: Yeah.

CAL: And we have so far to go in the United States about control.

I was talking to a mom the other day about her son. And I don't have his permission to talk about him, so we're just going to call him Fred for today. And Fred wants desperately to be in mainstream education. And his school keeps sticking him in segregated education. And he wants mainstream, his parents want mainstream, everyone wants mainstream, but they're sticking him in segregation.

And I was talking to his mom about how the teachers there are really pretty proud that they only use little bitty words with him, because, you know, "he really can't understand the big words". Well. This is a kid with an intellectual disability, and he's also a smart kid. And those two things coexist a lot of the time. He can learn. He's capable of learning, but he's not capable of learning if he's denied access to the information, and that's what's happening to him. It makes you want to scream.

ANNE: Yeah.

CAL: And I'm sure it's far worse for him than it is for me. I'm just hearing about it. This is his life.

ANNE: Yeah. And I can see —what's frustrating seeing and hearing about all of this here and in the U.S. is that there are groups that are trying to work on solving the problem such as ADAPT, the problem of people being pushed into institutional living or segregated education, and the solutions are already there. There are pilot programs, there are working, useful programs that are already going. It's frustrating, and for me to get my head around the fact that people aren't adopting this, aren't adopting the positive programs, are sticking with the negative programs. I wonder if you have thoughts.

CAL: I agree. It's not like we don't know how to do this. One of the issues for people when I was institutionalized is that I engaged in a fair amount of self-injury to the point that there was real concern I was going to cause myself brain damage. And, you know, I got out of an institution not because I got quote "better," unquote, but because insurance moved me from one place to another to another, they wouldn't fund the more restrictive stuff, and the last place I was in burned down--which, by the way, I did not do! There weren't enough beds in the system for all of us, and the first of us to find a place got out. That is the only reason I'm free today.

I still probably qualify for a GED if somebody really wanted to push it. I still engage in self-injury. It's not life-threatening, it's not really all that dangerous, but it can be pretty scary looking. ...I'm just a whole lot better at hiding it. But I also don't do the really dangerous stuff I used to do. You know why? Because I have control over my life. I have other ways to cope.

So I know this. I've supported people in the community who were fairly self-injurious, fairly assaultive, and you can do it if you've got people with the skills and the willingness, and that comes down to a lot of the training and workforce conditions. Not everybody wants to do this for minimum wage, which is fair. But it's good work, it's honest work, and you can support people to live safely in the community. We were doing it in the 90s where I was doing it. People had been doing it for some time before then. It's 2019. I mean, we really— we don't even need to reinvent the wheel. The wheel's there.

ANNE: If you look at the way, if you really started to look inside institutional living, whether it's a group home, residential facilities, nursing home settings, and many of them, it does something to a person living there. And when people get out, their lives will tend to improve because they have the freedom you're talking about. And I think bodily freedom and bodily autonomy seem to be really at the heart of a lot of the activism that you're doing and the activism that needs to happen around the institutions. Because they're such a site of control.

I wanted to bring this up, to refer to something we were chatting about briefly on a thread with John Elder Robison on Twitter some months ago. The topic of wandering came up, or roaming, and each of us mentioned in the thread that as children, we had a relatively good degree of the freedom to roam at times without so much--or much at all--adult mediation. And I'm wondering — you talked about having the freedom to roam giving you certain strengths, and I was wondering if you could talk a little about that.

CAL: Sure. An important thing-- it's important to note that many of us, our parents literally don't have the skills we're born to need in the world. And in my case this was partly because my parents were just really different from me. They had skills *they* needed to navigate in the world, you know. I would learn a firm handshake, which was really important in my dad's world. Hasn't been all that useful a survival skill for me. But I learned it from him.

But there were many things they just did not know, and as society changes faster and faster, I think this is true of more and more kids, to be honest. I mean, there are skills that, if I was 5 years old today, I would need growing up in this world, very different from growing up in the 1970s, that I as an adult do not know.

Part of going around the world unsupervised is learning this stuff. And yes, it's great that your parents teach you what they have to offer you. And it's great when you can connect with other disabled adults, which many of us in our generation did not have, and see how they do it. But I think we are such a diverse group of people that there needs to be a certain amount of trial and error. And I learned many things that I can do that nobody taught me, but I just figured them out because I had the space to figure them out, I had the time to figure them out. And I got myself into situations where they needed to be figured out.

ANNE: Yeah.

CAL: I also learned a certain amount about my limitations. For example, "Do not get on a city bus without a friend." Um, my capacity to get lost on a bus is just practically unparalleled. And I have found myself in places 35 miles away, no one around, no way to get on another bus, no money, no phone, 'cause back then we didn't have cell phones, y'know. And I've learned, do not do this. This is a bad move. There are things I'm just never going to be able to pull off, probably, so don't even try. And that's an important lesson to learn in the relative safety roaming in a small area. I'm not happy that I learned it, you know, by ending up 35 miles from home with no way to get back. But today, I don't go to other states and get on their buses either, which would be even worse.

And the third thing I learned, which is really vital, is just the sense that I can do this. I went to a conference recently with an activist who's much younger than I am, and who grew up without the same kind of freedoms that I did. And we're both wheelchair users, power chair users, and it turned out that the conference venue had not been entirely honest about the accessibility of the bathrooms in the residential area. By which I mean there was a too-small-for-a-power-chair toilet. In addition, we were in mixed gender rooms, and you couldn't use a wheelchair and close the door, which was another issue for many of us.

So, I think, some people were very panicked over that. So I went and started looking at the public restrooms. We discovered that the women's room had a stall too small for a power chair, power chair user, and a personal attendant, but the men's room stall was big enough. Well I'm perfectly happy using a men's room stall, right. [laughs] She was a woman. And I'm not sure she had ever been a position where people are just saying "What the hell, take over the men's room. You want somebody to stand over the door, I'll stand over the door. But it's a stall, people aren't going to see you if they do wander in." You know...

This kind of just, like, things are going really badly, let's figure it out. I have a faith that I can do this, which I think largely comes of being stuck in situations where I learned. Obviously, not everybody survived. We come from a sink or swim generation, and people sank. I'm not recommending

just free-range your kids. But certainly giving kids the space to explore the world and figure it out. And increasing amounts of space. Because when I was 5, I certainly wasn't blocks outside of my parents' home, but I was outside of their view. And when I was 6, I went farther. And when I was 7, I went farther than that. And by the time I was a teen, I was wandering around the city. And as an adult, I'm comfortable doing this, I'm comfortable traveling, and literally with disability all of this stuff goes wrong. So the sense that you can figure out, the sense that you're gonna be okay, and the skills to make it okay are really incredibly valuable.

ANNE: Right. There has to be a way to encourage that in everyone to whatever degree that's possible. But to have it even on the radar, as parents and educators, how important that is, is really interesting.

And now — do you still roam? What does it look like to roam as an adult?

CAL: Well, I don't do it as much. Because back then I walked, and now I use a wheelchair. And now I use a power chair, so in the winter battery life is an issue, and I have responsibilities. I have a dog, so I can only be gone from home so long. And I don't get on buses, which makes public transportation more challenging. I'm in a city with trains, but trains are slower than buses, they don't go as many places, which is part of why they're safer for me. A train can only get so many places. If there's no tracks, you're not going there. So I don't do nearly as much. But I do, when I get a chance to travel, I do wander around a lot more, because I have that freedom to do that. And in the summer I certainly do more than in the winter.

Intellectually, though, and in other ways, there's a lot of advice on how you ought to live your life, particularly if you're disabled, and people will tell you that all the time, random strangers, whatever...so that in a more metaphoric sense, I roam all the time. I don't do what I'm told. I don't do what I'm advised to do. If stuff seems like it makes sense at the time, I'll just do it. And it usually pays off in ways that I didn't understand how it would pay off. It's not always clear why reading some book that seems totally irrelevant will turn out to be useful in 3 years, but it often is. So that freedom to just explore and not to be rigidly constrained by all these rules by what are you are doing... a lot of things people think you're going to need in life, you don't think. And a lot of things people don't even imagine

you're going to need turn out to be incredibly useful. And I just feel like we ought to trust ourselves a little bit more. And we're gonna get some stuff wrong, but we're not going to get that much more wrong than if we follow the guidance. And it's rare.

ANNE: And so one of the key points of the disability rights movement is the idea that access is a right. And access to move freely, that seems like a form of access.

CAL: Again, well, obviously I'm deeply involved in the physical disability community, as that's where ADAPT has come out of. So certainly the ability to go into a store, to cross the street — I remember when that was a really big deal. You couldn't get a wheelchair across the street half the time because there were no curb cuts. You know, you'd have to go try and find a driveway or something. And then you'd be crossing in the middle and that might not be safe. Or you'd just go in the street. And of course we'd get this every winter, when nobody shoveled sidewalks. So certainly the freedom to move around is one that the physical disability community deals with a great deal.

In terms of just having the resources to move around, right. It's been 40 years now. This is the 40th anniversary this year of when 19 people in Denver lay down in front of buses at the intersection of Broadway and Colfax demanding lifts on buses. And lifts on buses is an amazing thing in terms of the ability to move freely.

But I think when we're talking about people with developmental disabilities who are not users of mobility devices, the issues is not so much, you know, what's the environment you can move in, it's when people are going to try and slap you. People are going to try to interfere with you. I think it's the same issue, but people understand it completely differently. And again, I think it comes down to this sense of control, and I think the control comes down to a sense of anxiety. Like, "Oh my God, what's going to happen?"

You know, there's real fear. You talk to some people and they...when you meet another developmentally disabled person out in the world, particularly someone with an intellectual disability and communication impairment, even then, the people with them get really tense. And it's not even so much tense that you're gonna hurt them, right, it's "oh my God, is he annoying you? I'm so sorry."

ANNE: Yeah.

CAL: And, usually, these are the best conversations I have. I'm like, "I'm having a great time, I'm having a ball. If he's not having a great time in the conversation, he should move on, but don't move for my sake." This fear that if we don't rope people in tightly, it's going to be a problem, it's going to be a problem. And of course some things happen that really are bad. You have some people... really bad things happen and I understand that these fears are not completely misplaced.

But they're used to an incredible degree of control without an understanding that that too is harmful. That roping people in, closing people in, is harmful. Not giving people a chance to meet people and give them a chance to talk about what they're interested in is harmful. And yeah, sometimes you don't want to talk to somebody about whatever they're interested in. We've all had that experience. But sometimes you find somebody who does want to talk about it. Or maybe doesn't want to talk about it all that much but is happy about it because they're interested in you.

ANNE: Right.

CAL: And I think having this kind of freedom, yes, I do think it's an important part of access to the community and access to meaningful integration, because I don't think it's enough just to be near people; you have to have relationships with people. And this roping people in prevents that. It closes off relationships and the chance of relationships. It closes off the chance of real participation in community.

And I think that's what we really all want. It's not so much access to a room or a building or a street crossing. We want access to the kind of life that we want. And those lives often involve pursuing our interests. Knowing other people. Having intimacy, and I don't mean — this would include sexual intimacy, but it also means emotional intimacy with other people. Having friends. Having stuff to do during the day. And I think as you close people off, whether you're doing it by not providing a way to get across the street or into a building or to the second floor, or whether you're doing it by not

providing a chance to get a little bit away from whoever's supporting you and try on your own or whatever — they close off what's really the best part of life. And we do it because we're afraid, in the developmental disability community. They have other reasons for not taking us, but fear is one of those things. When we limit people, when we consciously try to limit people, it's because we're afraid. And I understand the fear, but the harm that is done is just too overwhelming. ...Am I babbling?

ANNE: No! It's absolutely — the fear, I don't always understand it. Because I've had that experience too, especially talking — seeing someone in line, whatever, at a store. I'm sensing, I'm going to say hi to this person, and starting to have a conversation and having the carer or the parent just sort of shushing everything down. I don't know what they're afraid of. That's the part that's really weird to me. And I think it does tie in with this freedom to move, whether it's moving one's body, moving one's hands, or talking or speaking or expressing. And why that gets shut down in the way that it does -- it's mystifying to me in some ways.

CAL: I suspect that some of them have— I think one of the greatest advantages of autism is that peer pressure is not that effective. It's truly not. Because you never really know what's gonna upset your peers, and half the time you miss what they're trying to say anyway. So it doesn't really work. "I'm trying. I'm trying to cooperate with peer pressure. I'm not good at it when I try." But I think it leaves you a lot freer, and once you decide, "Just screw it, you know, I'm just going to have to live with the social consequences because I can't avoid them, I'm going to do what I'm gonna do" which is fairly recent for me, and I'll be 52 years old soon. So this is not something that came early in my life. But to just say, like the bad stuff that I'm afraid of, if I cross the line or if I say something, it's going to happen, it's gonna happen even if I try to make it not happen. So I'm going to ignore it because I can't change it. And that is incredibly freeing.

I don't really understand the, I think, the social stresses that many autistic people deal with. And we of course have social stresses, but they're different. And it's just fear of disapproval. But I think also, all of disability's that anxiety. You know, you take your kid to the doctor, and the doctor measures your kid and compares the kid on these charts and asks is the kid doing okay, or not. And if the kid isn't on the right pace on the chart, oh my God, what are you doing to do? You need to start getting diagnoses, you need to start getting interventions. And I think ABA does an amazing

job at inculcating fear. I think that's something it does really well. I think Autism Speaks does a really good job at instilling fear in people.

But I think in general, so much of disability is this fear that somebody going to be not typical. And of course it's ridiculous, because everybody else wants to not be typical. Bill Clinton never said, "Oh my God, they're going to make me be president, I want to work in a bank!" He never said that. People want to stand out. They want to be special. And then you get people who stand out, they go "Oh my God, what's going to happen, they're going to stand out." It's just utterly ridiculous and I think that's this fear of people somehow not fitting in. This overwhelming fear. And it's separate from fears of violence, which are real concerns.

We're never going to fit in. So we're just going to have to get over that, and find a way to live anyway, and we can actually live very good lives that way.

ANNE: Right. And that's what we're talking, what we've been talking about, is autonomy. And bodily autonomy and other forms of autonomy that might be harder to define but that are there. The Rotenberg Center, institutions like that, and other psychiatric institutions and other types of institutions, the approach is about control, it's about limiting freedom, freedom to move, bodily autonomy.

I wonder if you think there's any way to reform the residential institution system? Or what can and should and does exist in place of that to allow people, everyone to have the kind of autonomy that is, should be their right?

CAL: I think that every time we build a new institution, since we do it a lot, we have all these noble goals, right? And we look at the people we want to build it for, and we think, "What do these people need, and how can we give it to them?" I think that's always been there. And, of course, once you've duplicated the thing a hundred times, it's maybe not there, but as we're inventing these, you know— Pennhurst, Willowbrook— Willowbrook was meant to be a shining example...well, we know how that turned out. But the reality is that for the institution to exist, it has to prioritize the needs of the institution over the needs of the individual. And the best spin you can put on it is that the institution has to continue to exist in order to meet the needs of the individuals. So the needs of the individuals are best served by

putting the needs of the institutions first. That's the best spin you can put on it. But it happens every time.

Any time you've got a program and you slot people into it, it's going to be coercive. It's gonna involve control, it's gonna involve a loss of freedom. There was, um, a pretty famous book and it's really old, so you may not have heard of it. It's called *Missing Pieces* by Irving Kenneth Zola and it's about this guy who's got a physical disability but who's integrated, he works at a university, he does all this stuff. And he goes to the Netherlands and spends some time in a wheelchair, which he doesn't usually use, as a member of this institution, as an independent observer. And in many ways, because he focuses on the residents and ignores the staff as much as he can... it comes across as sort of an ideal sense of community. And for a lot of people in my generation who grew up isolated there was a real sense attractiveness, of "Okay, that sounds pretty good."

But you start thinking about it, and it's like, everybody's got their own room, which is great, but they also live in these little social clusters, and the social clusters there share support workers. All your neighbors, are, they're picked by functioning level, and literally how much work they are for the staff, because they want to balance the staff workload. You can't have like 5 quads all together, because if you have 5 quads all together, that'd be an overwhelming amount of work for the staff in that cluster.

ANNE: Mm-hmm.

CAL: But you can't have 5 people with paraplegia who are relatively independent off together, because that's going to be relatively little work for those staff, but it's going to shove all the people with greater support needs into other areas. So you realize suddenly that who these people's neighbors are is determined completely by staff needs. It has to in an institution, in a large facility, that way.

Even a group home with four people, you have to run it that way. If you have two staff and four residents, you know, I mean. I was the weekend supervisor at once place, and I had four residents there. Everybody got to pick — people made their own breakfast. And then I would cook, or some staff would cook lunch and dinner. Every weekend, everybody got to pick

one meal. I mean, in your house, I'm assuming you probably get to pick most of the meals.

ANNE: Right. Everybody gets to pick their own meal in my house.

CAL: And in families, there's some compromise, although families are sort of a voluntary unit, although it really isn't for a small child. But, you know. But these people, they were living together. They weren't living together because they'd chosen to live together, they were living together because they were people with physical disabilities and this was the accessible program. And so, you know, this one person is eating what the other person wants to eat, the first person that liked, and I would do my best to make it palatable to everybody and to take everybody's needs into consideration, but you're balancing it. And in a residential institution, you're always going to have to do that because you're using shared supports and shared facilities. And you're always going to lose kind of that individual control. Every time.

So you can— and there's a difference between if I'm choosing to live with you, and if my social worker has found a bed for me that is near you.

ANNE: Right.

CAL: Those are completely different experiences.

ANNE: I want to thank you for all the work you've done on these issues, and for also taking the time to talk about them today. I'm gonna put links up on the website to ADAPT and to the various projects ADAPT is working on, and other things, and anything that we talked about in today's podcast, so people can look at the blog and find those things.

CAL: Well, thank you so much. I'm lucky. This is my particular interest, and for much of my life, I wasn't really able to pursue it that much. I get this is work, and I get I put energy and whatever into it, but I'm also really spectacularly lucky, and I wish everyone could have this chance. I wish this level of privilege I have to work on this stuff, I wish that everybody had it. So thank you so much for this.

ANNE: Thank you so much for talking to us today.

[background music]

We were just speaking with activist and writer Cal Montgomery. If you're listening to this on iTunes or Stitcher, you can learn more about this podcast by visiting our website at noncompliantpodcast.com.

You've been listening to Noncompliant. I'm your host Anne Borden King. Noncompliant was recorded at DB Audio and MCS Recording Studios. Various episodes were engineered by Dave Boire, Nathan Grevat, and TJ Leibgott. Thanks to our engineers and thanks for listening.