

You First Podcast Episode 73: Data and Disability – with Matthew Cortland

Keith Casebonne (00:00:00):

You're listening to You First: The Disability Rights Florida Podcast. In this episode of You First, we talk with Matthew Cortland about their role at Data for Progress and the role that data plays in disability advocacy.

(00:00:11):

Hey, everyone. I'm Keith.

Maddie Crowley (00:00:32):

And I'm Maddie. And we're the hosts of You First. Today we have an exciting guest that I've been honestly dying to talk with for a really long time. Matthew is a huge advocate within and for the disability community, and they have so, so much knowledge about the broader social and governmental systems that impact our community.

Keith Casebonne (00:00:53):

Yeah, yeah. They're awesome. Here's a little bit about them. Matthew is a senior resident fellow at Data for Progress, working on disability and healthcare. They are currently a lawyer, a public health nerd, and the policy director at Be a Hero. They're a former beneficiary of SSI, SNAP and Medicaid, and their writing has been featured in outlets including New Statesman, Talk Poverty and Slate.

Maddie Crowley (00:01:18):

Yeah, so clearly an expert in this field.

Keith Casebonne (00:01:22):

Clearly an expert.

Maddie Crowley (00:01:24):

We're going to talk a bit about the impact that data has in disability policy, how we track and count disability, especially when everyone perceives disability and has different views on what disability is, what happened with the census this year, and how we can better translate data into action and better policy. Without further ado, here's our conversation with Matthew.

(00:01:49):

Hey, Matthew, thank you so much for being on our podcast. This is Maddie speaking. As a visual description I'm a white person with half blonde, half brown hair, wearing a white shirt and clear glasses. We're so excited to talk with you.

(00:02:07):

For our listeners who may not be familiar with you and your work, could you introduce yourself, share your name, a bit about yourself, your job, identities, visual description, all that good stuff. We'd really appreciate it.

Matthew Cortland (00:02:21):

It is so good to be with you. I am Matthew Cortland. I am a white they-them with incredibly unruly hair today, and I am wearing blue flannel for the first time this season because it is finally under 80 degrees in Washington DC today, and I am a huge fan of the fall.

(00:02:42):

In my day job, I am a senior resident fellow at Data for Progress. Data for Progress is a public opinion research firm and think tank that arms progressive movements and causes with the best available data to make a difference in the policy space. And I am thrilled to be with you both today.

Keith Casebonne (00:03:08):

Well, thanks so much Matthew for being here. We're thrilled to have you here as well. My name's Keith, I'm one of the co-hosts. I am a white man with dark brown hair and a salt and pepper beard, wearing a black shirt. I wish in Florida it would get down to under 80 degrees around this time of day, but it has been a little while since that's happened, so hopefully another month or so that starts happening for us too.

(00:03:30):

You mentioned of course that you work for Data for Progress. Tell us a little more about your role there, what work you do, and maybe educate our listeners a little bit about the

role that data plays in making decisions about social issues like healthcare or social identities and disability.

Matthew Cortland (00:03:49):

My background, my graduate training is in public health and in law. When I was in college, Cigna tried to kill me before the days of the ACA. They turned a 72-hour emergency appeal of their denial of a prior authorization for a Crohn's medication- I have inflammatory bowel disease, into a two and a half month long campaign of stonewalling, of doing things like pretending they didn't get the appeal package and then pretending they didn't get the facts, proving that they got the appeal package and then pretending that USPS, the green return receipt requested card that I can introduce in court as evidence, that didn't exist.

(00:04:34):

That really changed the trajectory of my life. I ended up going to public health school into law school to learn how to sue insurance companies and survive the healthcare delivery system.

(00:04:43):

Prior to 2017, I was in private practice as a lawyer really focusing on healthcare and disability issues at a individual retail level with a little bit of policy work. And then in 2017, the world inverted and I really started focusing on federal policy work because there were too many starfish. We were seeing these systemic changes, attacks on disabled folks and poor folks and just every sort of marginalized community in this country. And I started engaging more in federal advocacy.

(00:05:18):

Mike Pence said some stuff, to put it politely in 2017 that intimidated people who were chronically ill, did something wrong. I couldn't sleep that night. I stayed up all night making a video that did some numbers as the kids say, it went a little bit viral. And I got introduced to this world of federal advocacy in a way I hadn't done it before.

(00:05:46):

From 2017 through 2018 and through 2019, through the fights around the efforts to repeal the Affordable Care Act, Obamacare and Medicaid expansion, a program that has kept me alive, has paid for the incredibly expensive medical care, those claims that I generate, was under attack.

(00:06:09):

In lobbying, in advocating, in talking to members of the United States House of Representatives in the Senate, one of the questions we would get asked all of the time is, "Okay, but is it popular? Do people actually like this? Do they want what you are here advocating for?"

(00:06:30):

They were looking for polling data. They were looking for public opinion research. They were looking for some justification in their own electoral interests that Medicaid and the ACA and Social Security Disability Insurance and SSI, Supplemental Security Income, the other social security disability program that doesn't get talked about enough, they were looking for evidence that those things were popular and cutting them was unpopular.

(00:07:00):

We didn't have that evidence because people in the polling world at the time weren't really focused on those core disability issues like SSI. People were not polling on supplemental security income because a program, a grueling, sub-poverty, inhumane benefit doesn't have a lobby. People on SSI don't have a couple of grand to throw into a big pot so that someone in DC can hire a polling firm and prove to members of the House and the Senate that killing disabled people is politically unpopular by cutting social security.

(00:07:41):

That's the backstory. That is why I was looking for a place where I could do public opinion research and issue advocacy and finding the best messages. And Data for Progress turned out to be a great fit. It was that place. It's a very young organization which has been really helpful because they weren't entrenched in any sort of habits or policies or procedures that made it difficult for me as a disabled person to join the organization and do work that's really important to disabled folks.

(00:08:17):

I had been working at Be a Hero for Ady Barkan, and at the end of the election cycle four years ago, the opportunity to move over to Data for Progress as a senior resident fellow was just too good to pass up. And fortunately, the Ford Foundation launched a US disability rights program to really resource the disability field in a way we had never seen before. And so there was foundation funding, foundation support available, thanks to Darren Walker, the president of the Ford Foundation, and Rebecca Coakley was the Ford Foundation's first US disability rights program officer, who really started to move resources

into the field to enable us to do the sort of advocacy that we had not been able to do before then.

(00:09:09):

We were really working with not just popsicle sticks and duct tape, but used popsicle sticks in that off-brand duct tape that just leaves gummy residue on everything it touches. And so having a foundation like the Ford Foundation take the lead in resourcing the field sounds like one of those really wonky, really inside baseball things, but it has been revolutionary. It has changed the game for disability advocacy.

Maddie Crowley (00:09:40):

Yeah, definitely. Thank you so much for sharing a bit about your role. I think so often, I have to put the world in perspective when it comes to talking about disability versus other marginalized groups because exactly like you were saying about SSI, SDI, these are folks that 30, 40 obviously institutions still exist, but not that long ago did we introduce Olmstead and these other legal factors and changes, societally, legally and otherwise, to address some of these issues. That is still so very young. Olmstead is still not actualized in a way that's meaningful.

(00:10:25):

Anyways, I think how you frame that is really important to remind folks that for a lot of disability work, it's really, just within the past five to 10 years, really ramping up in a way that's more meaningful and more helpful for the work that every organization does within disability.

(00:10:49):

I wanted to ask you a little bit about your work within data and just data broadly because I think for folks that don't work within this space, within, I don't know, lobbying, the government, what have you, where data is a more salient or important thing, for lack of better word, how do you reconcile with how to count and perceive disability as a data metric, especially when people have different views about what disability is and isn't and people with disabilities themselves may identify with their physical disability, but not their chronic health condition or their mental health related condition as a disability? How do you navigate that?

Matthew Cortland (00:11:42):

That is a fantastic and really timely question. The Census Bureau, the part of the United States government that goes out and tries to count everyone in the country also records characteristics about folks. And one of those characteristics is disability status. They are in the process over at the Census Bureau of reevaluating how they determine who is and who is not disabled, who counts around disability.

(00:12:12):

Their first proposal, they made it without really consulting with the disability community because we have experts in demographic data. I am not one of those people, but we have genuine, brilliant experts in demographic data and how you think about disability at a population level and who counts and who doesn't count. They went ahead with a proposal without consulting experts in the disability community that would've been harmful to the community, and they backed down at the very last minute.

(00:12:42):

That census data forms the ground truth that other researchers like me and colleagues at Data for Progress use to understand the population of our country.

(00:12:58):

And so at Data for Progress demographic research, we're not really looking at how many disabled people are in the United States. That's more that demographic research where the Census Bureau with its federal government funding and resources and the brilliant folks over there are equipped to answer. At Data for Progress, what we are doing is the brilliant people on our staff who I get to work with take that data and use it so that when Data for Progress fields a survey and we get 1200 responses to a survey, the polling principal at Data for Progress, a brilliant PhD, Evangel, who...

(00:13:47):

I'm hesitating a little bit because in the interest of full disclosure, I'm a senior fellow at a polling firm, but I also have dyscalculia. I have a math learning disability that I discovered in college when I opened up the Diagnostic and Statistical manual one day for psych class homework and discovered dyscalculia and was like, "Oh my God, that's me."

(00:14:07):

So I rely on brilliant folks. I have the privilege of working with at Data for Progress, including our executive director Danielle and our polling principle, Dr. Evangel. What they do along with other folks, too many to name at Data for Progress is they ensure that when we get

1200 responses, it is representative of likely voters. That is the universe that Data for Progress is most often looking at. We're looking at likely voters because it turns out policy makers, i.e. elected officials really care about what likely voters think.

(00:14:47):

If you're trying to persuade policy makers that Social Security Disability insurance takes too long to get, or if you're trying to persuade policy makers that there shouldn't be a 24-month waiting period after you're approved for SSDI, your onset date for your disability before you qualify for Medicare, if you're trying to persuade them that's a bad thing. Or that, and this one is close to my heart because I was an SSI recipient. I relied personally on SSI to keep a roof over my head for many years, that SSI at \$941 per month in 2024 as a max benefit is a grueling, inhumane, sub-poverty existence.

(00:15:27):

If you're trying to persuade them of those things, it helps if you can show them what the electorate thinks, what the people who are likely to be in the voting booth, either rehiring them or firing them come November, think about those policy issues.

(00:15:40):

And so at Data for Progress, I've really focused on public opinion data and brilliant colleagues in the community who have math skills that I can only dream about, focus more on the demographic side. Did that make sense?

Maddie Crowley (00:15:58):

Yeah, definitely. It makes a whole lot of sense. What I'm wondering is, so you tease what's happening with the census and what had happened to neglect to acknowledge the fullest extent of the disability community through counting in the census, as how I understand it.

(00:16:21):

What were they considering changing, what were they understanding as what disability is versus maybe what they're reconciling with now? What is disability considered as, as an identity, but also what other things like SSI get impacted by the census and either an over or under or accurate count of a certain population?

Matthew Cortland (00:16:48):

You've really hit on something that is core to our field, which is we don't have a single definition of disability. If you look at just laws in the United States that control disability

stuff, there are a lot of different definitions. The Americans with Disabilities Act of 1990, as amended by the ADA Amendments Act of 2008 has a very expansive definition of who counts as disabled for the protections of that federal disability civil rights law.

(00:17:26):

In fact, the ADA was amended in 2008 because the Supreme Court had narrowed since 1990 through decisions, who counted as disabled for the purposes of protections under the ADA. So Congress and the President at the time in a bipartisan effort pushed back against the Supreme Court's narrowing of the original congressional intent to protect lots of Americans, big tent of who counts as disabled.

(00:17:54):

So the ADA includes things that are oftentimes surprising to folks. They don't know, and this is the kind of research I can do. I can ask likely voters, "Hey, do you think little people are protected under the ADA? Do you think people with migraines are protected under the ADA? Do you think people with cancer are protected under the ADA?" And of course, as a disability activist, I want that number to be 100% every time. I want folks to know where the state of play is for civil rights and they don't in large part because it's confusing.

(00:18:27):

So you've got the ADA, you've also got the IDEA in education. You've got other federal disability civil rights laws, section 1557 of the Affordable Care Act, the Rehabilitation Act. You've got all of these different laws that as I think of it, when we're talking about civil rights, you have a right not to be discriminated against on the basis of your disability. We use a pretty expansive definition of who counts as disabled for that.

(00:19:00):

When we talk about benefit programs, when we talk about social security disability insurance for people with a history of work, broadly speaking. I'm resisting the lawyerly urge to caveat everything I say in endless asterisks and parentheticals. If you're listening at home, and you know that when I say SSDI is for people with a history of work that I'm excluding disabled adult children, DACs, please forgive me. But for everyone else, we're trying to keep this followable.

(00:19:33):

So social security disability insurance, supplemental security income for folks living in poverty who have a disability, veterans, disability benefits through the VA, these benefit

programs where disabled folks are relying on the program for income so as to not lose their house or starve or literally die on the street. We use a much, much, much more difficult, more stringent, higher to clear definition for disability. You have to prove that you can't really work. You have to prove that to the Social Security Administration. And that's a different definition of disability, it's a much higher bar.

(00:20:25):

We also see this in programs like SNAP. I've also personally relied on SNAP to put food on the table. It's another program that's very close to my heart, very dear to me. We see work requirements imposed on SNAP where if you are disabled and you can prove you're disabled, you can still get SNAP. But in many places, if you can't and you're not working, they might yank your benefits away. We see the same thing with Medicaid.

(00:20:52):

There are all these programs where you have to prove that you are disabled in order to receive some benefit, and usually those programs have a much higher threshold for proving you're disabled. As a lawyer, I can tell you that if you're doing that without a lawyer, you're at a disadvantage. The programs are not designed to be fair and equitable. They're not designed to catch every disabled person. Those programs would rather have 100 bona fide from the administrative viewpoint of the program, they'd rather have 100 bona fide disabled people not get benefits in order to keep one non-disabled person from getting benefits rather than the other way around. So those programs are just crushing and inhumane and cruel to far too many people.

(00:21:37):

What I have found in doing this work is that this landscape is confusing to folks. They don't know, and I think that's partly by design. I can't help but think it's not a coincidence that SSI and SSDI are off by one letter. That's bad branding. You should never do that if you want people to understand the program. That's just bad branding. What that means is that there's a lot of debate that can be had about who is disabled when we're talking about demographic data.

(00:22:07):

Where do you draw that line? Do you use the ADA's big tent approach? Do you use the Social Security Administration's crushing, cruel, inhumane, incredibly high bar to clear approach? What do you do? At Data for Progress, what I have taken to doing while this gets

sorted out, we just ask respondents, "Do you consider yourself to be disabled?" We do self-identification.

(00:22:33):

So when we are reporting disability results as a demographic, I am literally just doing self-identification because there are a lot of reasons behind that. One of them is it sidesteps this debate while the lines are fluid. And there is this debate by the Census Bureau.

(00:22:54):

To the heart of your question, the Census Bureau is incredibly influential. They are the bedrock upon which other folks', the research of other people, other organizations, other groups is built. And so where they draw that line is really important. I think you asked what they were trying to do. I can't speak for the Census Bureau. Frankly, their approach here, I find befuddling, bewildering, at best incompetent. At worst, I don't know what they were thinking.

(00:23:28):

What I do know is how you ask questions to people. As someone who does public opinion research and goes out and asks questions of likely voters, quite often how you phrase those questions matters a great deal in how people respond. With something like disability where most of the electorate, I can speak to this part at least, most of the likely voting electorate isn't particularly familiar with disability in the legalistic formal way of what is a disability, what counts as a disability. They just don't know.

(00:24:08):

And so it's not clear to me what the Census was trying to do. I know that that leaders in the community, not me, but leaders on the demographic side really did push back and fight quite hard to make the Census Bureau reconsider what they're doing.

(00:24:27):

I think what needs to happen there going forward is a collaborative process. It's not enough to inform the brilliant disabled leaders who have PhDs and stuff. I don't even understand what their PhD is in. They need to be at the table with the Census Bureau, figuring out where we're going to draw that line and what questions are we going to ask to get that who is disabled and who is not data.

Keith Casebonne (00:24:59):

It's really fascinating that this organization has so much power, and yet there's different opinions on how to even define what it is they're counting. It's a little bit disconcerting, if I'm being honest.

Matthew Cortland (00:25:13):

They weren't expecting us to show up. I think they were surprised.

Keith Casebonne (00:25:17):

I bet.

Matthew Cortland (00:25:19):

There's this process when... That heavy sigh you may have just heard was me trying to convince myself, "Matthew don't dive down another legal rabbit hole." So I'll try to keep this fairly brief and at a high level, but when a federal agency is taking action like that, administrative law, the procedures that they're required to follow says that there's this principle that you're supposed to consult with the American people and the public most interested and impacted by what you're doing. They didn't do that the first time. I have some hope that they're going to do it now. The amount of pushback they got from the community from folks all over this country and from leaders was enough to get their attention.

Keith Casebonne (00:26:01):

Well, that's good. I'm glad it did get their attention. For sure. When you're talking about disability having no single definition, I think it's interesting in a lot of respects because it's not just... you talked about different laws and how they each define it somewhat differently, but I think there's even so many other aspects of that. First of all, even people who self-identify, I know several people who, if you look back two years ago, would have not identified as having a disability. And something just slightly changed or maybe something's got a little worse. And now, well, I feel this impacts me now, and I feel like, okay, now I would consider myself as having a disability.

(00:26:38):

So the idea of just self-reporting I think might just be the best approach because I think you're going to get the most honest and I don't know, descriptive look at people who are really out there living their everyday life and we are our own identities. If that's an identity you choose, then it should be respected as such.

Matthew Cortland (00:27:02):

I think that is a fantastic point, particularly when it comes to public opinion research. I agree wholeheartedly that disability self-ID is an incredibly useful tool there because electeds either are or ought to be interested in the block of voters who identify themselves as disabled.

(00:27:24):

When it comes to demographic research, though, I think my colleagues who know more about this than I do on the demographic side would say, we really want to capture people in that data set who are disabled but don't think of themselves as disabled. The CDC estimates that one in four, about 25% of adults has a disability, and for a variety of reasons having to do with funding and all sorts of federal government programs, we don't want to under count those people even if they themselves would not say, oh, I'm disabled. But they might say, "Yeah, I use a cane. I have some trouble getting up the stairs. I had my hip done. I had my knee done."

(00:28:08):

My grandma, before we lost her during the pandemic, would not have identified as disabled, but she had a bilateral knee replacement surgery due to arthritis and was very much a member of the community, but would not identify. If you asked her different questions though, she'd get there. And there are people like that all over the country. As folks age, disability increases. As people age, they acquire disabilities is one way to phrase that. And we want to capture all those people.

(00:28:38):

I think the real trick, and I don't know how to do this, but I think the real trick is de-stigmatizing disability as an identity so that as people become disabled, acquire a disability, they readily identify with the community instead of coming from a place of stigma and thinking disability is a bad thing instead of a thing that happens to human beings like many other types of things that happen to human beings.

(00:29:06):

So that is why in large part, I think the census is so tricky because unlike something like ethnicity, for example, or marital status or gender, it's less straightforward. It's less straightforward. I'm not saying all of those questions are straightforward, but for many folks, disability status is going to be less straightforward than I am or I am not married.

Keith Casebonne (00:29:37):

That makes sense. I think you're already starting to answer this, but honestly, my next question was going to be what are some of the ways in research that data organizations or other professionals can do better by disability, either as some sort of metric or data point or for people with disabilities to participate better in data and data collection? If you have further thoughts on that, we would love to hear that.

Matthew Cortland (00:30:07):

I am really focused and have been focused since 2021 on federal policy and the interaction, the intersection of federal policy and disability. The federal government is so large and controls so many aspects of our lives that even if you get crumbs, and I want more than crumbs, but even if you get crumbs from the federal government, the scale is such that you're going to impact a lot of people's lives, you're going to help a lot of people.

(00:30:37):

When I think about that, in 2023, a little less than a year ago... No, sorry, it's August. Time is slipping away from me. In July of 2023, from July 14th to the 15th, we went out with a survey of 1,216 likely voters. The results are weighted to be representative of likely voters by age and by gender and by education, race and geography and voting history. There's an English language survey, it's conducted on an electronic device. Those are some methodological limitations. I readily want to put those up top.

(00:31:16):

But when we ask voters who identify as disabled about whether they think politicians and public officials care about what people with disabilities think, even if it's just likely voters and not just those who self-identify as disabled, just amongst all likely voters, 37% agree with the statement, public officials and politicians care about what people with disabilities think. 55%. 55, more than half of likely voters disagree with that statement.

(00:31:51):

When we look at agreement and disagreement by disability status, you don't see a dramatic swing. There is a public perception in this country that public officials, elected officials, policy makers, members of Congress, members of the Senate, your State House, your local elected officials do not care about what people with disabilities think.

(00:32:19):

When you ask during that same survey, should the political party they belong to, so should the Democratic Party, should the Republican Party be doing more to protect the rights of

Americans with disabilities? Or is that political party already doing enough to protect the rights of disabled Americans? When you ask all likely voters that, 23% say the Democratic Party is doing enough already. 20% say the Republican Party is doing enough already. The numbers for those political parties should be doing more is 59% for the Democratic Party, 63% for the Republican Party.

(00:33:00):

I just threw a lot of numbers at you. What I'm trying to convey though is the data that the public opinion research data that we have gathered at Data for Progress, particularly about how the public perceives how elected officials view disabled Americans, it's not good.

(00:33:21):

I think the perception amongst the electorate is that public officials, people who make our laws and enforce them, and the political parties that they are part of don't care all that much about disabled folks.

(00:33:36):

And the downstream effects, and this is why I start there, the Census Bureau is part of the federal government. The head of the Census Bureau answers to ultimately the President of the United States. And Congress, the House and the Senate has what they would call oversight responsibility. They're supposed to check the Census Bureau's homework, make sure it's doing its job correctly. Not getting into the nitty-gritty of, "Oh, you didn't carry the two," but are your principles, your values, your policies... Are you doing it right?

(00:34:10):

If the electorate, if people who show up in the voting booth in November to pick the leaders who will make the rules that affect all of our lives don't care about disabled folks, that's a problem. That's going to mean that when the Census Bureau is making their decisions, well, do we really need to think that carefully about who counts as disabled? Is the President going to care? Is the House going to care? Is the Senate going to care? And that's not specific to any particular President. It's not specific to any particular member of the House or any particular member of the Senate. It's just overall confidence is quite low that those institutions, those power centers care about disabled Americans.

(00:34:57):

So I try to take an upstream approach because it's a very big country and we got a lot of problems.

Maddie Crowley (00:35:20):

Thank you so much for that. Just as I'm sitting here and listening to you explain this, I just want to say a name. I'm so grateful that you are here with us to talk through this. I'm not a data person, I'm not a science and math person. I'm not good at it, but I appreciate you laying these issues and different dynamics out in a way that I think folks are going to be able to understand in a way that's really important because people matter and their thoughts and what they care about and what spaces they're involved in, it matters. I think, anyways, I wanted to name that and recognize-

Matthew Cortland (00:36:02):

I want to thank you all because I know you have talked with, shared your platform with colleagues in the community who are trying to change the makeup of the people making these decisions. I think about whether or not we have disabled electeds, for example, and I know you've had conversations around that. That's incredibly important and I deeply enjoyed all of those. I will allow you to plug the episode number because I don't have it open in front of me. But thank you all.

Maddie Crowley (00:36:36):

Thank you so much. I appreciate it. It's always exciting to hear that other episodes and other messages and topics that we're trying to get across have impact, especially if we're talking about folks being represented in a political space or otherwise having influence, social influence, political influence, et cetera.

(00:36:58):

One thing that we've talked about it in concept but not really, maybe specifically, is data translation. At Data for Progress, you have all of this wonderful data that y'all are pulling or even something from the census. You can have all the best data in the world. It's important numbers. Like we mentioned at the top of the episode, this research specifically about disability is new, but what's most powerful is when it's connected to advocacy and change that accurately reflects that data.

(00:37:33):

What are some tools that Data for Progress or you use or broader just goals and ways that we can get disability data to reach stakeholders so they make data informed decisions?

Matthew Cortland (00:37:51):

We've talked a little bit about demographic data research. That's what the Census does, that's descriptive and describes the layout, the distribution of disability in the country. We've talked a little bit about public opinion data, asking likely voters whether or not they think public officials care about disabled people.

(00:38:10):

We also around this time last year, asked voters whether or not they support providing accommodations for elected officials with disabilities. 76% of likely voters agree that buildings should be physically accessible. 70% agree that an elected with a service dog, not a problem. 64% agree providing closed captioning to electeds. 61% agree that providing ASL is a good idea. 59% agrees allowing screen readers is a good idea. You see that sort of straightforward question, it's a neutral question. Some elected officials need various accommodations for a disability, which of the following accommodations do you think members of Congress should be allowed to receive for a disability? Very neutral. They're trying to understand where the electorate is, what people think, how they feel.

(00:39:00):

That's very interesting, it's very helpful. You don't find in this day and age in America in the 2020s, a high level of agreement on anything. So 76% agreeing that buildings should be physically accessible is actually quite high. I know everyone here wants that number to be 100%. You don't see 100% on much these days. Apple pie doesn't poll at 100%.

(00:39:28):

That's one part of it. But what is particularly interesting to me in what I think of when you ask that question is message testing. What is the best argument we can make to persuade likely voters that home and community-based services need more funding, deserve more funding? What is the best argument we can make so that when we're doing advocacy, we're advancing, we are echoing, we are expanding upon, elaborating on the arguments that are most persuasive with voters, because ultimately that's who the people in Congress, that's the people in the White House, it's people in the State House, it's who the government cares about. They care about whether or not they're getting re-hired or fired. They care about whether their party's going to do well or not do well come election time.

(00:40:24):

And so we just were in the field with some message testing on home and community-based services, which is another issue I've worked on for a while now and is really important to me because as many people listening to this will know, if you are someone

who, because of a disability need in-home supports, in-home Services to stay in your home, there are places in this country, it's really hard to get that. A lot of people end up warehoused in a SNF, in a "skilled nursing facility" who could and should and ought to be living in their homes.

(00:41:10):

We talk about Olmstead. Olmstead created a conditional right, you have the right to do this if and but. You have the right to live in your own home if the state's experts agree that you ought to be able to live in your own home, and the state has the money that they want to spend on it. Olmstead created a conditional right. I don't want to rely solely on Olmstead for the freedom of disabled people in this country. I need to go out and win the hearts and minds of the American public to support the freedom and independence of disabled people.

(00:41:44):

And it turns out, if you take about 10, 12 different arguments for why we ought to increase funding for what in the jargon we call HCBS, which is really bad. You don't want to talk like that. You want to talk in a way that voters connect with and they understand.

(00:42:03):

If we go out and present, and we just did this from August 16th to the 18th. You're getting fresh data from DFP. We surveyed 1,239 likely voters in the United States, weighted for all of the things that we weight for, age, gender, education, race, geography, 2020 recall to vote conducted in English, a margin of error associated with the sample size is plus or minus three points.

(00:42:32):

If you do that, you find that likely voters find the argument when you ask them, below is a list of statements from people who support government funding for home and community-based services. Home and community-based services allow aging adults and people with disabilities to live independently and receive care services in their homes and communities like helping someone bathe and dress or providing transportation. And then for each set of statements, select which statement you find most convincing as a reason to fund home and community-based services.

(00:43:10):

When we do that, the argument that comes back as most persuasive is that everyone, including disabled and aging adults, has the right to live their own independent lives. Funding towards home and community-based services would mean that more disabled people and aging adults would be able to continue having their own independent lives with a caregiver in their homes and in their communities, not in an institution.

(00:43:36):

Out of all of the arguments we tested, and I'm looking at three pages of arguments, I'm not going to read them all to you, that was the one that did best. The second most persuasive, and I'll stop with this one, was that aging adults and disabled people in this country should not have to wait for months on end to receive the care that they deserve. Increased funding for home and community-based services can help those 690,000 Americans who are stuck on wait lists without help in sight.

(00:44:05):

So what I am able to do because of Data for Progress and because our executive director believes in this work is I'm able to go out to the public and I'm able to say, "Here's a bunch of arguments we see in the HCBS space. Tell me which ones you find most important, most persuasive. Which ones work the best for you, which ones work the least?" And when I do that, I find that those are the best arguments and the worst arguments is something like care work is the work that makes all of the work possible. We need more funding for home and community-based services because when care workers have a living wage and good benefits, we all benefit. That's not persuasive it turns out to the electorate. I wouldn't have known that unless I asked. I would've thought that was a good argument. It turns out it is the least persuasive out of all of the arguments we tested.

(00:44:53):

So we don't have to guess is my point. The freedom of disabled people to remain in our own homes, in our own communities is too important to guess which arguments are the best. Too important. We should not mess around with that. We should do the research to figure out what are the best arguments and those are the arguments we should make. I believe that about home and community-based services, I believe that about Medicaid, I believe that about SSI and about SNAP.

(00:45:22):

It turns out SNAP is very close to my heart. I have an inflammatory bowel disease, which is basically a food disability, that's how I think of it. I got a food disability and I really like food.

It's not the best combination, but I try to navigate it as best I can. Living in poverty in this country, relying on SSI, which is only about 75% of the federal poverty line. You got this, what the government says, "Hey, if you're at this number, boy, you got it rough. It's poverty." And SSI provides a benefit that's only 75% of that number, it's rough.

(00:46:00):

And so SNAP, which used to be called food stamps, are how I put food that I could eat safely without being hospitalized at one of the world's best hospitals and scaring the hell out of my gastroenterologist who is one of the world's leading experts on this disease, I drew the short straw. I do not have an easy, uncomplicated course of Crohn's disease. SNAP was what allowed me to put food on the table.

(00:46:36):

And so other things that we do at DFPA, we ask about these programs that are really important to disabled people, particularly disabled people who don't have a lot of money. If you're SNAP is means tested, meaning you get to prove you don't have a lot of income, a lot of money in order to get SNAP benefits. And I have alongside colleagues at DFP done our best to defend SNAP because it is a program that is constantly under attack.

(00:47:01):

This is one of my favorite findings of all time. If you call it SNAP, you get a 19 point advantage in public support over calling it food stamps, a plus 19 point advantage. SNAP has a net score, which is where you take people who support it and you subtract out people who oppose it. Net support for SNAP, if you just call it SNAP, is plus 44. Net support for food stamps is plus 25. You get to pick up a lot of support just by calling it SNAP. I think that's great.

(00:47:48):

I think that is the sort of data we need on every issue that is important to disabled Americans, and you're not always going to find a massive advantage like that. That is really quite something.

Maddie Crowley (00:48:03):

I just wanted to hop in and say, that is fascinating. I learn new stuff every day. Obviously we all do, but I think that's one of the coolest... Obviously with context about what we're talking about, but that is fascinating, especially when I try to talk to people about HCBS, home and community-based services versus institutions and how it is more expensive to

have institutions and continue to institutionalize people, that's actually more expensive and will come out of more people's tax dollars rather than fully investing in HCBS. I've always found that to be one of the most influential things, and I imagine maybe it's high, I hope it would be higher on your list.

(00:48:46):

But just knowing that, I think what gives me so much pause and makes me emotional is that the most popular thing that people in your research is that people want people to be treated like people and have humanity and have independence and just the things that they need. I'm, I don't want to say speechless, but emotional in a way to that, in a way that I can't really put into words just because I feel like so much of what we see on the news or so much that we see and hear from other people is sometimes so negative towards people with disabilities and our aging population, our elders that we should be investing the most care into and love and support for, that it's incredibly moving to hear that was the most popular point. So I just wanted to name that.

Keith Casebonne (00:49:43):

If I could jump in real quick, I'm taking notes and I had the same thing. I said, surprised it wasn't that it's cheaper because that's to me, one of those, people just focus on the money. That's probably the most, oh, well, if it's cheaper, then we'll do it. But again, echoing Maddie's comment, it's so refreshing and inspiring to hear that's actually not the top answer. I love that. That's incredible.

Matthew Cortland (00:50:03):

I was pleasantly surprised that the freedom and independence in not being stuck on a wait list, waiting for freedom and independence was most persuasive and economic arguments like it's too expensive for a family to do home care, in home care, it's too much of a financial, they're further down on the list. Those arguments were less persuasive than you have the right to live in your own home with your own family.

(00:50:42):

It's a reminder to me that sometimes the arguments we make are a little bit too inside baseball, a little bit too inside the Beltway. 54% of Americans between the ages of 16 and 74 years old read below a sixth grade level, or below fifth grade. They're fifth grade or below reading. 54% of Americans between 16 and 74 years of age, that's adults.

(00:51:14):

If you are listening to this right now, I can tell you, you are an outlier in terms of knowledge of the American political system, in terms of knowledge of disability policy and politics. You are an outlier. You are in the top 1% of people with knowledge of those systems. When you look at the 320 or 30 million people in this country. You are in the bubble with us. Just by virtue of listening to this I know that you are in that filter bubble with us.

(00:51:43):

Knowing how to talk most persuasively to people who are not in that bubble is really important. And the only way I have found to know what's going to work is to go out into the field with a sufficiently high end, a sufficiently large number of responses that are properly distributed and weighted in getting that data. Because when, I guess sometimes I'm right, but I too thought that saving money was going to be a more persuasive argument to people, and I was wrong. I was completely and totally wrong about it. I would tell people, electeds that my grandmother and family members, I'm not going to draw out the family tree. It gets confusing.

(00:52:37):

The three family members who were disabled. And I was trying to keep out of a SNF, and I arranged for all of those home care services, Meals on Wheels, PCA hours, et cetera. And then I hit the wall, where even in the Commonwealth of Massachusetts, I couldn't get more hours because they did not live in a zip code that had a PACE program, a program of all-inclusive care for the elderly, which is the program most likely in Massachusetts to keep someone out of a SNF. It provides the most in-home support for an elder with disabilities.

(00:53:10):

Even though I had three people in the same house and they could share, would've saved hours, couldn't do it. It wasn't a PACE zip code. I thought that would be a compelling argument. And it is. I throw that argument out there when I'm talking to electeds, but I start with, you know what the American people want? They want the right to age in their own homes. They want the right to take care of their disabled children in their own homes. They want that freedom and independence. So it's time you deliver because this matters.

(00:53:42):

I would not have known that but for the work that friends and colleagues at Data for Progress enable me to do.

Keith Casebonne (00:53:50):

Data is cool, it really is. This is a trite statement, knowledge is power, but it's how you get the knowledge.

Matthew Cortland (00:54:01):

It is. It really is.

Keith Casebonne (00:54:02):

It is. Knowledge is power, but you have to get the knowledge. And how do you get the knowledge? You have to ask people and you get answers back. That is data. And if you know the data, you have the knowledge to better argue, to better support people, to better achieve your own goals and also maybe persuade others as necessary to get things accomplished out there. I know I'm a broken record here, Maddie just said the same thing, but this whole thing is just fabulously interesting and enlightening, and I feel like I'm learning so much from this conversation.

Matthew Cortland (00:54:36):

What I have learned is disabled Americans are really good messengers for improving life for us all. People who self-identify as disabled aren't the only people who would benefit from Meals on Wheels. Disabled kids aren't the only people who benefit from SNAP. But we're really good messengers, we're persuasive in the political sphere. And we're persuasive when it comes to educating the rest of the country about issues around fairness and freedom and independence. We're really persuasive messengers, and we are in this weird place where philanthropy, big philanthropy is starting to recognize us as a field that needs to be funded.

(00:55:33):

The Ford Foundation is already there. The Robert Wood Johnson Foundation is coming along even though public health is incredibly ableist and they have much work to do, even at the RWJF, even at the Robert Wood Johnson Foundation.

(00:55:49):

But certainly in my lifetime, it has never been more important for us to have this data and make these arguments at a time when the world, this country, our leaders want to move on from a disease, COVID-19, that disproportionately harms disabled, chronically ill immunocompromised Americans. It's not just folks who are immunocompromised, it's also folks, if you look at CDC's own data, folks with diabetes are more likely to have a bad COVID outcome than people who don't have diabetes, for example. And older Americans,

highest risk factor, greatest risk factor. R is the highest, if you are a nerd like I am. Age, people over 65 are at greatest risk from this airborne disease.

(00:56:42):

Trying to convince and persuade policymakers to pursue systemic interventions. So interventions in public health, we prefer interventions that help everyone. When it comes to drinking water, ideally, not saying that this is true everywhere in this country, but it should be, the water that comes out of your tap is drinkable if you are on some sort of public water supply without you having to do anything. Now, yes, there are places in this country, Michigan in particular, that still have lead pipes in the water needs to be filtered or not drunk.

(00:57:19):

But if you ask people, the electorate, should we have clean drinking water? The answer is overwhelmingly yes. Should we have flushing toilets? Yes. Should the air outside be breathable? Yes.

(00:57:37):

I have spent the last few years running into the brick wall that is public health and ableism in this country started when the CDC director, Rochelle Walensky, the former CDC director, went on Good Morning America and said she was relieved by the deaths of my people, by chronically ill people. She was relieved by those deaths.

(00:58:00):

Having public opinion, having the ability to poll to say to the White House, the American people aren't with you, they're not relieved by death. This is a political problem for you, fix it. It was really important. Did we get as much as we needed? No. Is there a lot of work left to do because we need systemic intervention? In the same way we don't ideally rely on individual people boiling their water before they drink it, we need clean indoor air. We've got an airborne disease. The possibility of other pandemics seems high, potential pandemic seems high, and we should be upgrading the air ventilation and filtration in every public building in this country, every place of public accommodation in this country. And we're not.

(00:58:57):

It means that disabled folks and older folks, and particularly older, disabled folks are at increased risk of really bad health outcomes, death, long COVID, stroke. There's all of

these "challenges" that we currently face because of COVID in the disability space, that if we look at the public opinion research data, we find that systemic interventions, that having 12 air changes per hour. What do I mean by a systemic intervention? It's not on you as the individual to take steps. It's up a level. It's at a systems level. So we're going to make sure that the air in the grocery store, that's what it's called, is cleaned and it doesn't have infectious aerosol in it.

(01:00:03):

The future of this work, what I'm trying to get at, and artfully, and thank you for hanging with me if you haven't turned this off, is we have a lot of work left to do to convince policymakers, electeds, that disabled people are worth protecting, just like any other group of people in this country. In some areas, that's fairly straightforward.

(01:00:30):

HCBS for example, I'm not saying it's easy, but it's straightforward. We know the arguments to make. There is a political coalition. We are seeing more and more talk of this at the national policy level, in newspapers, online, et cetera, et cetera.

(01:00:46):

But we still need philanthropy and that world, the people with the foundation budgets to come up, to step up, particularly as it relates to public health and disability. Because the overwhelming legacy, I can tell you as someone who went to public health graduate school, spent two years at Boston University's Graduate School of Public Health, most ableist place I've ever been, is incredibly ableist.

(01:01:15):

We continue to need the support, increasing support so that we can dismantle the sort of legacies of ableism that are driving public policy that is directly impacting disabled Americans. We are seeing anti-mask laws in Long Island, Long Island passing a law that says you can't wear a mask or makes it hard to wear a mask or gives police the authority to stop and harass people who are wearing a mask, which I guarantee you is going to be disproportionately wielded against. It's not like New York police, police in New York have a long history of neutral policing. They are racist AF.

(01:02:02):

So there's this need to expand the work is what I'm trying to say, because we are facing threats. We are under attack on any number of fronts. The difference is, 20 years ago, we

wouldn't have had the resources to fight back, but we do now. They don't get to kill us in silence anymore.

Maddie Crowley (01:02:39):

I appreciate you saying all of that. Transparently, we did an episode because I have long COVID and it's interrupted our podcast scheduling, our work and everything because long COVID is long COVID. And my sister started by doing the COVID data numbers for our county. So we're pretty invested in this work. I really appreciate you bringing this up and naming all this. We discussed the ever expanding mask bans on that episode as well as they were just being introduced in New York at that time.

(01:03:17):

I'm wondering, are there any tried and tested messages or themes of messages for COVID that you've found successful for folks that are listening with long COVID or people who want to help their loved ones with long COVID or just care about COVID advocacy broadly that are impactful, who may be feeling a little bit lost, and as you're in the data biz, you might have some information about?

Matthew Cortland (01:03:47):

That's such a good question. I have worked on this problem since the beginning, the early days of the pandemic. It's hard to communicate about public health in general, a field that tends towards ableism. It is hard to connect with the American people on COVID when there is...

(01:04:18):

Again, if you're listening to this, you're in the bubble with us. You're not normal. I love that about you. But we're not normal. We are not the mainstream. Most people don't know all that much about public health. They don't know much about COVID. They don't know much about evaluating the credibility of competing sources making diametrically opposed claims. And the information space around COVID is just such a nightmare. I'm trying to keep this PG-13. In Massachusetts we have certain terms, but it's a mess. Let's call it a mess.

(01:04:56):

What I have found to be successful messaging, messaging that has the broadest appeal, because I am not trying to persuade people who have long COVID or the minority of us who still take COVID seriously, those aren't the people who need to be.

(01:05:18):

The message that I have found, if I were to give some messaging guidance, how to talk about this in a way that advances our goal of decreasing the incidence rate of COVID and long COVID and increasing the freedom of disabled chronically ill and immunocompromised people, the top line I have for you is zoom out. Zoom out. Do not make your message just about COVID, because when you do that, you lose support, I lose support. That is what the polling has showed me.

(01:06:01):

If you're going to talk about clean indoor air, talk about how clean indoor air reduces the risk from the Flu, from RSV, from COVID, from wildfire smoke. Make the message broader so that you're bringing appeal to more people. You're bringing in more groups, people who care about different things. Don't make it just about COVID.

(01:06:27):

Now, sometimes when I say this, I get accused of not caring about COVID. Nothing could be further from the truth. I have a duty to win. I have a duty to win. I have a duty to win. There is no policy issue I care about more. I have lost family members to this disease. If I stand up too quickly, I fall down because of long COVID.

(01:06:58):

And so when I say my messaging guidance on COVID is to advocate for systemic solutions like clean indoor air and to talk about how those systemic solutions benefit a variety of people, guard against a variety of threats, Flu, RSV, COVID, wildfire smoke, other types of pollution, it's not because I don't care about COVID, it's because I actually care about COVID a lot. I have a duty to win and winning means advancing the best possible argument to get the American people on our side.

(01:07:37):

With regards to long COVID, what I would say is the House and the Senate, the federal government, what I would say is this, our federal government, our elected leaders, oftentimes those groups don't look like I would want. We see some vile ableism out of the House in particular, and the Senate too. We see people who ran on and were elected because they promised to slash every kind of spending that there is, including research spending, every non-defense spending category.

(01:08:22):

And again, I will make the argument that COVID is a national security issue, but I'm going to tailor that message to the right audience. I'm going to tailor that message to someone on the House Armed Services Committee whose job it is to care about national security, that the House and the Senate do not look like I would want them to look like.

(01:08:44):

If I were in charge of the budget, we would be "dumping," we would be moving billions of dollars into researching post-viral illnesses, including long COVID, including ME/CFS. We would be spending dramatically more money on medical research aimed at preventing Alzheimer's disease.

(01:09:13):

I am personally battling a SNF over a loved one's care because there was no alternative, there was no alternative. She did not live in a pay zip code. There were no other programs. It was either memory care or she was going to burn the house down with it in her, and that's a pretty horrific way to die. But convincing the company, the venture capital firm running that building that she is fully a human being is now a part-time job. And if they won't take me seriously, or I'm admitted to practice law as a disability rights attorney and healthcare expert, they're not going to take anyone else in that building seriously, any other family member seriously.

(01:09:55):

So my point is I would deploy resources very differently in terms of medical research. I would if I were in control, if I had a magic wand and the budget of the United States of America was mine to control, it would be very different. But the truth is, even senators in the United States Senate like Bernie Sanders and Ed Markey, who I can tell you are working on these issues, don't have as much control as people often think they do.

(01:10:30):

There is a bill from Bernie Sanders, even a United States senator who is the chair of the Senate Committee on Health, Education, Labor and Pensions or the HELP Committee for short, even Chairman Sanders doesn't have full control over budgeting. He puts out a proposal and then he's got to get support, got to get enough votes to put it through the House and the Senate. And unless you do both, it's meaningless. It does nothing. So Senator Sanders' Long COVID Research Moonshot Act of 2024 is a bill to watch. In my view, in my personal judgment, it's a bill to support.

(01:11:15):

Chairman Sanders and his staff are savvy operators inside the United States Senate. I can tell you members of his staff are personally invested, read between the lines, personally invested in long COVID research. And if those savvy operators think the long COVID Research Moonshot Act of 2024 is the legislative text, the best they can get, the best they can get, they have a hope of advancing through the House and the Senate, to my mind, that's a strong endorsement. It's a strong endorsement. These are people who are personally invested.

(01:11:59):

Would I like to see more money than the billion in mandatory funding for 10 years to support long COVID research that the Moonshot Act has? Yes, of course I would. Do I think if Chairman Sanders thought he could get more money, it would be in the bill. Yes, I do.

(01:12:16):

So part of the unfortunate reality of engaging in 2024 in our broken political system means we support the good, even if it's not perfect, we do not let the perfect be the enemy of the good, I could attack that bill. I could tell you ways I'd improve that bill. But I know the staffers who worked on it also would've wanted those things and they looked around the building from the inside and they concluded they couldn't get them. And so I support their work because they're trying to support us and themselves and their families.

(01:12:59):

It's an imperfect system. The American people will break your heart. It's what I've learned as a pollster. The American people will break your heart, but if you want to do this work and it's work worth doing, it's hard work, but it's work worth doing, because of the people it can help.

(01:13:20):

A billion dollars in mandatory funding for 10 years to support long COVID research is not nothing. A new grant process to accelerate clinical trials is not nothing. Public health education is not nothing. Requiring new treatments if we discover, when we discover, I'm keeping my fingers crossed, I'm knocking on wood that those treatments be reasonably priced so that they are actually available to everyone in this country, is not nothing.

(01:13:56):

We live in an imperfect country with polarized political ideologies and that limits what is achievable. As disability advocates we have to operate within a political reality that we

don't get to completely define. In fact, we're really just for the first time having a meaningful impact on it.

(01:14:27):

And so the messaging guidance I have is advocate for clean indoor air and other systemic interventions. Do it in a way that doesn't narrowly focus on COVID. I know it's important. Please don't misunderstand me. I'm just telling you the public opinion data says that you get more support if you include RSV, the Flu, wildfires, particularly during the summer when it's wildfire season.

(01:14:56):

We had a really bad wildfire season last year on the East Coast and for the first time, this was a salient meaning important to them issue to a lot of voters. It's going to continue being important with climate crisis continuing. So don't focus narrowly on COVID, focus on all of the benefits of clean indoor air that we can get through ventilation and filtration upgrades. On long COVID, understand the political reality that we are operating in is not one that the disability community would choose as optimal, and we have to operate within that context.

(01:15:42):

Hear me when I tell you that the Sanders Long COVID Research Moonshot Act of 2024 was drafted by people who deeply care about this issue, deeply care about this issue, and we can push, and we can push hard, but it's got to be an effort of education and advocacy directed not just at those members of the Senate and the House who already care about long COVID. That's not our persuasion demo, that's not who we need to convince. It's those who don't care. We need to make it a political problem for them so that they are encouraged to support Chairman Sanders' legislation. And then maybe just maybe, outside chance we can get a little bit more, but unless we do that, we're not going to get anything. And frankly, that's just not acceptable.

Keith Casebonne (01:16:39):

Thanks for sharing that and sharing your personal connection as well to COVID and long COVID. We'll keep our eyes on this bill as well. It's really interesting information. I was not aware that was out there. And so again, say it again, knowledge is power. This is what this is all about. This is why we have this podcast. We can all learn about these things and learn something new, which I think today we have learned a lot of very new interesting things

from you and so honored to have you here as our guest. Where can listeners find you or learn more about Data for Progress?

Matthew Cortland (01:17:18):

I have heard my friends who have been on your show tell me about it and tell me that I was missing out by not being on, so I'm glad I got to join and they were not wrong. Excellent time.

(01:17:32):

Data for Progress is at Data F-O-R progress.org. It's not the number four. It's Data for, F-O-R spelled out. And we are.org, so it's Data for Progress.org, and I am on a link in bio because social media has changed and that's how everything works now. The Link Tree is /MatthewCortland, M-A-T-T-E-H-E-W C-O-R-T-L-A-N-D. Link Tree is Matthew Cortland.

(01:18:09):

It was truly fantastic to be with you and you're doing incredibly important work. And we need more platforms that are distribution channels that aren't owned by the big platforms, that de-boost and de-monetize anything, anyone, anytime anyone talks about disability. So I'd thrilled to be hearing and big fans of your work.

Keith Casebonne (01:18:32):

Well, thanks so much. We're big fans of you and we appreciate you so much. Thanks again for being here.

Maddie Crowley (01:18:37):

Thank you. Thank you so much Matthew, for teaching us so much and for such a great conversation. For those who are interested, of course we have a list of various things we mentioned in the podcast, in our episode show notes for you to peruse and explore to learn more about what we discussed.

Keith Casebonne (01:18:56):

Also be sure to comment and subscribe wherever you're listening. We're on all the major podcast platforms and the recording and transcript are also available on our website.

Maddie Crowley (01:19:06):

As always, if you have any questions or comments about the show, please email us at podcast@disabilityrightsflorida.org. We'll see you in two weeks.

Announcer (01:19:18):

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