

Disability Visibility Podcast

Episode 75: Coronavirus and Disaster Planning

Guests: Germán Luis Parodi and Valerie Novack

Host: Alice Wong

Transcript by [Cheryl Green](#)

For more information: DisabilityVisibilityProject.com/podcast

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the *Disability Visibility Podcast* with your host, Alice Wong.

ALICE WONG: Hello, all you fellow humans. Is 2020 over yet? Can we all agree to cancel it? While we're in a public health disaster with the coronavirus pandemic, today's episode is about natural disasters and emergency preparedness with Germán Luis Parodi and Valerie Novack. Germán is the Co-Executive Director and Valerie is the Board Chair of the [Partnership for Inclusive Disaster Strategies](#), a coalition of local, national and global disability rights, emergency management, public health, and community leaders and allies committed to equal access and whole community inclusion before, during, and after disasters. Valerie Novack is a Board Member and volunteer with The Partnership. We're gonna talk about the interconnections between pandemics and disaster planning, systemic issues that impact disability community, and the need for improvements in infrastructure. Lots of good stuff! Are. You. Ready? Away we gooooo! [electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1.

ALICE: So, Germán and Valerie, thank you so much for being on my podcast today.

VALERIE NOVACK: Thank you. I'm excited to be here.

GERMÁN LUIS PARODI: Likewise. Thank you, Alice.

ALICE: So, why don't we have you both introduce yourselves and share a little bit about what you do and just your background for our audience.

VALERIE: Sure! My name is Valerie Novack. I am an Afro-Latina disability policy researcher. Currently, I'm in D.C. I work primarily doing disability policy in relation to emergency management, housing, and infrastructure. Prior to that, I worked at a Center for Independent Living in Ohio. So, got a lot of experience doing more local advocacy before I moved to kinda the federal sphere. And then I am also the Board Chair of The Partnership for Inclusive Disaster Strategies, which I think we're gonna talk a little bit more about. But I started volunteering with them right around the time of Hurricane Harvey and have been working alongside the folks there for the last several years doing response work.

ALICE: Great. Thank you, Valerie. How about you, Germán?

GERMÁN: Thank you, Alice. I am the Co-Executive Director of the Partnership for Inclusive Disaster Strategies, along with my Co-Executive Director, Shaylin Sluzalis, under the guidance of our Board, Valerie Novack here. And we also have our Marcie Roth, Director of World Institute on Disability on our Board, and also Katie Pechon, who's the Vice President of Triton Relief, who do first response during natural disasters. I also worked with Center for Independent Living for five years where I live in Philadelphia, Liberty Resources, and been in leadership and collaboration with them since I moved from Puerto Rico to Philly in 2004. I have a spinal cord injury, which I acquired in Puerto Rico, and Liberty Resources, as the Center for Independent Living, along with Philly ADAPT really showed me that people with disabilities can live independently in their own communities. And then I began working with The Partnership right after Maria hit Puerto Rico, where I was first deployed to right after, for two weeks. And seeing I'm the first person with a severe spinal cord injury to do first response, being able to open the doors that normally other first responders can't really get to in response to persons with disabilities. And more recently, I still go deeper into the work that The Partnership has done.

Impacts of the pandemic on Valerie and Germán

ALICE: Great. Thank you for that. This episode is gonna be about emergency preparedness, but also clearly right now, we're talking in late March, 2020. We are right now in the middle or pretty much early stages of a coronavirus pandemic in the United States. So, I guess I'd like to take a minute and just check in with you both in terms of how you two are doing and just how you two are kind of taking care of yourselves right now. Because, as we all know, people with disabilities are always, I think, much more disproportionately impacted during any sort of disaster, emergency, pandemic. So, Valerie, do you wanna go first?

VALERIE: First, thank you for asking the question. I think when situations like this happen, we really try to put the best foot forward and the best face forward. And it's actually been really hard, not only as a person with a disability, but married to somebody who has a disability. And so, it's a constant, we're trying to find the balance of making sure that we're both safe and both getting what we need without putting the other one at additional risk right? And so, it's every day has felt kind of like walking that balance more so than it does on a regular day. I think pre-pandemic, I guess you can say, we had gotten that down because I've been married for so long and knew where somebody might need help. And now it's, those roles have changed a little bit. And so, in addition to that and kind of finding that new balance, because Germán and I, because of the work that we do, it's also been just a tremendous amount of hours and the push to go, go, go. Because we also know that the longer it takes for us to figure out an adequate response to what's going on and making sure that people get what they need, the more our community is at that risk and the more that our community is being impacted. So, trying to balance taking the time to make sure I don't cause myself to flare from not giving myself the rest I need, not getting the nutrition I need, and things like that, with this very, very real urgency to have as much impact as we can is a constant battle. And so, it's been stressful and exhausting, but I'm still here. And today I'm smiling, so I'm taking that as a win. [laughs]

ALICE: Exactly. We gotta take what we can, right?

VALERIE: Yep, yep.

ALICE: How about you, Germán?

GERMÁN: Definitely. As Valerie said, it is the changing of lifestyle so quickly, so drastically, it is something that impacts us all in so many different ways. I, myself also, you know, living with a disability and concerned with not only washing hands but using my wheelchair. And what does

that equal when you have to navigate back home with all the interaction with the ground. Also living with my mother who's 75 and her disabilities and just life: just changing styles and the pretty much daily reminders. And also have two beautiful pets. They need their daily walks a few times. And just the thought of each time the cleaning after each walk that needs to be done for them immediately in the area that they step on, it's crucial. We're just starting, but this will be long-term if we are going to make it. And realistically, this is what we need to try to prevent is to, as a disabled person, go to a hospital, whatever we can do. Because in the hospitals, we will not be prioritized. If they have a bed, if they have a ventilator, and nobody younger, nobody with no disability needs it, then we can access it. That is the reality we live in, and it needs to be understood.

ALICE: Yeah, and I think this relates to the broader general idea of emergency preparedness where time and time again, as the three of us know, disabled folks and older folks are usually the ones who are most left out. And when we see these situations happen, it really shows how much, who is valued in our society.

[bright, rhythmic music break]

The Partnership for Inclusive Disaster Strategies and emergency preparedness

ALICE: I wanna ask you both kind of just how you both became involved in The Partnership for Inclusive Disaster Strategies and just your own interest in emergency preparedness and disaster planning.

VALERIE: So, I was very fortunate to go to college in Toledo, Ohio, where they have a Disability Studies undergrad. And in one of the courses that I took, we did an accessibility survey. And it was eye opening, to say the least. And at the same time, my body, I was going through some really intense physical changes in my mobility. And so, I was simultaneously learning about access issues in a classroom while also getting used to not being able to use my legs the way I was used to, and starting to use things like rollators and canes, and so, getting a really practical view at some of that as well. And I, just to be quite honest, started to get very angry. And so, I actually added a second major in Geography and Urban Planning. And I really wanted to focus on how do we make cities accessible? Rather than looking at let's make this building or that building, but how do we make whole cities accessible? And in doing this, ended up getting an internship with the City's ADA Coordinator. And she asked me to review the emergency plans as part of their assessment that they were doing for all the buildings in the city. And of these tens of buildings, not a single emergency plan had anything more in it than something to the extent of, consider people with disabilities, or address issues of disability or something very vague. And I realized that, in the places that kind of have the highest level of accessibility that we have in our country, we got two sentences in an emergency evacuation plan that really gave no tips, no promising practices, no guidance on what that meant.

And so, I really started studying that and realized that that was just kind of common all across the country. And that's really what kind of fueled my interest in that. So, I went, and I went back to school and got a degree in Emergency Management at the same time that I started volunteering with Partnership for Inclusive Disaster Strategies. Because I had been connected to Paul and Marcy, or their names kept coming up when I kept asking people in the community and at the CIL I was at like, who's doing this work? Because it's really, really important, and I don't know who's doing it. And so, started volunteering with them right before Harvey hit. And so, that was an immediate like sink or swim kind of moment, because we were getting so many calls to the hotline from people, disabled people that had been affected that were waiting for transportation that never came. That we're trying to access food, that were trying to get housing.

And it just solidified to me very much how important and necessary this work is. Because we are that after thought, like you said. You know, we are often, even the stuff we're hearing, you see on Twitter or you hear even news anchors that we've heard say with COVID-19, well, there's not much you need to worry about. It's just affecting old people and people with underlying medical conditions. As if that is no big deal. Once I kind of had that first look at it, I knew that that was something I had to work towards making better.

ALICE: Thanks, Valerie. How about you, Germán?

GERMÁN: Well, having gained my spinal cord injury when I was 17 back in 2001, the first year that there was, I was bedridden. I didn't have a wheelchair. So, bad storms always happened in Puerto Rico. So, I lived there for the first three years and just did live the life of someone disabled going through disasters and how there's nothing. There's nothing. Moved to Philadelphia and got involved with the CIL and Philly ADAPT and quickly saw the systematic problem, that it is pervasive that people with disabilities are ignored everywhere, all the time, in every service. I, after working for five years at the CIL, decided to go to college. First, went to the community college and then to Temple for a Political Science degree. And learned very well how there is no history of people with disabilities before 100 years ago. Before that, there isn't. There could be people that you could identify that could have a disability, but as communities, we are not part of history. And that could easily change.

Soon after I graduated, we were camping out, ADAPT, outside of the Russell Building for a week, and we met Paul Timmins. Then after, immediately after Maria, as it was hitting, Paul called and he asked me if I could go. And it was not only myself. It was a team of us. Shaylin Sluzalis, Stephanie Woodward was part of that. Some of you may know her. And being there really again, meeting almost weekly or weekly with FEMA in their headquarters where everyone was in air conditioner and hot meals as if nothing was happening, and the rest of the island was living in a complete disaster. After that, we committed almost all our time to understanding how systematically disasters impact us. We then pushed and advocated and were influential in the drafting and passage, well, and introduction of the Disaster Relief Medicaid Act and the Ready for Disasters Act.

[bright, rhythmic music break]

Problems and challenges that agencies face during emergencies

ALICE: I was wondering if we could dig a little deeper. Because I think a lot of people, especially non-disabled people, are like, they have this faith or this very weird belief that FEMA and non-profits like the Red Cross are just, you know, it's covered. Like, oh! Don't worry. Things are gonna be okay. And no, that's actually not what happens. And I was wondering if you both could also just kind of give some real examples of the problems and challenges that local, state, and federal agencies face when responding to disabled, older adult, and other populations that are considered vulnerable during emergencies. What are some very kind of real gaps?

VALERIE: Yeah. So, like Germán sort of alluded to, the gaps go all the way from huge, systemic infrastructure gaps to the very, very local response. We have seen, whether it's calls into the hotline, whether it's personal experience, whether it's anecdotal information from community members that have called in to one of our calls or that we've gotten from a CIL, we see as local as the E.M.S., individuals not being trained how to transfer somebody to looking at places like Houston when the hurricane hit, and the way that the city itself was actually built and expansions to the city, which caused additional flooding in low-income neighborhoods where we know a lot of people of color and a lot of people with disabilities lived right? And so, we have

seen and gotten calls for things like, for example, the big one is registries. And Maria Town tells a frustratingly heartbreaking story about when she was in Houston and the number of people they had on this registry versus the number of people in the Houston metropolitan area that must've had a disability, right? And so, people put their names on things like these registries and think, like you said, Alice, well, everything's OK. But we've heard stories.

I remember once personally taking a call after Irma of a guy who had signed up for the registry in his county and purposely did not leave his house because he was under the impression somebody was gonna come get him. And no one ever came. And now his house has been destroyed, and he's still there. And so, that, I mean, that stuff we hear all the time. You also hear things about I mean, we have, if we can have a really frank conversation, sometimes we have conflicting accommodations. There are stories we hear about people that go to like a Red Cross shelter. And maybe the Red Cross shelter is accessible in one way for them, but it's causing somebody that is a loved one is not accessible for them, right? And so, deciding are we splitting up our family? Or whose accommodation takes precedent in this situation, right?

And so, North Carolina put together a report. I believe it was called [Storm After the Storm](#). And it was full of stories of several people with disabilities or families that tried to navigate the system of Red Cross and support. And you have stories of things like being kicked out of shelters. People, there's a story in there where one person was autistic, and another person had a service dog. And part of this autistic person's fears was dogs. And they were very, very scared of the thing. And I believe, if I remember correctly, that shelter had some weird policy where all the people with the disabilities were in one area of the shelter, so they wouldn't let this person who had a service dog be separated from this autistic person who was scared of this dog. Because they wanted them all put in the same place, right? So, even in times where you might technically be covered, right, well, you have shelter, and the Red Cross can give you food, you're really not, your needs are really not being considered in a way that's making that any less traumatic for you.

And then, like I said, we have, I mean, I think what we're seeing right now with COVID-19 is a really, really stark just kind of example of the systemic ways that we're not considered when we're talking about—I mean, I think the Washington State triage plan came out a handful of days ago, and there's already been a formal complaint issued because they essentially said, well, if it comes down to it and we run out of ventilators, if a person seems too tired or too sick or too cognitively unaware—or some kind of terminology that they use like that—that you might as well send them home or to palliative care. And so, those are things that are happening right now that are kind of built into our procedures of doing things when we talk about not inclusively planning and we talk about not making our community a priority, even when we're told, oh, we have you covered, or oh, it's the ADA. I think the easy idea is if we know that after all the years since the Rehab Act in the late '60s and the 30 years since the ADA, and we still can't go to a local coffee shop, it's unfortunately, maybe asking a little bit too much that organizations like FEMA and the Red Cross are being accessible because they need to be, and they aren't.

GERMÁN: Valerie has put it very well, and it is a stark reality. Federal government is violating their own law, as every federal dollar spent in anything needs to comply with the ADA. And any service in a disaster, the reality is that we're last thought, if ever. In the wildfires in California, over 1,000 people died, all over the age of 65. Right now, there was a case in New York City where a group of people with developmental disabilities, of young adults, had to go to the hospital to get tested. A number of them were negative. Some were positive. The negatives are trying to go back to a congregate type of setting, housing, and the workers are denying these people entry back into their homes. So, they, at this moment, as far as I read yesterday, they

are still in the hospital. What may be ending up happening to these people very soon is institutionalization. Sadly, here in Pennsylvania, as they were applying for, they applied for a new Medicaid waiver, and part of it dictates that nursing institutions can be used to quarantine when other services are overused. So, if hospitals are overrun, some states already have their payment mechanism to store us in nursing homes.

VALERIE: And this is Valerie. And it's just in this particular instance, it's also just very dangerous. I mean, Kirkland has been a good example of that. Louisiana has been a good example of that. With something like what we're seeing with COVID-19, it seems it's particularly angering to me that we have these two things happening simultaneously, right? We know that we're asking people to social distance; don't congregate in groups. And then saying, oh, but let's just put, you know, we'll put all these disabled people and all these old people in a nursing home and wait for this to blow over, right?

ALICE: Mmhmm.

VALERIE: So, it's like not only is it a gross injustice and a violation of our civil rights, but it's also against these medical recommendations right now. So, it's really just showing how little care and thought there is of that to be telling everybody, well, social distance, except these people. We'll just keep them all in a nursing home and quarantine them all, right? Put them where we can't see them or what have you.

[bright, rhythmic music break]

Infrastructure and systemic changes needed so that disabled people and older people aren't left behind

ALICE: So, I wanna kind of ask you a final question, which is what kinds of infrastructure and systemic changes that need to take place so that disabled people and older people aren't left behind? And I think, you know, this speaks to any sort of public health emergency like the pandemic we're living in right now, but also any sort of emergency or disaster.

VALERIE: Yeah. Sure. I could talk for a long time about this, but I'll highlight. I think there's a few things, particularly that I think this pandemic has highlighted that a lot of people maybe weren't aware of. I think one is access to Internet as a utility and the buildup of Internet nationwide. I think a lot of people, particularly if you don't live in a rural area, think everybody has access to Wi-Fi or everybody has access to Internet. And I think this situation, particularly I saw when a lot of the schools moved to online classes and people were starting to remote work, that people started realizing you have a significant number of the population, whether it's because of income, or a lot of times it's because of where they live, that they either don't have access to Internet, and they especially don't have access to broadband Internet or Wi-Fi, even just the ability to get communication, which while we're at that should also be accessible and often isn't. But whether it's getting news, whether it's getting updates from CDC, accessing other people when you're social distancing, working, not everybody has the same access to that.

And also, I'm really hoping that we make some permanent changes regarding access to the utilities for not being able to pay, people who lose access to their power and water. And these are kind of basic infrastructure type things that we can do very kind of quickly over some of the bigger things, like creating more robust transit infrastructure, building out our healthcare infrastructure, which we're seeing very, very real shortages here. But we just, we don't ever plan for a lot of people maybe needing services at once or caring for a lot of people. But I think as we get closer to 2030 and 2050 when we are gonna have an increase of older people as we get

longer life expectancies, those are real infrastructure needs that need to change. I think also just as we, you know, what would our hospitals look like maybe if people could access care? Maybe we just have a failing infrastructure as it is because not everybody who needs care is currently getting it anyways, right? Those are just a handful of things that I can talk a long time on infrastructure, but. [laughs]

ALICE: Yeah, this could be like a three-hour episode, but it's not.

VALERIE: Yeah! [laughs]

GERMÁN: Well, just to add to what Valerie said, disasters continue. You know, we had an earthquake in Salt Lake City a few days ago, and there was a tornado in Nashville a couple weeks ago. And disasters are gonna be oncoming. Hurricane season may come at us a little earlier this year. This has been a warm winter. And there are not only the infrastructure to serve us now, living through COVID-19, but there is zero to no known guidance throughout the system on how to do disaster relief in a quarantine situation. The best ways, at least some people, the best way that we can occupy our minds is be as busy as we can be.

Now is the time that we need to be contacting our state officials that are in charge of our long-term care services and make sure that in their 1115 waivers, they are including community services in it. And that in their 1135 waiver, they are really dis-encouraging the use of the expedited placement of nursing home placement. It is the two things that states are, people can advocate from their home right now. And surely, that the continuity of service that what we were receiving and that the lifestyle that we had three weeks ago, a month ago can be as close as it can next week and next month and year.

ALICE: Well, Valerie, Germán, thank you so much. And keep on keeping on.

VALERIE: Yeah, thank you. You, too.

Wrap up

[hip hop]

♪ How far will they go? (Oh, yeah yeah)
How far will they go? (Oh, yeah yeah)... ♪

ALICE: This podcast is a production of the *Disability Visibility Project*, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more about Germán and Valerie on my website.

The audio producer for this episode is Geraldine Ah-Sue. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening! And see you on the Internets! Byeeee!