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EMILY HARRIS:

As part of our commitment to accessibility, our panelists and I will each provide an audio description of ourselves. I'm a white woman with dark, curly hair and glasses wearing dark blue, white, and black. Behind me is a tan and white 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. This member learning session is being recorded, and you will receive a link to the recording in the next few weeks. If you come on screen to ask a question and would like it to be edited out of the public recording, please let us know via the chat or via email at [communications@disabilityphilanthropy.org](mailto:communications@disabilityphilanthropy.org).

During the first portion of our program today, we'll be spotlighting our speakers, and you will be muted. You'll use the chat through this session to share links to information. You can also use the chat to post questions at any time. We'll try to integrate them into the discussion as they come in, and we'll also make time for questions at the end. During the dedicated Q&A time, you can place questions in the chat or come off camera and unmute, and our moderator and panelists will address as many questions as they can. If the chat is not accessible to you, feel free to send your questions to [communications@disabilityphilanthropy.org](mailto:communications@disabilityphilanthropy.org).

Before we start today's conversation, just a short reminder that disability is a natural part of the human experience. One in four adults, 61 million people, have disabilities, and our community continues to grow as the population ages and as people contract long COVID, other chronic illnesses, mental health and other conditions where society creates barriers to full participation.

To moderate our panel, I'm delighted to introduce my colleague, Sarah Napoli, Learning Services Director here at the Forum. Sarah is joined on the panel by two disabled professionals and advocates. You can learn more about the panelists from their bios that are linked in the chat. I'll turn it over to Sarah.

SARAH NAPOLI:

Thank you, Emily, and yay. So happy to see all of you here today. So I'm going to set the context first with a poll question, if you don't mind answering it now while I talk a little bit. So what percentage of employed people with disabilities request changes in their workplace? And that might be schedule flexibility, assistive equipment, et cetera. So do you think it's 14%, 33%, 21%, or 9%? So go ahead and answer that, and if the poll is not accessible to you, you can email your answer to [communications@disabilityphilanthropy.org](mailto:communications@disabilityphilanthropy.org), or feel free to share your answer in the chat.

So as Emily said, my name is Sarah Napoli. I use she/her pronouns. I am proud to be part of the disability community as well. As Emily said, I'm Learning Services Director here at the Forum, and I come to you from the unceded land of the Lenape people, now known as New Jersey, right outside Manhattan on the Hudson River. I am a white woman with dark blonde hair

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wearing a black top. Behind me is a wall filled with some of my favorite nerd posters. And I've been really looking forward to this conversation because as someone who has self-IDed in the workplace for a long time now, I know how difficult it can be in the worst of times and how lovely it can be in the best of times. And I hope we can have an honest dialogue today about what it looks like in both these scenarios and how we can navigate this and the nuances and the context of both.

But before our panelists introduce themselves, I want to give the correct poll answers. So can we pull up the poll? So 53% of us said 14%, and the correct answer is A, so most of you got that correct. According to the US Bureau of Labor Statistics, about 14% of people with disabilities reported that they had requested a change in their current workplace to help them do their job better. You'll hear more from our panelists about how disability inclusion can show up in the workplace.

So I'm pleased now to welcome Aida and Kevin. And rather than read their bios, you can please share your name, your pronouns, and a visual description, and just one sentence that you would like the audience to know about yourself. So Aida, I'm going to start with you, followed by Kevin.

AIDA AKIM-ESCRIVA:

Hi, Assalaamu 'Alaikum. My name is Aida Akim-Escriva and my pronouns are she/her. It is true joy to connect with you today. I'm an Asian person with long, dark, curly hair cascading over my shoulders. Behind me is a simple and adorned wall with playful yellow stickers, which I hope adds a touch of whimsy to my otherwise minimalistic space. I'm adorned in a sleeveless sky blue top and a star ship necklace. My access needs are met with CART captioning today.

I'm joining you from Wilmington, North Carolina, the traditional and ancestral lands of the Cape Fear Indians, the original caretakers of this area. And I would like to honor their lasting connection to this land and express my respect to their descendants and elders, both past and present. And as an activist, mother, immigrant, and an artist, my narrative is full of these varied experiences that fuel my work for disability justice, and inclusivity. In my activism, I champion the living of disability inclusion into the fabric of gender justice and bold human rights initiatives.

SARAH NAPOLI:

Take it away, Kevin.

KEVIN IRVINE:

Thank you, Sarah. Hey everyone. My name is Kevin Irvine. My pronouns are he/him/his. A quick description of myself, I'm a middle-aged white guy with short, dark blonde hair, reading glasses. I'm wearing a green T-shirt that says RUSH Celebrates Disability Inclusion, and behind me is just a framed picture on a dark, green-gray wall. And I work at RUSH University Medical Center in Chicago, where I've been for five years and working on disability inclusion in recruitment and throughout RUSH. And excited to be here.

SARAH NAPOLI:

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Awesome, thank you so much, you two. And just so you all know, we are going to go through a few questions, and I know as we move forward, we really hope this is going to be a dialogue with you all, and you might have questions as we move along. So feel free to drop your questions. As we move forward with our panel conversation, I will try to incorporate those into our live conversation, but we're also going to have time for Q&A at the end of the panel, so feel free to drop them in the chat. I'm going to try to incorporate them, and then at the end know that there's going to be dedicated time for Q&A as well.

So both are fine, but know this is a conversation, so don't feel like you have to wait until the end. Get your questions in as we move on, because I really do think that this is such a lively dialogue about how to self-ID, "How do I show up at work as a disabled person?" So I think it's going to be something that inspires a lot of conversation. So don't hold back as these questions show up.

All right, so let's really dig in here. And Kevin, I'm going to start with you, because I really feel like as someone who does this work internally, specifically focusing on recruitment of disabled talent in the workplace, I was wondering if you can talk not only on recruitment but also on the retention of disabled talent, which I feel like probably doesn't get as much attention, because I think, especially as someone who has worked with HR teams myself, there is so much chatter about "How do I bring in disabled talent?" And then I often tell people, "That's wonderful that you want to recruit disabled talent, but I'm not sure you're ready, because I'm not sure that you're ready to retain that talent."

So can you talk a little bit about what that looks like about how you recruit disabled talent, but how do you keep them? So talk a little bit more about the retention, and probably a little bit of those examples at RUSH.

KEVIN IRVINE:

Absolutely. So thanks, Sarah, and you're exactly right. Recruiting is just one small part of it. So I've been at RUSH for five years, and my background is not in HR or recruitment. My title is Senior Talent Acquisition Consultant, Individuals with Disabilities. In that, my charge is recruiting people with all kinds of disabilities and chronic health conditions, but also veterans, people who live on the west side of Chicago, and transgender and gender diverse folks. And when I got to RUSH five years ago, my background is in disability rights advocacy and training, and most of my career has been working on helping people understand what their rights are, people with disabilities understand what their rights are in a variety of contexts, including in employment.

And so I get to RUSH and I'm saying, "Okay, well, I'm working on disability inclusion. Where are all the disabled people already working at RUSH?" Because I recognize that when we talk about recruiting people, we also need to find out, what are the experiences of people who are already working in the organization? So as I would meet people with disabilities at RUSH, who would self-disclose to me, I would say, "Hey, would you be willing to have your photo taken so we could make you part of the face of disability inclusion at RUSH?"

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And so what we did is we would get... I was really fortunate. I got a number of volunteers, people with a variety of different disabilities working in a variety of different roles, and we built a collection of people that we could put on our career site to showcase people with disabilities working at RUSH, because I wanted to not just send a message to people that were applying for jobs at RUSH that this is a safe place where you can be yourself, but also I wanted to send a message internally.

Because when we're talking to hiring managers, RUSH is a huge organization. We've got well over 12,000 employees at RUSH University Medical Center, and throughout our whole system we have over 17,000 employees. And I wanted to send a message to hiring managers that when we're talking about recruiting people with disabilities, it's not just this exotic species out there in the wild. I want them to recognize there are people all around you right now with a wide variety of different disabilities, because most of us have non-apparent disabilities.

I've got hemophilia B, the bleeding disorder, I've had that my whole life. I've had HIV for over 40 years, and most of the time my disabilities are non-apparent. And so I really wanted to send that message internally as well as externally. And so to do that, I really wanted to raise the visibility for all of us at RUSH. And so I also added my disabilities to my email signature right below my pronouns, and this was also to set kind of a tone that when kind of normalizing talking about disability identity in the workspace.

Because the pronouns had really done a nice job at setting the table for talking about disability identity in the workplace, and so I thought disability fit in really nicely right below pronouns. It's just something you put out there about "This is who I am." And so I'd meet people, and every time, when we started our disabilities employee resource group, we would do a... We'd post a profile, a short profile or a spotlight of an employee with a different disability, to again, show folks that were already at RUSH. And every time we would spotlight a different employee with a disability, more people would come out of the woodwork that we didn't know about.

And so basically, we just kind of continued to grow and expand this network of people who are already working at RUSH, and that way, I also wanted to send a message to people that when they're outside coming in, you're not going to be a pioneer. You don't have to be a pioneer. Yeah, maybe there's no one with your exact disability or who has had your exact experience, but there's a lot of other people before you. And also really want to set the tone that this is a place where you can be yourself. And so not everyone wants to self-identify or self-disclose, but if you want to do that, want to make sure that we're creating a climate where people feel comfortable to do that.

And I also know from my own experience with non-apparent disabilities that it is much easier to ask for accommodations in the workspace if you've already disclosed a disability. Because usually when you need to ask for an accommodation, you're nervous. "How are people going to respond to me?" And if you have never disclosed a disability, then it's also, "Well, how are they going to respond when I disclose my disability?" So when you put it out there proactively, and it's something, that's a term I love, which is "political disclosure". You're, again, setting the table

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and setting expectations that you're going to be more visible and more out there and more open. And I think it makes it easier for others.

And part of that also is encouraging leadership to self-disclose whenever possible. So we can get more into that in a little bit, but that's a little bit about retention and getting people on board.

SARAH NAPOLI:

Kevin, I don't know if you noticed, but there was a request to see what your email signature looks like. So I don't know if you...

KEVIN IRVINE:

Oh yeah, thank you. I will absolutely share that. Yeah, because again, I didn't ask anyone else to add their disabilities to their email signature. But in fact, as I've been at RUSH for five years, a number of other people that I work with have added their disabilities to their email signature, and I love it every time I see it. I think over a dozen people have done that. I also added to my social media profiles.

And there was one little thing that came up, which, we're an academic medical center, a lot of people are dealing with health issues and health information and HIPAA. And there was an email thread that I got looped in on where someone who had their disability on their email signature, it was in an email thread, and someone said, "Oh no, that's protected health information. We can't share this email because that's protected health information." And I was like, "No, no, no. You can share that protected health information when it's your own information."

But again, I think I just really want to normalize disability in the workspace and disability visibility. And I've thought a lot about people that are either pregnant or have newly given birth, and things have really changed over the last number of decades where it used to be something you didn't talk about as much, you weren't open. If you had to pump in the workspace, you didn't necessarily have a space to do it, or it was something you just kind of kept hidden. And now there's lactation rooms, there's a lot more support for people, for nursing parents in the workspace, a lot more understanding of pregnancy issues in the workspace. And I want disability to be normalized like that. Because I do think that, again, it all supports retention and people staying and feeling like this is a place they can be themselves. They're not having to hide or juggle different stories.

SARAH NAPOLI:

Aida, I think your side of it is slightly different, because your focus is not retention and recruitment of disabled folks in the workplace. In fact, your focus isn't even disability justice and rights. Your work is gender justice and gender rights. And so I'm curious, how has disability inclusion shown up for you in the workplace, and how has it impacted workplace culture? And for you, how vital has affinity groups been for you in the workplace?

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AIDA AKIM-ESCRIVA:

Thank you. It's always so good to hear when Kevin expresses this amazing, big structures that he has built and is part of, and it makes me really excited towards the futures that we are going for. In the present, where I live in, we don't have those things at my organization. We do not even have the affinity group at the moment. We have been discussing it, but it's not something that happened yet. We are trying to go through the pros and cons of having an affinity group for people with disabilities.

And I think one thing that I wanted to say is, counter to what Kevin was saying in some ways, is that you don't owe anyone your diagnosis. You don't owe anybody an explanation of yourself. You don't owe that at all. And oftentimes, I feel like we tend to fall into this, especially on the days when we get sick, especially on the days when we get some kind of chronic pain, is really lots of guilt and lots of pressure to really be this person that you aren't. We do get, as somebody who has chronic pains, has flareups, it's just something that I really needed to learn to accept is that I don't owe that to anybody.

So if you would like to disclose your disabilities or even just come up, not necessarily being very detailed about it and just say, "I'm a person with disabilities" the way I'm doing right now, it's your choice. And for example, I am a person who's vocal about it, and I think it made a strong cultural change within my organization, but also generally within the philanthropy as people are seeing this conversation, because there is no gender justice without disability inclusion. There is no human rights without disability inclusion.

So disability goes through all of it, racial justice, whatever you can think of. Anything you want, philanthropy, disability will be part of it. And as people who are working in the spaces, we really need to start recognizing that it isn't only something for the other people that we are working with as philanthropists, but also for us inside of this. Big part of the... If you decide to disclose yourself as a person with a disability, it's incredible. There's tons of amazing positives around it, starting with really building that community around you.

Maybe it's informal, maybe it is in a way that is like, people will reach out to you for help. Maybe it is about really true allyship, maybe the support from your peers and your supervisors. The other thing in that to think about is that the intention with which you're coming into that disclosure, what is your goal? And really be clear with yourself before you embark on it. Because again, I think this will help you with your own boundaries.

Oftentimes with people in the workplace, once you disclose that you're a person with disability, if there's not specific things that Kevin has built, you will become the source, which means people will reach out to you for help, which means people will reach out to you who are non-disabled trying to understand what's going on, which means there will be a lot of different things that you might get involved in that you may not want to be part of, or you don't have capacity for it, or not interested in it.

And I'm somebody who's an educator, so I have welcomed that. But I also wanted to be very clear with that. What is your intention? And build your boundaries around it. You don't have to



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explain everybody what your disability or anyone's disabilities are. You don't have to become the HR person that deals with disability things, because you aren't. Maybe you are, but more likely than not, you aren't. So in terms of that, it's a really good space to build something, a really beautiful community. And there are also, as somebody who's co-chair for Celebrating Disability Across Philanthropy, there are other spaces in which you can exist as a professional and person with disabilities and really look for the accommodations and really think about it.

One other part of it is, we are so deeply internalizing ableism, that oftentimes when people talk to me, they ask, "Am I disabled enough? Is it something that I can..." Whether it is in the workspace, whether it is in the other spaces, they're like, "Can I even ask for this?" And so to me it's like, if you are asking this question, if whatever accommodation I requested to be available for everybody because I need it, and you are using that recommendation, yes, you are disabled enough.

But generally if you are asking the question, "Am I disabled enough?" Most likely than not, you are disabled enough. And so that means that there is a community behind you. And also, that means that you have accommodation you can reach out for. You might not even know what they are. Oftentimes I think people come to me, they also don't know what they can ask for. We have been such a long time in pain that we may not even recognize that there might be some other ways to help you, and this is where the community and other resources are really, really important.

SARAH NAPOLI:

One thing that you said, Aida, that I think is really important, and that I think the three of us can relate to, is the role of the educator. Because we sort of potentially put ourselves into that space or that role that we welcome. And I'm in that role every day in my role at the Forum, but also in my career for the last 25 years, I have been an educator. And so I don't mind. When people ask me very specific questions about disability, I don't mind, because that's something that I have put my hat on and I put myself in that role. But I think it's very important what you've relayed that you don't owe that explanation, or you don't have to be in that role. And we'll talk about that in a minute, especially because there is so much fear, stigma, and there's so much around that self-ID culture that we have to explore that isn't always safe for everyone.

And so I think that that's important to acknowledge, and it's not everybody's job to be in that space. I also wanted to shout out, thank you for shouting out CDAP, because it's important to have spaces, if you don't have that space in your own workplace, to have a place to go. And so we linked the Forum's resource group in the chat if you're interested.

Kevin, I know you mentioned this a little bit in your other statement about the importance of self-ID. And I know that you have your own amazing story about your journey of self-ID. I don't know how much you want to elaborate on that, but you talked a little bit about the importance of leadership self-IDing and the power of that, because also there's power in owning your own narrative. But when people in leadership roles self-ID, how much that sort of changes the culture of an organization, I was wondering if you can talk a little bit more about that.

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KEVIN IRVINE:

Yeah, sure. Absolutely. And yeah, just going back to my personal story. So I'm 54. I had HIV since the '80s, but when I was a kid in the '70s, I was just a kid with hemophilia. And it was kind of like I was out, I was open. There was certainly some stigma in terms of being different, but I didn't have that internalized ableism at that point. But then going through a combination of middle school and everything that happens there, and then HIV coming onto the scene in the '80s, definitely it changed things pretty radically.

So I went through a period of some years in high school and going into college where I kind of compartmentalized. And so there were people that, a small number of people that knew I had HIV and hemophilia, and most people did not. And I did not want to share that. And I was very worried about it. I was honestly probably more worried about dating than about employment discrimination or discrimination in school. I do have a lot of things that are privileged about me. So I definitely had a lot of advantages that not everyone has.

But when I got to in college, I decided... There was a class on HIV that was taught at my college, and that really gave me some of the tools I needed and the strength to come out. And so I came out when I was in college, wrote an article in the school paper coming out to the entire school all at once. My school was about 3,500 students, and it was liberating, and having this experience where I just kind of told my whole story to everyone, and everyone knew, I didn't have to have single one-on-one conversations. It was great. I did not want to go back.

So my first job I applied for after college, I had not planned about what I was going to do, but they said, "What are you most proud of?" in the job interview. And I thought about it, and I said, "Well, I think I'm most proud about living openly with HIV and hemophilia B," and came out, and they were a little bit surprised, but they weren't freaked out. They just said, "Oh, that wasn't exactly what we're expecting." But it was like, "That's not a problem." And so it really reinforced for me that people respond to what you put out there, and how you talk about your disability is as important as talking about it period.

And if you can talk about yourself and your story with confidence and self-assuredness, people feed off that. And then if you also talk about it with discomfort and make it clear it's not something you're comfortable talking about, people feed off that too. And that discomfort kind of sets that tone for how you interact with other people. So I think that's what I always tell people when they say, "Should I disclose or not?" I say, "Well, if you are going to disclose, really lean into it and talk about it, how it is a strength and how you manage, and how you know what you need to be successful.

But then again, people also need to see examples. And so that's why those of us that are in a position to disclose, to be open about it, I think a lot of us really should, because there's other people that may be in different stages of their careers. And again, if you don't want to do it, that's your choice. But I do think that it makes a big difference when people in leadership roles self-disclose. And when I got to RUSH, and working on discipline inclusion, we have a Diversity in Leadership Council, and it's about 18, 20 people, senior leaders from different departments in the university and the hospital and the clinics. And I'm looking at this diverse group of leaders



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and saying, "Okay, so where are the disabled people in this diverse group?" Because they were diverse in many, many different ways, but I did not see anyone who'd self-identified with a disability.

So I was presenting to this group during my first year and I said, "Well, one thing we really need to continue to grow on disability inclusion is for people in leadership roles with disabilities or chronic health conditions to self-disclose." And so during that meeting, one of the members of the council emailed me and said, "Hey Kevin, I've got multiple sclerosis, and some people on my team know, but most people don't know, and so I'd like to share that."

And so his name is Justin and he was one of our senior counsels and he came out, we took his photo and added it to our Careers page, and we used it to promote the next meeting of our Disabilities Employee Resource Group. And that led to a bunch more people coming out of the woodwork, including some people who also had MS. And it really set a great example and a great tone. And then when Justin moved onto another organization, I went to the leadership and I said, "Hey, we had one person who self-identified their disability on that council. We need to find someone else, so there's at least another one person on that group." I know there's more, but again, not everyone's ready to self-disclose, and not everyone sees the value in it, but I do think that there is a lot of value.

And I also think that when, for those of us with non-apparent disabilities, there is this issue of imposter syndrome, and "Can I own this term, 'disability?'" And I think that it is really important that there's a lot of people out there with noticeable disabilities who don't have the choice about whether or not to disclose, or whether or not to have that be part of their open identity. And so I think when you own the word "disability" publicly and in a very open way, you are making that connection between your experience and someone else's experience.

Maybe you've had very, very different experiences, but you're not keeping disability at arm's length, you're bringing disability in, and other people with disabilities in, and all the things that I see people do with, they say, "Oh, I don't want to use the word 'disability,'" or "It doesn't affect me that much," or all these qualifiers, is a way of keeping disability at arm's length. And I think that's a mistake. Because again, I think we're stronger when we're together. And I've also seen what happens when you do share your story is people connect to that and you find these connections that you didn't know existed.

I can share one more quick story. So when you go to the disabilities page on RUSH's Careers site, you'll see photos of a bunch of people. And it doesn't just have their first name, it has their full name, it has their full title, and also what their specific disability is, because again, I think the people respond to that specificity of connecting all these different chronic health conditions to the word "disability". We also did a video where we had some RUSH employees with different disabilities talking about their disability and how it affects them at work and the accommodations that they need to be successful.

So you're going to see Parul who's a nurse with low vision talking about the accommodations she has to do her nursing position, Cassandra, who's got PTSD and anxiety talking about the accommodations that she has to do her work, and then Carlos Olvera, who co-chairs RUSH's

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Americans with Disabilities Act Task Force with me, and he manages our interpreter services programs. And when I got to RUSH, Carlos had been on the ADA Task Force for years, because one of his roles is getting interpreters, in both spoken language but also sign language interpreters.

And so Carlos comes to me and says, "Hey, listen, I've got rheumatoid arthritis and I have an adapted keyboard and an adapted screen that I got when it was affecting my jaw and my hands." He was like, "Do you think I have a disability?" And I was like, "Yeah, I think you do." And again, he'd had rheumatoid arthritis for a few years, and had actual accommodations that he'd procured to do his job, but he hadn't gone through the accommodation request process, and he hadn't owned the word "disability" before then.

But then he did, and he shared his story. And when we showed that video a couple months later, there was a person that was also on the ADA task force that I had figured was probably a person with a disability based on how they moved. And after we showed the video, that person said to Carlos, "Hey, I've got rheumatoid arthritis too." And so there were two people on the same disability focus committee with the same disability. And until Carlos shared his story, neither one knew that the other had the same condition. And so that connection was there, and once Carlos shared his story, it rose to the surface, and that made a big difference.

SARAH NAPOLI:

Thank you for sharing all that, Kevin. I don't know if you saw Jenny's comment in the chat about how it is sometimes, I think, hard for people with non-apparent disabilities to name it, because they're not sure how they fit into this narrative.

KEVIN IRVINE:

On that question, I just want to say I think that being open about your disability identity, I describe it as a muscle that everyone has, but that is atrophied. And it's there, but it is hard to use it at first. And the more you use it, the easier it gets. I mean, I'm here, I've been doing this for, and I've been out since really 1990, so that muscle's strong. But when you're first starting, that's okay.

But again, the more you do it, really, the easier it gets. And I think every time you share your story, you find those connections, and that reinforces the value of it. And ultimately I think that we need to have positive experiences with disability identification to build up that muscle and to push away and suppress some of those negative stories we're telling ourselves, but the things that might happen.

SARAH NAPOLI:

Well, I think it's also connections with the disability community, which is something that I know working with Aida with CDAP has been super powerful for me. I mean, I've identified as chronically sick since the '90s. I haven't used the terminology of disability, I think, since the early 2000s, but I didn't understand it. And I think that's also part of the thing. How we define disability

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is such a fluid, and people within this community have such different ways of defining the same thing.

And so Aida, a question for you and also to the audience. We're going to move into our more Q&A type land in the next five minutes or so. But Aida, I'm curious, because Kevin's coming from a space where there's a lot of support and built-in support for disability inclusion. And I'm curious, in your experience as someone who's not, doesn't have that sort of built-in... When I was working, I work in spaces where I was that person as well. I was the disability inclusion person. But that's not you, right? But you're sort of this de facto person in that space. How difficult can it be to self-ID, and what are some ways to improve workplace culture to sort of alleviate that burden of self-ID? And what has been your experience in how difficult that experience can be for people?

AIDA AKIM-ESCRIVA:

Well, first of all, as much as I like the idea of self-ID, I work in human rights, and the reality is our structures are built within the capitalism and patriarchy, and all of this is dangerous. And as we are seeing many of our rights being rolled back in the past few years, this is where I have a big, big concern when it comes to self-ID. First of all, the discrimination in the workplace and biases against people with disabilities, they exist. They are not going anywhere. It's something that we need to work with.

So at the moment you ID, you might become that person that, I don't know to what level is a person with disability can handle that in the moment, right? At different stages of your life, you might be a little too sick to deal with that. And the other part of that is privacy. Sharing disability is a privacy concern, to what level you want to share that. The information being so easily spread, the coverage and premiums when it comes to insurances might be affected with you talking about disability, with you being disclosed with that. And so there's certain levels of legal protections that we currently are afforded by ADA, but there's only so much, and it's limited.

And again, we see things being rolled back. It's not the guarantee that they will stay here within the next 15, 20 years. Hopefully that's not the case. But seeing the trends, it would be wrong of me not to mention that. So I think this is kind of the all to say that it is difficult to self-ID, because there's just so many different risks depending on your position. And as somebody who started ID in the more junior level positions, you are at the mercy of your supervisors who may not necessarily be understanding, or want to understand in that moment.

And this is where it comes to the level of, I really enjoy the idea of a spoon theory for people with disabilities, that we have only so many spoons a day, and the question is where you're willing to spend it. Once you self-ID, you might need to dedicate that extra spoon for explaining to your supervisor and colleagues what it means to have a disability in your specific context, versus that spoon may be used for something that brings you joy or anything else in this lifetime, genuinely. So the question is, where is your boundaries and to what level you would like to share that.

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And so this is the hard part of it. I think what would make it a lot easier for people to self-ID, or not necessarily even need to self-ID to that level, is the recommendations that are already built-in within a lot of the spaces. One of the biggest things that my current organization does really well is flexible work hours, and being able to rely on that, being able to decide when you work and when you can't, and it's not necessarily being the limitations. Or some organizations, there are very, very few of them in the United States, but they offer unlimited sick leave time, and things like that that we really need to consider around how to make everybody's life easier.

Yes, remote work is good for people with disabilities, but it's also good for a lot of other people who are not necessarily having the most apparent disabilities in this moment. And the things to remember is we are designing this different ways to accommodate the whole organization, is that the more we do this type of policies that are applied to all and not something that you need to request, that even if you have a disability and you are not aware of it, then you already cater to it. Amazing, considering how long it takes for a woman of color to get diagnosed with anything.

Sometimes complex diagnosis takes seven, eight years, and you might not know, not at the moment, but those recommendations that are already in the workplace built for everybody really make a big difference. And I think this is my biggest call is that flexible hours, remote work, fair pay, unlimited sick hours, really takes that into account. There's also, for example, there are sick bank hours. Sometimes people who don't get sick that often, they offer their hours towards people who get sick, but depending on the policies, it might be challenged to get there because oftentimes they're like, "You are not allowed to access sick bank hours until you use up all of your paid time off." And that is an issue as well, because then, well, people with disabilities do not deserve paid time off? And that is also, we deserve rest. Even when we get sick, we still deserve rest that is not necessarily connected to us being sick.

So really working, I think, with your management, with your HR, with your whole organization to build those things that you don't have to ask for, and making them as a part of your normal culture. Because also disability is something that's not necessarily always there. I'm somebody who has a disability since I was six years old, but there's some other things that happened within my chronic illness journeys that at times I'm way more sick than other times. And I know people who are around me who are healthy that come in and out and have disabilities. So this is not necessarily an accommodation for just that moment. It's for your lifetime, even if you don't have any disabilities, or your disabilities might change over time. So really thinking about it in a holistic way is a cultural accommodation to us as human beings. Really helpful.

KEVIN IRVINE:

Yeah, and just piggybacking on that, Aida, I'd love to see all these things be considered part of universal design. We're going to universally design our workspaces to be accessible and inclusive. And a great example that I learned about a while back was UCSF, University of California, San Francisco Health System out there, for a while, for a long time they were providing ergonomic furniture to employees on request. And then at a certain point they realized, they recognized, "Well, we all have different body sizes, body types and different

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needs." And so now they just provide ergonomic furniture to everyone that is adjustable to their specific bodies and what they need.

And again, it takes something that went to be this specialty thing that you had to get, had to stick your neck out for, to just being something that everyone has, and it benefits everyone. And I think flexible policies, flexible workspaces, all those things are incredible. And I have to say, if you're a manager, don't you want your employees to have what they need to be successful? And if you have a disability, it could be something very specific to that. But again, we all need different things to work well, and giving your employees the tools they need to do their best work is, it's just good business.

AIDA AKIM-ESCRIVA:

Yeah, I 100% agree with that. And I think that Emily Ladau says that in her book at some point, and I really love that moment where it's like, when we talk about disabilities, we are like, "Oh, this is a person who needs an access for this specific thing or cannot do this specific thing." Oftentimes it comes from this deficit moment, but realistically, it's like, not every healthy person is an athlete.

Not every person who does not have a chronic illness can do all the things mentally that some other person who doesn't have chronic illness can not do as well. So this idea of it being disability accommodation only for people who have this specific diagnosis, rather than we all are very different and we all have different needs, and we cannot ever equate to each other, and treat each other regardless in every situation with respect and give each other support is so necessary.

SARAH NAPOLI:

Well, for me, it's this idea that accommodations are special, right? Accommodations are for everyone. Everyone needs accommodations to do their work effectively. Every single person has had a request for a keyboard or a mouse or a certain kind of chair or a footrest or- these are all "accommodations," right? And so when I asked for captions on my first day of work, because we were an international global company and we had international video calls all the time, this was before COVID and there were no captions. And I was like, "How do you not have captions? You're an international organization that does video calls all the time, and I'm the first person that has asked for captions? I find this wild." I just could not understand.

Because if you think about it now, the idea that a piece of software doesn't have captions... And it took them six months to get the captions for that piece of software. And now the idea of not having captions in a video platform is just something you couldn't even understand, right? Because now even just- Gen Z and everyone's using captions, right? This is just par for the course now. Everyone's using captions now. So it's this idea that these accommodations are just completely normalized. Some of these are just, will be used.

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Does anyone have questions? Olivia, I saw that you had... Does anyone have their hands up for questions? And we can keep talking, of course, but I would love to... Oh, Emily has a question. Emily, did you want to ask it or should I just read your question? Oh, go ahead Emily. I see.

EMILY HARRIS:

Always happy to ask, and hope I will inspire others to do the same. I'm just listening to Aida talk about workplace flexibility as one of the key accommodations, and I'm wondering what you're seeing as employers are pushing people back into the office. It was this incredible moment of universal flexibility that happened during the lockdown, and we worked remotely, so we're able to continue to be flexible, but many people are really insisting on going back and being pushed back increasingly. And I'm wondering if you feel like those lessons were learned and it's easier in the workplaces that you're aware of, and whether you're seeing any employers who are doing it well.

AIDA AKIM-ESCRIVA:

I think the workplace, I definitely have seen that quite a bit, people searching for different ways of being in person a lot more. And part of it is definitely extremely negative of that you have to be involved and you don't have any other choice. And part of it I've seen is more connected to people wanting to have that in-person connection and really building the relationship. So the issue that I'm seeing is around the mandatory return to the office, and people are really forced to leave those jobs and not being able to stay.

And I think this goes to the beginning of our conversation, about the retention rate. Retention rate, I think, is a problem, and also recruiting people who have disabilities, but then the moment you change these policies, it's not something that is doable. But other thing that I'm seeing is that then the people really are having difficulties with seeing themselves in the future within those spaces.

There is this sort of moral dread of what my next 15 years are going to look like if my health will continue to decline, and I will not have the support of this organization to accommodate me, as well as, there's no government support to accommodate me as well. It's this almost inevitable moment of, "Do I end up being a person in poverty?" And with that comes a whole other piece of it, of incarceration rates and so on and so on. So there's just the increased risk of these policies changing and becoming more difficult for people to stay in the position that they need to be remote and flexible hours is really disheartening.

I think I would like to add to that also, around the part of the travel, some of the work requires travel, and during the COVID, people have become a lot more aware of how traveling can be impactful to your health. And as we are, I don't know, somehow post-COVID era, which it isn't, but a lot of people are referring to it that way, is this requirement for a lot of jobs in terms of travel, but also not necessarily providing the accommodations for travel to make sure you are safe as possible or the place that you arrive is safe as possible, as well as safe hours around the fact that if you are taking on the travel, you might come back home with something that you will need to recover from because neither your travel in the airplane or the conference that you



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went to are safe. And putting people into these moments of like, "Well, I no longer have sick hours, but I'm sick because I had to travel."

Yeah, and people's conference COVID policies are all over the place. There's no standard practice, I feel like, after attending several conferences this year. We have one question in the chat, and then I think it sort of flows nicely into our last comment on moving philanthropy to act, like what are some sort of tips that we wanted to leave people with?

But Vanessa had put, "What advice you have for a new disability advocacy employee resource group at a foundation? What comes to mind as a top priority?" And I know that we had talked about that a little bit about affinity groups and such, so maybe we can weave that into our final thoughts on moving philanthropy to act on this. So Kevin, did you want to kick it off?

KEVIN IRVINE:

Absolutely. Yeah, so I have some thoughts about this from a variety of different perspectives, but we started our Disabilities Employee Resource Group at RUSH at the beginning of 2019. And again, we started it by showcasing, the first month before we had our first meeting, each week, we would showcase a different employee with a disability in our intranet site. And so that would definitely, it led to a pretty robust turnout for our first meeting, which we also offered lunch, which made a big difference. This was pre-pandemic. Now all of our meetings are virtual.

But one thing I was really gratified to see was that the majority of people that were involved with our Disabilities Employee Resource Group were people who self-identify with different disabilities and chronic health conditions. I have known from other people in other organizations that what can happen with some of these disability-focused ERGs or BRGs is that parents of kids with disabilities can get really actively involved.

And I understand that. I'm a dad. I've got a 17-year-old non-binary daughter with physical, mental and developmental disabilities. And my daughter's doing great, a senior in high school, has had a ton of surgeries, and actually I was a stay-at-home dad for 12 years before coming to RUSH five years ago, because of D, and my daughter had a bunch of surgeries and therapies. So I definitely have experience as a parent of a kid with disabilities, but I also recognize that my experience as a parent of a child with disabilities is very different than my experience as a person who's grown up with and also acquired a disability, and that there's definitely some overlap and some shared concerns, but also shared different perspectives. And so I would not want a group of people that are primarily parents of kids with disabilities to be seen as representing people with disabilities overall.

And so actually, we've had some people that have gotten involved with our ERG that identified more as caregivers, whether it's parents or for older family members. And we realized recently that we really need to have a standalone ERG just for caregivers, because there were people that were not really engaging with our group as much when it was really focused on those of us with disabilities, but when we had a separate meeting specifically to focus on caregivers, a

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bunch of different people came to that meeting. So now we're in the process of starting a separate ERG specifically for caregivers, because again, I think people are going to connect to that who won't necessarily connect to the people with disability space. So I think that's one thing to think about.

Our ERG, one of the things that we did early on, which I thought worked really well was, one of the people that came to our first meeting said, "I would like for people at RUSH to know more about how to make events and meetings and town halls inclusive and accessible." So one of the early things we did our first year was we had someone come in from the Great Lakes ADA Center, and she gave a fantastic presentation on all the different things you need to do to make events accessible, whether they're in-person or virtual.

And we had about 75 people show up in person, and then another couple hundred people participated through a webinar. And that was a great activity and something that I think was very helpful, and we also amplified the impact of that by having our communications folks do a writeup about the presentation, which we then shared on our intranet site a month or two later.

We've also had some webinars where those of us with non-apparent disabilities have shared our stories. We've had webinars on mental health awareness and resources. So both people with lived experience with mental health conditions, sharing their stories, but also talking about all the resources that are available for employees at RUSH. So those are just some examples of things we've done. We've got these T-shirts. We have a Disability Pride Parade in Chicago. We've had an annual Disability Pride Parade every July since 2004.

SARAH NAPOLI:

Yeah, Chicago has got it going on.

KEVIN IRVINE:

So RUSH has a contingent that walks in the parade every year, and we got these T-shirts for our parade contingent this year. And then we also have, I'm going to turn off my camera for a second so you can see, we got lapel pins, say "RUSH Disability Inclusion". They've got our logo, and ordered a few thousand of those in our first year, so people can... Because I want to normalize disability in the workspace, and I think getting the word "disability" and the face of disability in as many different places as possible is key to doing that. And so when you talk about new ERG, there's a lot of great resources out there about different ways that you can increase the visibility for people with disabilities in your workspace, but I think the ERG is a great place to start in getting people to brainstorm.

SARAH NAPOLI:

Aida, I'm going to give you the last minute, and then I have 30 seconds worth of closing to do, but Aida, please, I'll give you the last minute.

AIDA AKIM-ESCRIVA:

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Thank you. Yeah, in terms of what to do, I think I generally believe that really building the community, whether it's a formalized ERG or non-formal place where people will come together and really share with each other what's going on. The other part of that is education. I think it's really important. There's lots of fear around the word "disability". Most importantly, people are really afraid to say it and mess up.

And so it's very helpful to just give, I write simple, short things for people like, "Well, this is what you can say, and it's totally okay." And the other part of this is really showing that we all make mistakes and it's okay, and we'll survive it, and it's humorous and you'll not be punished forever for it. As long as people approach it with a sense of learning, I think we have a lot of opportunities to really build that skill. As Kevin was saying before, it's a muscle, it's similar muscle in terms of others too, how to speak about disability, how to work with disability. And if there's nobody who's talking to them about it, they will not be able to learn.

SARAH NAPOLI:

Well, thank you so much, Kevin, Aida. This was really rich. We obviously could probably spend a whole other day talking about this. I want to let you know you're going to get a short survey following this conversation. The link's going to also be in the chats. I also want to let you know we have our last public webinar of the year coming up on December 7th, talking about disability and long COVID, and we also have our 2024 series on the horizon.

And not only do we have public webinars coming up, but we're also going to have an entirely new model for our member series. Instead of member webinars, we're going to have member training. And so we're going to have a whole different model in the coming year where we're going to have a two-hour member session training that you can sign up for, along with public webinars. So stay tuned for that.

And with that, we'll see you soon. Thank you for joining us today.