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EMILY HARRIS:

Welcome to the Disability & Philanthropy Forum's Learning Series. My name is Emily Harris, I use she/her pronouns, and I'm proud to be part of the disability community. I'm executive director of the Disability & Philanthropy Forum and come to you from the Unceded Land of the Council of Three Fires, the Ottawa, Ojibwe, and Potawatomi Nations, now known as Chicago. As part of our commitment to accessibility, our panelists and I will each provide a brief audio description. I'm a white woman with dark, curly hair, wearing a purple, black, and maroon striped sweater over a black turtleneck with a silver necklace. Behind me is a white and tan screen. My access needs are met today because we have cart captioning. A few housekeeping items. There are two ways to access our live captions today. Use the CC button at the bottom of your screen or to access the captions in a separate window, see the link to the external caption viewer in the chat.

If you find that the captions are slow on Zoom, we encourage you to check out the stream text link using a separate screen such as another monitor or your phone. Again, that link is in the chat. Today, only our moderators and panelists will be on camera. You will be muted throughout the event. This webinar is being recorded and you will receive a link to the recording in the next few weeks. Although we will be using the chat to share links with you, it will not be available for you to communicate at.

Instead, please use the Q&A button at the bottom of your screen to share your questions anytime during the session. We will try to integrate them into the discussion as they come in and we will also make time for questions at the end. My colleague, Learning Services Director Sarah Napoli, will join the panel at that time to read the questions. If the Q&A is not accessible to you, please feel free to send your questions to communications@disabilityphilanthropy.org. We will be live posting on X, formerly known as Twitter today, and hope that you will join us on social media using the #DisabilityPhilanthropy. You can also follow along with us on X @DisPhilanthropy.

Before we start today's conversation, just a short reminder that disability is a natural part of the human experience. One in four US adults, 61 million people, have disabilities, and our community continues to grow as the population ages, as people contract long COVID, other chronic illnesses, mental health, and other conditions where society creates barriers to full participation. I also want to take a moment today to acknowledge, sadly, the recent passing of National Council on Disability Chair Andres Gallegos this past Friday. Andres spoke on one of our early webinars and was an incredible champion for equitable access to health for disabled people, and I'd like to dedicate today's webinar to his memory.

We have a poll question to help set the context for our conversation today. Please answer it now if you don't mind multitasking a bit while I talk. The question is, under the ADA, can long COVID be considered a disability, yes or no? If the poll is not accessible to you, feel free to email communications@disabilityphilanthropy.org or note your answer in the Q&A button at the bottom of the screen. To moderate our panel, I'm delighted to introduce Ana Oliveira, president and CEO of the New York Women's Foundation. Ana is joined on the panel by two disabled

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health equity advocates. You can learn more about the panelists from their bios that are linked in the chat. And before we start, the correct poll answer is yes, long COVID is considered a disability under the ADA and most of you recognize that. You'll hear more from our panelists about that. Ana, over to you.

ANA OLIVEIRA:

Thank you so much, Emily, and thank you so much for having me in this opportunity to create a learning and a conversation so needed for all of us. My pronouns are she/her/hers, *ella*, and *ella*. I am coming to you from the unceded land of the Lenape where New York City is located. I want you to know about me in my professional and work trajectory, service trajectory that recognizing coming out as somebody living with a disability has been one of the most transformational aspects of leadership for me. It has allowed the New York Women's Foundation to be an environment that values, welcomes, and is more holistic. So I am very pleased to welcome Gabriel San Emeterio and Dr. Zoie Sheets as our key panelists today. As Emily said, rather than reading their bio, we want you to use the link in the chat so that we can get started and I'm going to ask them to do abbreviated self-introductions.

Please share your name, your pronouns, your visual description, and one sentence you would like the audience to know about yourself. Before I turn it over to you, Gabriel, I actually want to do my visual description. I'm a light-skinned Latina, which short black hair, dark brown, black hair, wearing glasses, kind of squareish glasses. I am wearing a black sweater with a scarf that has tones of light blue and black, and behind me is a white wall with a small painting hanging on that. So Gabriel, please, let's start with you and have Dr. Zoie follow you in the introductions.

GABRIEL SAN EMETERIO:

Thank you so much, Ana, and thank you for having me here. My name is Gabriel San Emeterio and my pronouns are they, she, and he or *elle*. You can interchange them or if you want to default to one, you can use they/them. I am a light-skinned Mexican / Latine genderqueer femme looking person with shortish curly hair, dark, and I'm wearing a black shirt that has a gray color with two black buttons on it. My access needs are met because I got to rest before ahead of time in preparation for this webinar and because there's a wonderful team of people supporting us with the tech and monitoring chat and Q&A.

So thank you to everybody supporting us. I am in New York City, which as it was mentioned, is the unceded land of the Lenape people, and I would also like to acknowledge that in our history, there's the forceful removal of the people of Seneca Village, which was a Black community that had property owners and whose village was destroyed in the creation of Central Park. So in honor of those ancestors, we do our work. And something about me, just that all of the issues that I work on professionally are very dear and near to my heart and I have lived experience in all of them. So thank you for having me. And Zoie?

DR. ZOIE SHEETS:

Yeah, hi everyone, and echoing, I'm so grateful to be here and be having such an important conversation. My pronouns are she and they, and I'll start with my visual description. I'm a white woman with light brown hair that hangs several inches below my shoulders. I have a blurred background behind me, small hoop earrings, and a reddish-brown sweater on right now. I am a resident physician in both internal medicine and pediatrics here in Chicago. I've been engaged in disability advocacy for about 10 years or so with a focus on the intersection between disability and medicine and accessibility for both patients and providers. Much of my work has been in the Docs With Disabilities Initiative, which aims to make healthcare more accessible for doctors with disabilities. And as noted earlier, I'm a disabled doctor myself, which I'll talk a little bit more about earlier. I have been in Chicago for about a decade now and I'm grateful to Emily for sharing the land acknowledgement for Chicago earlier as well.

ANA OLIVEIRA:

Thank you. We're going to begin by grounding our conversation on your personal experience. So beginning with you, Zoie, can you talk about how your personal experience has shaped your views along COVID and its impact on people with disabilities?

DR. ZOIE SHEETS:

Absolutely. So I mentioned earlier that I live with a disability, and I think it's important to acknowledge, especially in a conversation about something like long COVID, that my disability is almost always invisible. I do sometimes use a cane and I sometimes use a wheelchair on days that I'm doing more demanding things or won't have an opportunity for seating, but much of the time, my disability is invisible. And the main manifestations of my disability are chronic pain and fatigue and muscle weakness. And I've seen, unfortunately, how in many spaces, but particularly in the world of medicine where I spend much of my time, those particular symptoms are stigmatized. I've had my symptoms and my disability since I was about 11, so not for my entire life, but for a significant portion of my life stemming from an experience with a house fire. And having developed my disability when I was 11, coming into teenage years, figuring out a little bit about who I am, especially in a rural area, I found myself often feeling really dismissed by healthcare providers.

I think that most of the time, my symptoms were chalked up to anxiety or mental health concerns, which I want to be clear is a valid disability in and of itself, it just simply wasn't what I needed help for at that time. Or I'd be accused of making things up or perhaps it was just hormones as I aged. And it wasn't until my early twenties that I had a physician who ran appropriate diagnostic testing. It wasn't until my late twenties that I had a physician listen to me long enough to actually connect me to the therapies and supports and mobility aids that would benefit me.

And I think that unfortunately, this experience is really far from rare for people with invisible disabilities and I think that most of the time, we experience doubt from our communities and our providers and for long COVID, this is only amplified by the fact that there are people who simply don't believe COVID itself was real. There are people who doubt that it can have long-term impacts. And so when we have all of that and these stigmatized symptoms within a society like

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ours that really demands productivity and particular types of productivity, I hear so much of my story echoed in those experiences and it really calls me to understand that this is an urgent need to develop supports for this growing population. Tangible supports and infrastructure, but also just a commitment to reducing that stigma and increasing empathy for these things.

ANA OLIVEIRA:

Thank you. Thank you. Gabriel, how has your personal story and trajectory shaped your views on long COVID, the impact of people with disabilities?

GABRIEL SAN EMETERIO:

Yes. Thank you, Zoie for sharing your story. I have so much identification. I also started having problems when I was a teenager. Mine were very much dismissed by growing pains and things like that, although I had episodes of spontaneous inflammation. But I was able to push through both because I am an immigrant and I have to survive until I zero converted, I became HIV positive, and after that, I think the reality of post-viral illness just set in. Likely after I contracted HIV, I also contracted Lyme disease, and so that complicated things a whole lot. It went undiagnosed for a really long time because the HIV diagnosis made everything, doctors took an easy out most of the time.

It's like the first easiest explanation they found. That's what they blamed all of my symptoms on. It's a long road, but I was treated eventually for Lyme disease. Then I got better but not well, then declined again. And I was told many times that by infectious disease experts that I had been treated and I should be fine. I had been treated and I should be fine, but I wasn't. Then eventually I got a fibromyalgia diagnosis and much later, I got a myalgic encephalomyelitis diagnosis, or ME/CFS. So my disability, just like yours, is about chronic pain, chronic fatigue, and muscle weakness.

And it was a very interesting experience, to say the least, to have an HIV diagnosis, which nobody doubted. They did the test test, test positive, and all of a sudden I was channeled into all these services and specialists and medications and treatments for which I'm grateful. That's why I'm alive today. But for my other issues, which are actually what kept me from working, what disabled me, I used to be a hairdresser and I'm no longer able to do that for a living. It's too physical and it just puts you in a great deal of pain and fatigue. Just every time I went to any of those specialists for my myalgic encephalomyelitis and fibromyalgia, I had to prove to them that I was not well, which I never had to do for an HIV specialist.

An HIV specialist just saw the chart and immediately believed me. So fatigue, chronic pain, were not only just stigmatized, but disbelieved. I had to prove, especially being a young person, I had zero converted when I was 28, so my issues really disabled me by the time I was around 32. So for a young person in this society where we have to work so hard and where burnout is a badge of honor, it was really difficult to have to convince both my employer and my doctors that I was not well, that I wasn't just whining, that what I had was debilitating and disabling.

ANA OLIVEIRA:

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Thank you.

GABRIEL SAN EMETERIO:

And so that's how I came into the work of long COVID and then unfortunately, I got COVID and it just worsened everything.

ANA OLIVEIRA:

Thank you. Thank you both for sharing that and I just wanted to highlight that I hear, we all hear from both of you the impact of being dismissed, right? The impact of the devaluing of your voice, of your own knowledge of your body, of your own ability to say, this is what I am feeling, and I'm going to say incompleteness in the medical dimension to recognize and to be able to meet you there, to be able to be with you and take your knowledge seriously to produce better care for you.

I also just want to point out that so to speak, this false hierarchy of illnesses diagnosed, right? That you are talking about with the HIV attention being very important, but in a really very problematic way, overwhelming the attention to other symptoms. And I see that Dr. Sheets is nodding her head as a medical practitioner, so I want to see if we can continue this conversation around these connections to long COVID. So Gabriel, let's begin with you now, about which communities do you feel and think that long COVID affects the most? We hear that in your conversation, but let's expand a little bit about what are the emerging health disparities that you see related to long COVID and associated conditions?

GABRIEL SAN EMETERIO:

Yes, thank you for that question. It's interesting because the data shows it, right? Even the Pulse home survey that the census puts out and some of the data that exists, for instance, from here in New York City. I live at the intersection, I embody the identities of the people most affected. So long COVID rates are higher in bisexual people, they're higher in trans people, and in Hispanic adults and then in African-Americans. So also in low-income people and people who have frontline jobs that don't have a lot of job security or that require people to be exposed to the public or are very physical and have no job protections, namely the gig economy or essential workers. So we are the people who bear the brunt of this crisis in addition to kids now going to school and getting COVID over and over and over and not having really any care or having specialists who look into pediatric long COVID.

So it's the communities that are generally already marginalized, also people with disabilities, people with chronic illness who are dismissed. This even happened to me. When I went to my doctor after having had COVID and developed new symptoms, worsened symptoms, a whole new host of things, my doctor said, "Oh, but you already had a lot going on before you got COVID," as though it was just expected that I should be doing worse. So the ableism that exists and is embedded in our systems, even in the systems of care, we need a culture change and we need to pay attention, which is what we're doing in our work. We're doing a needs assessment, although by the pilot because we're such a small organization, but we're grateful to

have some funding to do a needs assessment, and we're going to focus on three key populations. Trans people, people living with HIV who are four times as likely to develop long COVID than other people, and pediatric, young people, because we are the people who are typically left behind or sidelined.

ANA OLIVEIRA:

Thank you. Thank you. Zoie, let me ask you, how long does long COVID impact the lives of people with disabilities? What do you see that relationship of that impact? And from a point of view of a healthcare provider, what do you think is the experience for supporting patients living with long COVID?

DR. ZOIE SHEETS:

Yeah. So I think just thinking broadly about medicine first, medicine is something that so often emphasizes objective findings, and I think what we often forget and don't excel at as much is recognizing the power of the subjective and how critical it is to hear the patient's story as not only a key tool in diagnostics, but also as the tool that allows you to recognize the patient's context, what they need and why they need it, and why they're setting their goals for themselves. And so when we have something like long COVID emerging where the research is limited simply by the amount of time it's been around, but also by lack of investment and knowledge and data, and it's something that there's no specific test that I can run for. Really, the way that it's diagnosed is through a really good history, the subjective of what the patient is telling you.

I'm seeing more and more patients, and I'm very early in my career as a medical provider, too, but even having become a doctor in the era of COVID, I'm seeing more patients talk about feeling dismissed by these long-term symptoms. And so I think a lot about people who were not living with a disability before having long COVID and everything that myself and Gabriel have said about the challenges seeking a diagnosis. But I also think about the challenges that they will face in seeking the disability community itself. We have a society that so deeply stigmatizes disability. I know for me, the first time I called myself disabled, I had technically been so for nearly nine years, and there was that hesitation there because of the stigma. And so if we think about the challenge of these symptoms, of the challenge of that stigma, I'm really worried that folks who are coming to disability through long COVID may not have access to the critical support of the disability community as easily.

And for me, and it sounds like for you all as well, it was the engagement with the Chicagoland disability community that transformed my relationship with my body, myself, the world. And then of course, there's also people who've certainly had disabilities and are being diagnosed with long COVID. And I think about the lack of access to equitable healthcare that these folks already had. Whether we think about physical barriers, so exam tables that aren't accessible, wheelchair scales not existing. I think about the communication barriers, not having ASL interpreters or clear masks. Sensory barriers and critically, attitudinal barriers, the ableism that makes people not access care. And if you're now experiencing long COVID that is poorly understood and deeply stigmatized, combined with all of that, I worry about these folks finding

the care they need for their increased needs. And I apologize for this being a long answer, but to make sure I touch on the doctors as well, for the doctors and the many other healthcare professionals that are providing care for these folks, I think there's a spectrum of how the pandemic and the repercussions of the pandemic are being experienced.

But I think one of the challenges is that even the best doctors, the most empathetic, the most engaged, the most trustworthy, can still fall short if we don't have infrastructure and resources to do what we in our heart know we need and want to do for our patients. And so honestly, the culture of medicine is not one that prepares us well for these types of situations. It's often we're taught cure the concern, investigate, diagnose, and treat, heal, cure. I don't know that I have what I need to do much of that for patients experiencing long COVID. And I think in some ways, that might not change simply because it's such a nebulous illness, but in so many tangible ways, it can change, and that's what we need to talk about is what can we do to build the infrastructure to show up for these folks?

ANA OLIVEIRA:

Mm-hmm. Absolutely, absolutely. And I hear how important the voice of life experience is. We're talking about the knowledge of patients in the case. So in that vein, Gabriel, let me ask you, leveraging your intersectional experience of diagnosis, as you said, what do you think we can learn from, let's say the HIV fights and struggles and epidemics, and what do you think we can learn from that to identify and remove barriers for those that are getting care for long COVID?

GABRIEL SAN EMETERIO:

Well, I think that we see that there are really robust programs to have providers have the information that they need and standards of treatment for HIV that are the same and constantly improved across the country and the world. So there's a big effort in provider education. I remember when I had to bring things up, I used to be a patient with private health insurance from an employer, and then I became disabled and a Medicaid recipient, and so the care that I was getting was different for specialists, but I remember having to bring things up to the rheumatologist and when I said, "Is it possible that I have MECFS because I'm on all the proper medications, I'm doing all the right things, I'm not getting better, but the fibro is a little controlled?" And this doctor said to me, "Yeah, you might. It's a comorbidity with fibromyalgia, but there's nothing you can do about it."

And that was a patent lie. It was completely wrong. Later on, I became connected to the MECFS community and to MEAction, which is a great organization that does myalgic encephalomyelitis advocacy. And then I learned about pacing, which absolutely changed my life. I learned that it was exerting myself that was making me worse. So provider education is paramount to giving proper care. We don't really have specific treatments or a specific cure, but there are things that people can do for the ailments that come with long COVID. So we can start with provider education and also with empowering the community members. A lot of the HIV effort came from the grassroots, came from people stating their needs and knowing what they needed and making their voices heard. It is more difficult for people with long COVID because we face all these debilitating symptoms.

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So although there's a groundswell of people looking for community and looking to take action, we have very small organizations that are struggling to survive because there's not an ecosystem of funding for organizations that deal with long COVID and associated diseases. Of course, when I came into HIV advocacy, I came on the shoulders of 30 years of advocacy, of the Ryan White Care Act, and of tons of funders, private funders, who put lots of resources into HIV care, HIV prevention, HIV services. And I think we need not reinvent the wheel. Meaningful patient involvement, both in peer support, creating research protocols, standards of care, listening to people's experiences is important, doing the advocacy. But all of it takes resources.

And in order to get the government moving, we need to get the people the tools and the funds to really organize and create that people's power. With the ailments and long and associated diseases, for instance, we need to change our culture. If we used to have one person doing one task and burning them to the ground doing that one task, maybe we need to have three people that can share that task so that people can step in and step back. It's a re-imagining of how work is done and providing the resources needed so that people can do that work. So that befalls on funders as much as government, but funders I guess can do that faster. Government's a little slower to respond.

ANA OLIVEIRA:

Absolutely, absolutely. Yes, that is the case. So I'm inspired by your comments to note that the struggle, the movement, the HIV and AIDS movement, as I would say, changed medicine in many ways. And just heard that not only the disability rights movement has been very long and very deep and very determined, but also that it can continue to benefit and change medicine and build on that, but also change our conceptions of work. It's another sphere that is impacted by this movement. So in that vein, I want to go back to you, Zoie, and ask, were speaking about the infrastructure that medical providers need to be able to better respond to the needs of long COVID living people. And I wanted to ask you, how can they better diagnose what would be helpful to advance their competence?

DR. ZOIE SHEETS:

I think taking a step back and just thinking about doctors as individuals first, I think the answer sounds simple and sometimes is not, and that is simply to listen. Listen, listen, listen to your patients. But not just listen to hear, listen to truly seek understanding beyond the surface of what is being said, to ask followup questions. And I think that part of why that's so challenging in medicine is medicine promotes a culture of perfection and of unwillingness to fail or to be wrong. And especially in something new like this, you have to be humble. Sometimes you won't know and sometimes you will be wrong. But I also think it's important for us to remember that as healthcare leaders and activists and funders, patients not being heard and not receiving the diagnosis and care they need is not always, is not often because of just a bad doctor.

It's because we have a failing healthcare system. And so when I tell someone that the solution is to listen, that would absolutely be transformative and is only possible if we didn't have 15 minute or less appointment times, if we didn't have overflowing hospitals, if we didn't have folks who were delaying care for extensive periods of time because of cost or confusing infrastructure

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or lack of access. So for listening to your patient and hearing their story to be the answer, there first has to be the setup for that to be able to be possible. And that's where we call on things like making sure that everyone has access to the insurance that they need.

Gabriel was just talking about his transition and as they were talking, I was like, I had the exact same experience. I shifted it to Medicaid and everything, too. So the insurance system, making sure that medical education itself is accessible and people can engage with it who are from the communities most impacted, who are from lower income areas or have disabilities or are living with HIV or maybe have long COVID or whatever it may be. All of those structural things have to be in place for doctors to be able to do what they hopefully want to do to do right by their patients.

ANA OLIVEIRA:

Yes. So soon we are going to open to questions from our audience, but before we do that, I want to ask each of you, where do you see hope and what would you like philanthropy to do? What is the call of action that you have for us in philanthropy? Let's begin with you, Gabriel.

GABRIEL SAN EMETERIO:

I see hope in this webinar. I see hope in philanthropy actually taking an interest and having these conversations, not just about long COVID. Long COVID is the tip of the spear, but we can really push for broader disability justice because long COVID is such an umbrella that covers so many diseases and presentations, we can really work towards a more disability-just world. And the call to action is to fund the small organizations, fund the people with lived experience so that we can do the work and move the levers of power to really create structural change.

One of the things that I was thinking about when Zoie was talking about treatment and listening to patients is, for instance, who gets bed rest is a thing that gets prescribed to certain people. Mothers who have a pregnancy at risk or people who just had certain procedures. But why is that not prescribed to people with long COVID? Bedrest, a lot of people could benefit from it, but it's stigmatized. And we also see how Black women die more from being pregnant, and so they don't get the same treatment as white people, white women would. So it's the same. There are ways of managing these illnesses and we need to get that information out quickly. And the best way to do so is by changing narratives, and so that's one of our focuses and I think philanthropy can really help empower the people.

ANA OLIVEIRA:

Thank you. Zoie, where do you see hope and what can philanthropy do? What would you like us to do?

DR. ZOIE SHEETS:

Yeah. A lot of what I'm about to say is going to be echoing Gabriel. I don't mean to steal their answers, but they're true. So I think where I see hope, I so agree, is that the conversations are

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happening. They're happening in spaces like this. I see hope in the disability community and the resilience and creativity of that community and in the Docs With Disabilities community, too, which is a group of people who are really lighting a fire under medicine and saying, we've got to do better. And I think my call, yes, yes, yes to funding and centering the people who are most impacted, yes to making sure that philanthropy and funders understand what disability justice means and not just disability rights.

So the disability justice movement being that that was founded by queer disabled women of color and said, this goes so much further than just legality and litigation, but also to anti-capitalism and intersectionality and sustainability and all of these tenets that they so beautifully captured. But also, my final call would be to set the example as well. So if you are an organization that is looking for ways to support those living with long COVID or the disability community, your events must be accessible, your events must require masks, your events must be spaces that have virtual options and are accessible for immunocompromised people or the people who have so much to add, but may need to do it from bed.

ANA OLIVEIRA:

Thank you. Thank you. I am now going to turn it over to Sarah to let us know about the questions of our attendees.

SARAH NAPOLI:

Thank you, Ana, and thank you Gabriel and Zoie. It's been so great listening to you. Well, we're going to kick it off with some questions and I'm going to start on a little bit of a slightly personal note and then lead in to questions. So the idea of post-viral infection is nothing new. We've had post-viral infection forever, and speaking from experience, I had a post-viral infection from mono in the nineties and had it for, gosh, a couple of decades, really. I'm just coming out of this post-viral infection phase myself. And so this idea, and when I heard about long COVID, I was like, wow, that sounds a lot like what I experienced and all the same sort of symptoms. And I was curious if you, this question is really posed to both of you, if you have found that there has been any sort of disability community mentorship or there's been any community around these ideas of post-viral conversations of coming together and talking about, yes, this is something we're familiar with.

And Gabriel, you talked about this a little bit about this was my story, this is the world I was coming from. Because I feel like I have not seen that because people are coming into disability, Zoie, you've also talked about this, people are coming into disability with long COVID and then realizing, oh, this is a disability, this is what this feels like, and then not having that mentorship of the community. So I'm just wondering if you have found that there's been any of that mentorship happening, and if so, where have people been going to find that? And so if you have anything to share, I'd be curious to hear a little bit about it. And so Gabriel, we could start with you and if Zoie, you have anything as well, that'd be great.

GABRIEL SAN EMETERIO:

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Yeah, absolutely. I think that because post-viral illness is not a new thing and long COVID can affect anyone. It can affect anyone who gets COVID. So we have people becoming disabled across the political spectrum, across all demographics. So there's been a lot of people trying to find community and trying to find answers. We used to have The Body Politic, which unfortunately collapsed because of lack of funding. That was a support group that was even given as a resource by health departments in California and New York City. The health departments were referring people to this support network so that they could find answers.

Most of those answers came from the myalgic encephalomyelitis community, from the MCAS community, from other invisible disabilities and other ailments and diseases that exist under long COVID. So there's been a connection between different diseases and people with long COVID. So they have benefited from previous knowledge that other communities have, but unfortunately the conduits through which this happened, one of them folded, it just completely collapsed, which was The Body Politic. It happens on the web, but to really create these networks and make them sustainable, there needs to be funding so that people can carry this work, which is not easy, especially when living with a disability.

DR. ZOIE SHEETS:

I don't have a ton to add other than echoing what I mentioned earlier, which was my fear that people with long COVID may not find the disability community. And so just a call to folks who have the power to introduce long COVID as a disability. We are screaming it from the rooftops in this space, but I think for physicians, people in the disability world, just putting those two words together as often as possible, because from my experience, the disability community is one where there are niche groups that will support each other in very specific experiences, but there's also so much shared experience.

So when someone gets plugged in from the get-go, they will both find their niche subgroup, but also just find people that know what the experience of having a body that works outside the norm, a body that may not work the way it's being expected to, what that feels like and how that impacts you. That comes with all disabilities, and so I think it's a yes and. Get folks plugged in from the get go, and then the smaller communities will come, they will find these folks.

SARAH NAPOLI:

Yeah, I've been a big, strong proponent of finding disability mentors because I think, what a powerful tool that would be for folks who've become newly disabled, and I think this has been a massive disabling event for our planet and how powerful it would be to be connected with disability mentors. So just wanted to put a plugin for that, and we've got some work to do, it sounds like. We've definitely been really laser-focused on talking about the medical community, which I think has been vital and very important.

But I wanted to pull on something, Gabriel, that you had talked about re-imagining work. And I love how you started off the call when you said that your access needs were being met because you had time to rest, and I can appreciate that. And so I was wondering if you could elaborate on that a little bit and just talk a little bit more about what that can look like for employers and

obviously especially those in philanthropy, what would that look like re-imagining work? And if you could just talk about maybe what your vision for that would be so those on the call can think a little bit more about that?

GABRIEL SAN EMETERIO:

Yes. Like I mentioned before, I was a hairdresser and I had to stop doing that because it's just way too physical. And I was out of the workforce for a long time until the pandemic happened, and then remote work became available, so I can do work and lie down and continue to work, and that has been life-changing. It's not easy to lie down in a workplace. I made it through school, like my higher education, lying down several times a day in the library and finding the spaces where I could hide and lie down. And so that has been very important when I learned about pacing.

Medications have helped and everything, but what's really made a big difference for me is pacing. So I think changing how we balance life and work. I do know that for myself, at least, the last thing I lost was my job. I lost everything in my life. Friendships, I lost the ability to have leisure time to do anything. I was caught in a cycle of work, crash, work crash. I would go home, crash, get up, work, rinse and repeat until I couldn't do it anymore. And so not working people to the bone is so important. Giving people time to rest and giving people the accommodations needed to work from home.

Most people that I know who live with invisible disabilities, there's this stigma that if you give a niche, people are going to try to take advantage and not work and slack off and get benefits, be greedy with the benefits, and it's so not true. People want to, in my experience, want to just lead a life that has some dignity and we are entitled to it. So building that into our work culture is really important. And I can't imagine for doctors, and doctors are raked through the coals just to make it through a degree. It needs to change.

DR. ZOIE SHEETS:

Yeah, this is true. I could comment extensively on how medical education should change, but I think perhaps my biggest takeaway from beginning my work as a doctor applies to all work, which is the times I have been able to be the best doctor that I can be is when my mentors, the attending physicians, have asked me what my strengths are and how I can make those strengths shine. Actually, Ana asked us that at the beginning of this panel, too. Having spaces that allow you to speak to what you can bring to the table, but also what tools you need to actually get it to the table. Those simple conversations with leadership and colleagues open so many doors to not just say, what are my accommodations, but to center on these accommodations matter because I've got something to offer and this is the only way I can actually offer it.

SARAH NAPOLI:

Yeah, I was going to have you come in, Zoie. You just immediately jumped in, so thank you. But this idea that, you can imagine what it's like in a place where the medical model of disability is

so prominent, obviously, on the medical side of the house. And so I wonder if you want to elaborate a little bit more on that, especially as someone who has self-IDed in that space, if you have any maybe advice on, we talk about that a lot in philanthropy as someone who has self-IDed for a long time myself, I know how difficult that can be, and that's a topic that the forum has brought up many times, whether or not to self-ID. And I think that depending on other identities that one might hold, that is also compounded. And so just curious if you have anything to add, and then I have one more question that I'd like to pose to Ana before we close with the questions, but anything else to add to that, Zoie, would be great.

DR. ZOIE SHEETS:

Yeah. I think for me, I have chosen in all spaces for many years now to identify myself as having a disability even when I'm not using a mobility aid. And it took a while to get there. It took the mentorship of a lot of disabled folks before me to feel comfortable with that. But I hit the moment where I realized, and I hope that folks who are creating these spaces hear this as well, that I realized that the cost, which is the ableism and the harmful comments, which I promise come in abundance in medicine. Just this past week, I was called lazy for using a stool during rounds. These comments are common.

But the benefit to me, which is that I think being a disabled doctor makes me an excellent physician. I think that the empathy it brings, even as I'm still learning the medicine itself as a resident physician, I think that the empathy and the understanding that it allows me to bring as someone who's been on the patient side many, many times is worth it. But I also need the other parts to be addressed. I need there to be an infrastructure that when I self-ID and the cost becomes great in the form of comments or discrimination or exclusion, I need there to be somewhere for me to go so it's not just me reminding myself the benefits weigh more, but actually, we're reducing the cost over time, and so the benefits are really the experience of self-IDing.

SARAH NAPOLI:

Thank you. Yeah, I'm glad you talked about the benefits of self-ID. I know sometimes it's hard and it can be scary, but I know for me, I've seen the benefits have far outweighed the cons in this regard. So thank you for sharing. I'm going to turn it to you, Ana...

GABRIEL SAN EMETERIO:

Just a very quick comment.

SARAH NAPOLI:

Go ahead. Thank you. Yeah, come in.

GABRIEL SAN EMETERIO:

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Just very quickly with long COVID, one of the things that has become really well-known for some people, or stigmatized, is the cognitive effects of long COVID. And that creates a really tricky space for people to self-ID in the workplace because they can be discriminated against. It can prevent you from accessing promotions, et cetera, and create this idea that you can no longer do your work. And you might be able to still do your work with the proper accommodations, but that needs to be understood, I think. Thank you.

SARAH NAPOLI:

Thank you for adding that. Most definitely. Ana, I'm going to jump back to you, and before you go into your closing, I'd also just like to point out that the New York Women's Foundation has been speaking out a lot about long COVID, and I was just curious if you had, yes, thank you very much for doing that, but I also was wondering if you had been incorporating any of that into some of your workplace accommodations, and if you could speak just briefly about that, if possible. Thanks.

ANA OLIVEIRA:

Absolutely. Thank you. Yes. We have several members in our community, staff, board, grantee partners that are living with long COVID, and we haven't made any particular accommodations to that because it's included in our approach to this less extractive relationship to work and to ourselves. So we work on a flexible hybrid model. We have a gazillion accommodations, which are a very simple process. I think it's important that accommodations be a very simple process for people. I think that cumbersome process that would just repeat that "I don't believe you" kind of thing that we were talking about in the medical care do not help people, and in fact, hold people back. Two other comments about long COVID. We know very little about it. It's happening in front of our eyes. We are learning about it. And I'm going to say that as somebody that has had COVID, I have no idea, to be very totally candid, if I have still symptoms or not.

I'm learning. And in that same way, learning from my colleagues, learning from others, and we all collectively are. So thank you for asking that, Sarah. I think that the response is that, look, I have an enormous amount of privilege running a mid-level, but still very fierce foundation, enormous amount of privilege, that we can raise policies and we can change policies, and we can model to people and decouple these issues of quality, of value of people and performance from a particular style of getting something done. And so I wanted to say that and decouple a flexible thing from trust or non-trust and belief or non-belief. We all have to evolve as humans, but our workplaces need to decouple these kinds of things. And I think that that's one of the great contributions that the disability justice movement is making to the world. It's important to be owned.

My last commenting and want to close and thank Gabriel and Zoie and you and everybody attending here is that problems and solutions are found in the same place, and they need to center the voice of those who are by definition creating those solutions, but it requires also the participation and the engagement of others because everyone is living in that reality and is not something that can just be carried by those who are particularly engineers of those solutions out of their own individual and community practices. I think that's something that certainly the forum

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gives me. I wanted to acknowledge the community that this creates. And one quote unquote advantage as you were speaking about taking our identities fully, is that we become part of a very powerful community. A very loving community, and a very powerful community. And I want everyone that is attending today and the ones that you're going to talk about that are not here today to know that. So I want to thank you all and send it back to you, Sarah, for your final comments.

SARAH NAPOLI:

Thank you so much. Thank you, Ana. Thank you Gabriel and Zoie for this incredibly rich conversation and call to action. We obviously couldn't address everything. We couldn't address all the questions, but they're going to inform our programs and our resources. And following the close of this session, you will receive a short survey. Please take a few minutes to fill it out. The link is also available in the chat. We hope you're going to join us for our 2024 learning series, which begins in February with a webinar centered on disability justice and labor rights. And that is the close of today. Thank you so much. See you next time.