

Yes. OK, thank you, everyone. Can I get a sound check from Debbie, who's our live transcriber? Can you hear us?

I can hear you. Thank you.

OK, thank you, Debbie. Yes, welcome everyone to the second of our five events as part of the disability in planning speaker series. We are live-streaming the event, so I am putting a live transcription document in the chat. Please, use that to follow along. So we have a live transcriber captioner on the call. She'll be typing as we're all speaking. So please, refer to the stream text link if you need that. And I'll hand off to Natasha to open us up. Thank you.

Thanks for joining us today. My name is Natasha Ansari, and I'm a first-year planning student. This is a student-led initiative that emerged as a result of noticing a glaring gap in planning discourses about disability.

Given that this social justice issue is more spatially connected to the built environment, and given this moment in time in the midst of aftermath of the global pandemic, we thought it was urgent for these overdue conversations to take place, especially at this institution.

We started out as an independent study this semester with a group of students from the Masters and PhD program. That's when we realized there was a heavy interest in listening. And so thought the speaker series would be an important first step in taking this initiative meaningfully forward. This is the second of five events that continue weekly for the rest of the semester, every Friday from 12:30 to 1:30 PM.

Some other goals for this initiative include developing teaching modules and tools on disability, potentially setting up a course at the department on disability and planning, and implementing new research agendas here with disability in mind. With that, I would like to hand it back to my co-organizer and [INAUDIBLE] to introduce us today.

Thank you. It is my pleasure to introduce our speaker, Professor Michael Stein, co-founder and executive director of the Harvard Law School project on disability and a visiting professor at Harvard Law School since 2005. Dr. Stein is one of the world's leading experts on disability law and policy.

He participated in the drafting of the UN Convention on the Rights of Persons with Disabilities, worked with disabled people's organizations and NGOs around the world, actively consults with governments on the disability laws and policies, advises an array of UN bodies and national human rights institutions, and has brought landmark disability rights litigation globally.

Professor Stein is the recipient of numerous awards and has contributed over 220 publications and nine edited volumes published worldwide. Dr. Stein earned a JD from Harvard Law School where he became the first known person with a disability to be a member of the *Harvard Law Review*, and a PhD from Cambridge University. Thank you for joining us.

We'd also like to thank Professor Chris Zegras, Professor of Mobility and Urban Planning and our department head for the Department of Urban Studies and Planning at MIT for facilitating today's conversation.

[APPLAUSE]

Thanks. I will only say a couple of words, mostly, first of all, I want to congratulate the students for organizing this, filling a glaring need, and doing it in such a inclusive and compelling way. I would be remiss to not call out Natasha specifically. I'm sorry to call you out, but I remember the day you came to me early last semester saying we need this. And as epitomizes the MIT student, she did it.

And also, I really want to thank all of the students who've been involved, everyone else involved, especially the faculty, Delhi and Mariana who have been playing the necessary role as faculty conveners. I won't say anything else except to talk about how we're going to try to run today. About 20 minutes from Professor Stein. Then we'll open up for Q&A. And we have until--

1:30.

1:30. So without any further ado, Professor.

Thank you for this. And it's wonderful to be here. It's my first time actually at MIT. Although I've lived up the street for 18 years. And hopefully, not the last for the next 18 years. And congratulations to all of you for coming together and doing this really wonderful initiative. Congratulations to Natasha. Thank you.

I had the pleasure of having Natasha in my HKS class on disability on policy, and she's been inspiring and also inspired. And I hope she continues to move forward. And I hope that I can help support you in future.

I was asked to talk about disability and international development. And by development you mean the other side of the coin of human rights. Although, for those who are roughly my age and younger, we see the two of them as inextricably linked and don't view the old days of US on one side and Russia and China and the other side. It's either one type of right or the other.

But when we talk about development, we're talking about the ways in which large financial institutions, like the World Bank, the Asian Development Bank, the European Development Bank, and bilateral and multilateral donors, such as USAID, DFID from UK, FINAID, AUSAID, European Union's Aid, which is the largest donor organization in the world, and so on.

Try to work towards alleviating poverty, increasing economic development, improving the lives of, as they call it, vulnerable and marginalized populations around the world. So to give you a sense for that, it ranges for everything from building banks in Nigeria to creating a dam in Bolivia to creating employment policies in the Pacific Islands to HIV and AIDS awareness and alleviation efforts in the Americas. So it can cover all those things in different ways.

Note that, when we describe them, much of those actually sound very much like human rights endeavors. They're just looked at from a different side of view. They're considered more of a not changing the law and changing the way that legal institutions and policies work, but rather providing the physical means by which societies are improved and increased.

And the history of disability and development is actually one of exclusion. So the idea that everyone benefits from, when in the high tide all boats rise and everyone benefits, is a great idea, except for if you're part of the population, either the really, really poor, or persons with disabilities, who very often are disproportionately represented in the really, really poor. They stay at the same place.

So if we don't include them, everyone else does better, which is good and laudable. But the equity gap, the equality difference increases, and that's not good.

So in the history of disability and development, if we were to start, say, at the year 2000, we would look and see that the largest endeavor in the world were the Millennium Development Goals, which ran from 2000 to 2015. They were eight goals, and each of them related to disability, but not a single one had the D word in it. And none of the targets and none of the indicators had the D word in it either.

So try to pull your hair if you like. At that time, they said that, of the persons who were living below the dollar-a-day level of global poverty, 20% were individuals with disabilities. And yet disability didn't appear in any of the programs. Kind of an oversight, right?

They said that children in K to 12 range, as we would put it, who are not in school numbered seven million around the world, and that one third of those were children with disabilities, but the D word did not appear there. HIV/AIDS is another issue where people with disabilities thought to be asexual or uninterested, also excluded from it. And yet, the empirical data suggests that the population participation is of a level and should have been there.

And so the UN was going about just doing development work without including people with disabilities. And they were cautioned at the time. So Nobel Prize winner, Amartya Sen up off the street, then President of the World Bank, James Wolfensohn-- may he rest in peace, wonderful man-- actually made public statements that the MDGs will fail unless we include people with disabilities.

Well, the MDGs did fail. They did not fail solely because people with disabilities weren't included. There was a 2008 financial turn that the globe experienced, precipitated by lending and other very bad practices here in the US, and elsewhere. But the MDGs didn't work.

Their successors, the sustainable development goals, which are part of the UN's 2030 agenda running from 2015 to 2030, are a very different story. Disability is featured 17 times, both seven particular mentions, and especially in SDG four, which is about education. And they're also included among vulnerable populations in other parts of the SDGs.

So just giving you a big overview from UN programming, what we've seen is the shift from total exclusion, not looking at it. And if you speak to economists, they'll tell you the old phrase, you're not counted unless you are counted. So unless we have the data about you, unless we include you, you're not there-- to a world in which disability is expected to be included.

Although, again, it's not as complete and as inclusive as we might like. It would be nice if vulnerable populations were spelled out across the board. It would be nice if we had more disaggregation of data to segregation of identity statuses. But disability is considered part and expected to be part of the programming. And there's this whole world going on at the moment of data collection and data entrepreneurial shit that we can discuss.

To put this into a different context, let's point a finger at USAID, US Agency for International Development, because it's always better to be polite and point to oneself and one's own country rather than point the finger abroad.

So in 1997, USAID came out with a white paper policy that said, we're going to include disability in our development endeavors. When we give money to build dams in Botswana, when we have employment programs here, when we have clean water and sanitation programs in Nigeria, and so on. But it's not an enforceable policy.

So here you are in the US where the Rehabilitation Act was passed in 1973, '74, and it states that any recipient of federal money cannot discriminate, i.e. exclude persons with disabilities. And yet, the US State Department has always taken the position that the Rehabilitation Act and other civil rights acts are not extraterritorial. They don't necessarily apply outside the physical boundaries of the United States.

Many international law experts, including myself, think that that's wrong. And on a political or moral basis, we also think that it's obnoxious. If disability inclusion is such a great idea that we do for our own citizens, why on Earth would you not want to do it for the rest of the citizens of the world that we're trying to help?

And if we look at it from an international relations perspective, being a good global partner and part of a society means that you share good practices. You share good endeavors, and you support others the way that you would want your own citizens supported.

Americans with Disabilities Act 1990, again, it's not recipients of federal money-- although some of the entities that are covered are recipients of federal money-- but the idea of nondiscrimination.

And then in 2004, Senator Tom Harkin of Iowa, who is one of the co-sponsors of the ADA and probably the best disability supporter that we've ever had at the US Senate, issued a decree to basically a senatorial decree attached with funding to USAID and said, you need to become disability inclusive. This is ridiculous. We do it for our own citizens. We do it because we say it's the right thing to do. Why aren't we doing the right thing outside our boundaries?

And I was with them at the Library of Congress on the day that they released it into the [INAUDIBLE]. Well, we're in 2022 right now. USAID has yet to make disability inclusion a mandate. We have not ratified the Convention on the Rights of Persons with Disabilities, whose negotiations I participated in and which I have implemented in 40-something countries. We haven't done that, which would bind us to do it.

And USAID is now reviewing their disability policy, reviewing. And they've taken comments from the outside, including from experts like myself. We've had to post them in public. The person who is leading USAID's disability sector is very old friend and is very much in favor of pushing it.

But it's a bureaucracy, and it's entrenched. And if you read about the sociology of large corporate institutions where the USAID or the World Bank or another, they're very slow to change unless there is a mandate, a mandatory one.

So I've given them comments, and of course, it's been wink, wink, nudge, nudge because they knew exactly what I was going to say. And they're trying to use that leverage on the inside. But in 2022, USAID is still at about maybe 2 and 1/2% disability inclusive. So those \$50 million that go to the Congo to up their education system does not have to include children with disabilities.

There is within the RFP's, the call for proposals and scoring sheets, numbers where you can check disability inclusion, do the absolute minimum things, such as get window dressing, local DPO, a person's organization that will enforce a module or pilot project. This is all window dressing. And you get a little tick points for it. You can put in for reasonable accommodation funds in order to support some of this work. But there's not the mandatory inclusion of it.

And if you really want to get techno geek with me, if you look at the foreign service indicators, which is how you apprise grants and their implementation, you'll see that some of them are the inclusion of persons with disabilities. Some have to do with civil society groups, et cetera.

But a \$50 million grant that goes out to the Congo is going to go to one, possibly a second, large international development firm that exists down outside the DC belt. So it's going to be harmonics, or it's going to be Learning USA because they're the only ones who can handle \$50 million and it's implementation.

So do they really care about including a disability module? No. Do they include it? No. The USAID also has a encouraged internal training session on disability, and I've given some of those training sessions. And usually, it's myself, the person who's organizing it, and maybe two people. And so I've stopped doing those because I don't find them very useful.

And let me put it even more concretely with two classic stories. One is USAID goes down to Jamaica to work targeting, right, targeting to work with the deaf community. And they bring an ASL translate, American Sign Language. Only one problem.

They sign in Jamaican

Right. ASL and Jamaican sign language are not the same. It's not the cool thing of Braille where, no matter what language you speak otherwise, you can all read in Braille and communicate with each other. It's not a universal translator. It's not Ladino. It's not Esperanto. It's nothing like that. So they couldn't communicate.

Another one, which actually aggrieved me a lot, was USAID doing an employment training program in the West Bank. And they were training and hiring tour guides in Bethlehem to take tourists around the various Holy sites. And they had something like seven slots for-- plus a supervisor, plus et cetera.

And someone that I know for a bunch of years was named Hamdan, who's opposed polio, Israeli Arabs with disabilities, applied for, and they said, well, sorry, you're not qualified. And he said, well, why? And they said, well, because-- he said, my English is very good. Why am I not qualified?

They said, well, because you get around on crutches. And he said, well, yes, but I get around on crutches now as a private tour guide and I never make fun of the fat, slow Americans who can't follow me up and down the stairs and into all these Holy sites. So why am I not qualified? And they said, well, you're not qualified because you have a disability. And they wouldn't let him be a supervisor. They wouldn't let him be a trainer. He was excluded totally.

That's an extreme case, but it tells you what goes on on the ground. Most of the time, it's just not thinking about it. So most of the time it's we're going to do women's sexual reproductive health. And so, why think about women with disabilities because they're supposed to be asexual.

It's supposed to be not an area that is of interest or relation to them. And why think about outreach to the group, and so on and so forth. And I can give you numbers on the number of mammogram machines that are accessible, not only in the world, but also even here within our backyard.

So that's been the thought about how disability has been historically been treated. There was the UN Convention on the Rights of Persons with Disabilities, which I've been working on pretty much full time for the last 20-something years. And it has changed everything, not as rapidly as we would like, but in the right direction [INAUDIBLE].

So during the negotiations, the European Union, actually, the largest donor organization in the world, said you know what? We should be doing only disability inclusive development. We should be including these groups. And any time that we pass around money, whether it's a donation or loan or et cetera. And they agreed to do that. And therefore, in this treaty, there is the first article of any UN Human Rights Treaty that relates to development. It's Article 32, International Cooperation.

It says that any time money is being transferred, any time that technology is being shared, any time that best practices access to scientific information, and so on, it has to be not only inclusive of persons with disabilities, but it has to be done in consultation with them and response to their needs.

This has changed things. I mentioned to you, but AUSAID from Australia immediately went into high gear and has changed their development practices. So now it's not the [INAUDIBLE] and the large organizations that are applying for these block funding. Instead, it is persons with disabilities and the representative organizations who, if they want to reach out to an academic like your professor, to support them.

Or if they want to reach out to a large international development firm to be able to coordinate and get the work done, will do so. But the dynamic is upside down now. Start with the targeted stakeholders to figure out what support they need, and they stay at the top of the pyramid rather than being the window dressing at the bottom of the pyramid.

Other states have followed suit. DFID, even though they went through their economic cuts, made great commitments to people with disabilities. USAID, we're still a work in progress. And most of all, the best thing that we've seen has been the World Bank. So let's stop for a minute and think about the World Bank and its history.

The World Bank, if you're old enough to recall this, during the apartheid South Africa, when the UN General Assembly sanctioning South Africa, the World Bank said, OK, but we're just a bank. We're just a bank. I know the rest of the states here can't give money, but we're just a bank, and we've got loan agreements.

Well, you know what? PS, you are just a bank, although you're a hell of a bank, but you're also a UN specialized agency. You are part of the UN whether you admit it or not. It's in their charter. You are required to abide by UN mandates. You're required to abide by UN Human Rights treaties.

And it was over a period of years where one of our [INAUDIBLE] became general counsel for the World Bank that they started to push the human rights agenda in the sense of creating these safeguard protections. But they didn't include disability.

So if it was a matter of race, Indigenous status, women, and the environment that before any project that came through the bank had to be assessed, were they doing harm to these groups? Were they including these groups, which is not to say that that nearly \$200 billion a year is doing it as well as it can do it. But there's at least a consciousness and a mandate to review things. Disability was not part of it.

During the CRPD negotiations, we talked about this. And the World Bank, again, was not committing to it. But fortunately, the representative of the World Bank at that time and at the UN was Judy Heumann. So mother of the American Disability Rights Movement, Independent Living Movement, very, very old friend, person from Brooklyn, so she had chutzpah-- actually talked about how we had to include the World Bank.

And then another old friend, Charlotte McClain-Nhlapo's background is human rights commissioner of South Africa. At one point was Obama's point person USAID on disability. She is now taking over the World Bank. And over the last six years or so, we've all worked together, even under the shadow of the orange monster, to get the World Bank to move towards including disability in these environmental statements and have committed to it.

So they've got deadlines that, to me, are a little bit too far out there. It's 2030, which aligns with the sustainable development goals. Although some of the earlier ones are before that, they've got 10 commitments on including disability. What does it mean?

It means that, in the same way that the best thing for the Americans with Disabilities Act has not been the non-discrimination provisions. The disability-related employment rate has not moved one tick, not only since ADA, 1990, but since roughly 1924 because we do not commit to policy initiatives that get people with disabilities in the workplace.

However, however, under Title II, which is very relevant to MIT, and under Title III, the built environment and access to goods and services, we have seen a dramatic, dramatic difference. If you don't believe me, you can look at the National Council on Disability Surveys, some of which I was on their blue ribbon panels and assessing. And just the idea that a person with a disability can go to the public library on accessible transportation, have access to alternative formats in books and other materials, be given support while there, can go to the movies, attend restaurants, go to the theater, and so on and so forth.

Not perfect, but the expectation is now that this is part of our world. Everyone should be able to go everywhere. Of course, we have lots of challenges on other areas, and we're still working on this. But that expectation has changed.

And so, even in my lifetime growing up without an ADA, right, having to call ahead to places because there's telephones attached to the wall, that sort of thing, and ask them do you have handicapped access? And people have no idea what that meant, right?

Or going to a hotel, is your door wider than 32 inches so I can actually use your bathroom because, otherwise, it's going to be a very uncomfortable stay, right? That has gone to the point of we expect that, at least in largely urban areas. And in other places, public transportation is accessible. Public buildings are accessible. Places of goods and services, if they're not directly accessible, at least use alternative means.

This is what's going to carry over from the World Bank. Close to \$200 billion a year in loans or semi loans, and each of those countries has to go through an assessment of how are you including people with disabilities? Perfect? No. Lots of gaps? Yes. But in my opinion, this is what's driving the difference as we move forward.

But I think I've spoken enough, Professor [INAUDIBLE]. And maybe we can dialogue.

Sure. Yeah. Thank you.

[APPLAUSE]

So I understand that people on Zoom can post questions. Correct?

Yes.

And you'll let us know those?

Yeah.

I'll start with a question but then open it up. First of all, just thank you for such a comprehensive overview, and a huge number of questions. But I just wanted to start with one and bring it probably too close to home.

But I was very interested in your point on the need for data disaggregation, collection, and if I heard you right, entrepreneurship, with respect to understanding the phenomena enough, being able to find innovative ways to confront it or confront the challenges of a universal accessibility.

And I'm wondering if you could reflect a bit on that from-- or challenge, I guess, us, as academics, in how we can bring our abilities to bear. So we have a new College of Computing, and we're trying to bring computing into the relevant realms of practice, including urban planning, urban studies, urban action and design. Could you give us some thoughts on how we should be grasping this ability, broadly defined computation, to bring to bear to push forward universal accessibility?

Sure, well, if we're doing the university talk, and we have to give a shout out to Mary Ziegler and her colleagues, as well as Judy Brewers down the street, right, and others that you have really nearby, and are wonderful.

Universities, as Paul Harper and I have written, are places that can set the example for inclusion of persons with disabilities and for increasing their prospects because we always say employment, education, employment. OK, but education towards what and employment as what?

And universities have been rather slow off the mark. There are-- we're going to talk about Australia for a minute because it's [INAUDIBLE]. There are good practices, like Australia, where the eight national funded universities and the 39 total universities are all part of a scheme that have to develop disability action plans and how you make campuses, classrooms, learning, teaching, and so on, accessible to, inclusive of persons with disabilities.

And even then I would argue-- and Paul, I think, would agree-- they don't go far enough because it's still in that compliance pain-in-the-rear, oh, we've got to do it kind of mode rather than wait a second. We can actually encourage this really great cohort of individuals. Some of them will be great. Some of them will not be. But this really great under tapped population to come.

The same way that universities have, over the last two decades now, started to think about first gen. And they've altered their financial structures to encourage first gen, and they've decreased their legacy reliance and admissions. So they've done it. We don't want to say too much about race based and gender based because the Supreme Court is about to slaughter us all on it.

But since *Bakke*, right, over at least 30, 40 years, we have seen an effort among many, not all, not enough, universities to try to increase diversity. So the first one is, how do you increase the number of persons with disabilities, types of disabilities, et cetera?

Part of it is doing the compliance and the inclusion. And that means having a master plan on how to do it. And that goes beyond the old ADA or we have that easy-to-modify list, which is what they're required to come up with.

Easy-to-modify is great. What about the difficult-to-modify? And what about the attitudinal ideas of can blind people actually do x? Can people in wheelchairs actually do this? And the answer is, hell, yes. Why not, right? I have a friend who's an African-American, Arab Muslim, blind data scientist with a PhD in physics. Physics, as in, in her head she sees these things and puts them together. Why not? Why not? So one is that.

The other is universities are very, very slow to think about proactively making themselves accessible and welcoming. So I will point the finger at ourselves. I'm even wearing Crimson today, so god help me.

[LAUGHTER]

Pointing my finger to ourselves. Why-- and I can't answer this question. I can only answer rhetorically because I'm bound by attorney-client privilege. Why would Harvard University, and MIT, defend against a lawsuit brought by the National Federation of the Blind to make the Harvard MIT MOOCs and open access education accessible? Why?

The law, to me, is very clear. I've written on it. I'm very sure about it. Although, to be fair, the US Department of Justice only released their regulations last year, after only 30 something years. But why would you resist that rather than thinking about, gosh, here's a population that we should reach.

Oh, and by the way, it's not just-- "just" quote unquote-- those who are blind, visually impaired, et cetera. But you know what? Captioning also helps non-native English speakers. If our mandate is to educate and to reach and to uplift society, why on Earth wouldn't you want to include it?

Why would Harvard University defend against captioning a lawsuit brought by-- one of my friends. So again, I can't talk about it-- National Association of the Deaf? What are the-- what's the word we use now? Optics. What are the optics of Harvard doesn't like deaf people? Is this the optics you want to--

So why do that? And then, of course, Harvard always gets it right in the end, and we have now a very good mandatory, binding accessibility policy as far as captioning and websites. But it draws a line at a certain date. Doesn't go back in time. So they got it right eventually, sort of, kind of.

But we're also-- all of us universities are still a work in progress as far as just basic understanding of including individuals with disabilities and also different learning styles and modalities into our classrooms. Why was it at Berkeley, [INAUDIBLE], disabled Disneyland, home of the disability rights movement, that the TAs went on strike about eight years ago because they said the professors were not providing them with accessible materials so they could enable students with disabilities. They had to go on strike for it.

Why? Right? Why is it that the same place Berkeley, Disabled Disneyland, right? They actually said, you know what? To heck with you. We're not captioning anything. So we're taking down all our public-facing materials. Spiteful, right? Exclusive. Why do that?

So what do we do about when we do pedagogy, right? For me, because obviously I'm up to my ears in the sector, and I would have many various friends come by and stick their white canes in my wheels, et cetera, and do other things to me.

All my materials, I don't assign case books, and I don't assign written materials. I do everything online, in Canvas in accessible formats. Everybody has access at the same time, to the same materials. No one is behind the eight ball.

I'd like to say that's the rule. It is the rule formally. I'd like to say it's the rule as far as what faculty do. But I hear it from my students all the time about this one's class and that one's class. And why do I have to be three weeks behind? And how do I engage in a discussion about that?

We can do so much better. We can do so much better. And of course, we can also have visibility. It was only like two months ago, and this is after years of work, that Harvard University had on its main web page, accessibility. Now, I don't say I like it because they put my horrible picture on it.

But I like it because it wasn't just pain-in-the-rear, have to make ramps, have to have toilets or grab bars. It was about welcoming people, including people, and understand that the background of that was pulse survey, blasted across the entire university.

We care about you. We want to hear about your experiences. We want to support you, enable you, and nothing about this [INAUDIBLE]

But it's not happening. I have blind friends at Harvard who are being-- freshmen in their dorms who can't do laundry. They're not-- there's nobody for them to report to. The data back inside-- I teach assistive technology here. I have for a very long time. I love this topic.

I'm an advocate, but I'm also kind of a realist, and I face constant struggles of trying to do things, which is there's a difference between saying, yes, we want it, and we know how to actually implement that. And that's the computing-- how do we report up these issues so that they can be addressed?

Right now, it's by force of will. I go in there, and I bang on doors. And I say, why did my student, who's a freshman here, have to go and beg their classmates to help them do laundry? How much of an extra emotional burden are you going to place? And whose job is it to actually address this? Becomes one of the hardest parts.

And defending against lawsuits helps us have that discussion. It helps us to-- it's not just to exclude. It's to say, OK, let's get into the dialogue and figure out the details about who's responsible for what. It's not just to say they don't want action. They want some details.

No, I'm not exactly against those cases. They're my friends.

No, I know. My tone is more intense than I intended to use.

But no, it should be, right? And it should be. It's 2022, and it's one of the very few visibly disabled persons on faculty anywhere in my university. I'm the one that-- I'm the faculty advisor for the undergrads because they have nobody else. I'm the one that the students come to and complain about it. And I hear you, and I agree with you.

But I think we are moving slowly, but in the right direction.

I agree with progress. I'm sorry. I didn't mean to make it sound like I was not thinking we're moving in a good direction.

And I'm not an apologist for the university. But if we're talking about computer design, right, there's an issue there too, which is how much do we teach-- I don't mean here at MIT, but how much do we teach across the board, schools of design, both computer, physical, architecture, et cetera, about compliance, and not just compliance, but also how to create welcoming spaces?

And the answer to that is not very much. Just as the answer to how much do we do in medical schools about having something beyond two hours during vulnerable population day, about treating disability, when it's even given a variety, variation, et cetera, 20% or so of the population.

From a public health point of view, if you're not serving 2% or 3% population, up goes to the red flag and the alarm bells. So where is the red flag and the alarm bells? So I agree.

Forgive my excitement.

[LAUGHTER]

Forgive your excit-- I encourage your excitement, thank your excitement.

Thank you. My graduate student intern from Harvard is sitting right up there. And I think, I'd love to have a conversation at some point. So good luck.

Thank you so much. Yes.

Can I ask a question?

Please.

Yeah, first of all, thank you so much for the question. I [INAUDIBLE] talking with the assistant director of digital accessibility service of Harvard. And after this case, they set up a team directly to work for those students and also work for outside of university, have been approved by [INAUDIBLE] law. But they do change a lot. Yeah, so I definitely think there's some progress that we need time to make it up.

And I'm so glad where we talk about digital accessibility because I'm curious about one thing. You also mentioned a lot about ADA and [INAUDIBLE] question, we said, under the pandemic, as we all know, digital accessibility is more and more important globally, all over the world, for people with disabilities.

However, current law and statues, such as US ADA Title II and Title II have a white definition to workplace, not only US, but also many places, which sometimes render digital accessibility to be hard to make more progress. not to mention globally.

So I wonder what would be a good solution for current statutes of the [INAUDIBLE] and solve this problem, and how to help the world to really realize this problem?

OK, that's a great question. And people who actually want to see really interesting nuance and to find data about digital accessibility around the world, including the 80% that's in the developing world, can go and look at the Dare Index, D-A-R-E, just published by the UN G3 ICT, which actually does that every few years. And it's very nuanced.

So there are parts of Colombia that are more wired than, say, outside of Richmond, Virginia. And it's not uniform in any way. But the answer to you, [INAUDIBLE], is actually a pretty simple one. And that is, just down the street we have our good friend Judy Brewer, who runs the World Wide Web Initiative. And they have WCAG 2.0 guidelines.

They're fairly simple to implement. They're fairly straightforward. They are not subject to really cultural differences and difficulties. And there have been many places that have said, you know what? Let's use the WCAG 2.0, or even the 1.0, as the standard for it.

And in the US Department of Justice's "guidelines" quote unquote, that took them 30-something years to pass, they basically say, oh, by the way, we're not telling you exactly how to do accessibility. But you would find that this WCAG 2.0 thing actually covers it.

So it was a good thing after 30 years way too late, is also a bit of a cop out. But at least we have something there. Natasha.

You have been responsible for creating a disability focus at the Kennedy School and institutionalized a regularly offered class. Could you talk a bit about your journey with that, your successes and challenges?

Whoa, in ways that will not get me into trouble?

[LAUGHTER]

Well, I came back to Harvard in December of 2003. I still had a chair, tenured chair elsewhere. But I was on grants and other things, and so on, and I've never left. And they won't get rid of me.

And early on, I went to speak to my next door neighbor, who was the vice dean at the Kennedy School. And I said, what can we do to encourage HKS to have more, or have something, on disability? And he said, oh, you know Ron Kass over BU Law School, the Dean?

I said, yeah, I know Ron. He said, I'm sure they'd love to have a course there. This is called NIMBY, right, not in my backyard. And I said, I'm sure they would. And I'm not asking to teach here, but what is it that can be done to encourage something, awareness, inclusion, something here? And he said, you know, Ron Kass, that's the guy.

That was in 2004. That was the last time I talked to Fred Schauer, now a real big shot, big academic name. Years later, supported by HKS grads, I went and had a chat with Michael Ignatieff, who's in similar position, and is allegedly a human rights advocate.

[LAUGHTER]

And I said, what can we do to have this ability? He said, well, why would that be important to HKS, not in a mean way, but in an open way. And I said, well, disability-related funding and costs are the largest US government expenditure. They also tend to be among the highest government expenditures for OECD and other Western countries and in some others.

And it's almost 20% of the US population. And it's a cross-cutting issue, and it really makes for interesting policy analysis, as I hope those who take the disability, long policy in HKS agree. I hope that makes for interesting policy analysis. Shouldn't we be doing that? And he said, well, but there are more women than disabled persons. I said, yes, there will be overlaps. He said, in that case, we'd have to actually have courses on women and policy.

[LAUGHTER]

My gosh.

[LAUGHTER]

Oh, my word. And I said, yes. He said, well, he said, let's discuss it over the summer. And then, somehow my multiple emails and telephone calls managed not to be answered. And then he went off and killed the Liberal Party in Canada, went on to other breaking things as well.

I started teaching at HKS with my very dear wonderful friend Charlie Clements who is heading up the car center, who was a Vietnam vet protester, Quaker, helped formed the universal mission, one of the creators of Physicians for Human Rights, and other things, shared in the Nobel Prize for the Landmine Convention. Just a wonderful, wonderful human being.

And he was just outraged that there was nothing on this at all. So he said, we approached HKS and said, can we teach-- can I teach disability? And you've got the global expert-- and not to put too big a spin on it. And they said, well, no, not of interest. He said, OK, well, how about if we jointly teach social movements, human rights and social movements? Because Charlie had been involved in the FDA releasing HIV drugs and Pueblo Indians land battles and other things.

And so he and I taught human rights and social movements for a bunch of years together, which was a great privilege. He's a beautiful, beautiful human being. And then he retired. And HKS said, well, would you like to continue the course? And I said, thanks. No, I'd like to teach what I'm known for. And no offense, but I'll put my reputation in this area against anyone else on your faculty in their area. And it doesn't make sense to me why I shouldn't teach it. And they said, OK. And so I've been teaching that since.

HKS is an interesting place. About five or six years ago, one of my students who came to HKS to study with me, and others of course, but with me, put together a disability justice caucus. We helped to fund it. They have remained in business, as it were, since. But they also held their meeting on Wednesday as a open house and didn't bother inviting me.

So it's a very interesting kind of dynamic. And frankly, it's reflected in many other parts of Harvard University, as in, we've got now a Disabled Law Students Association who are often running on their own, and I rarely hear from them, which is both good and not so good. Not so good because I can support them in ways, and I'd be happy to do that. Really good in that it's their years of law school and their student lives. And they've taken hold of it and ownership of it. And that's really good. That's really good.

And it's really good that, if there's a disability event, they don't have to have style. That's good. It's as it should be. But it's a work in progress across the university. We have an affinity group at the Medical school that focuses mostly on mental disability. HGSE, the graduate school, has always had a head chapter, Association Higher Education and Development. Although, again, these things over time go through different metamorphosis.

So HGSE, for many years, I used to do two lectures a year with them. And I received the award for blah, blah, blah. Now I don't hear from them, other than having one or two students come to class. I don't hear from them. So it's always very interesting the students everywhere. And I'm sure you have your perspectives too, right?

You get wonderful kids who come by, and I want to do this, I want to do this. You say, wonderful. Come and do it. And then you never hear from them again. And then you get wonderful students to tell you that. And then you're with them all the way through school and then afterwards, and then they come back, and you continue your relationship.

And then new ones pop in and discover that they really like this area. And that's where they want to spend a lot of time and focus on. And it's hard to generalize among the very large, diverse, interesting, talented population.

But the bottom line is I could say that there [INAUDIBLE] questions. So that's always a good thing.

Are there any questions from the--

Yes, we do have a question on Zoom. This is from Alex Chen, who works at the Poverty Action Lab at MIT. Alex's question-- well, first they Thank you very much for speaking to us and for all your many contributions. Alex is wondering if you have any recommendations for how policy organizations that fund international development research can increase disability inclusion efforts in engaging with both researchers and PIs and the partners and donors.

And specifically, Alex is wondering how you think these organizations can better include persons with disabilities in annual requests for proposals, or if there are specific educational resources or methods that you'd recommend in training staff at these organizations.

Great, wonderful. There is no end of toolkits and workbooks on inclusive international development. One or two I've done, but there's lots and lots, including great open access resources at the World Bank for how to do the inclusion.

The short answer to it is you begin by reaching out to representative organizations ensuring that they're representative, and asking them if you could be of use, going with humility not with imperialism, and finding out what their priorities are, and then trying to scope or work the project around them.

But the longer one is we're sort of In cultured now, where we go into a room visually, virtually, physically, or whatever. And if we look around and we don't see a certain variety-- it's never perfect, and inclusion is never perfect, and so as a challenge, we won't fail. But it's a process.

If we don't see a person of color in the room, then hopefully, something scratches the back of the heads [INAUDIBLE], whatever. Or if we're having a discussion, we don't hear enough about a particular group, then we'll generally get a little scratch. Keeping that in mind, as in, here's a project on education in Malawi. And does it say anything about how kids with disabilities get there or what happens when they're in the classroom?

If there's nothing there, then there's not likely to be there. So doing the reverse, which was also Alex's question, in crafting RFPs, not only emphasizing that inclusion of marginalized populations not otherwise represented, et cetera, should specifically list people with disabilities, including-- and this is a good USA practice now-- including the idea that DPOs, disabled persons organizations, and otherwise should be front and center and included in these proposals, that maybe even setting aside a percentage of the budget for reasonable accommodations.

There are very well established, known practices. But it comes down to humility and to openness.

So we have a project that we hope will be funded that-- we work for a bonus. We don't take money from it-- that we hope will be funded in Ecuador on behalf of various disability groups and climate justice and has to do with sustainable jobs, et cetera.

We reached out to the group because I know them, having worked in Ecuador, et cetera, and work with them and said, what do you think about this? Is this something that might be of interest because it goes through the [INAUDIBLE]? What do you think about this? Not, hey, here's money.

We're going to come and take the money and control it. But rather, is this something that you want to do? Is it something of interest to you? And if so, let's talk about it and figure out how you're the ones who receive the money, and we're here to support you if you want it, and help you think through it, and help you do that.

So turning around the hierarchy is also really important and a challenge.

Can I ask a challenge question for that?

Great, please. I like you. You're good.

Oh.

[LAUGHTER]

We have conversations that have. We have-- and I'm not going to dump them all at once. So NGOs, nonprofits that are meant to help people with disabilities, often end up infantilizing and protecting. And how does one evaluate the NGOs that are incentivized mostly to keep themselves fed, not to actually serve, because we don't have proper metrics on whether or not they're serving.

Because I also, for context, travel around the world and do assistive technology development on the ground with individuals. And the variety of value that you get out of certain NGOs and the way that they will treat and engage is-- I'm sure you know there's a lot of subtlety to how you evaluate and partner with NGOs, and then, how that ends up trickling down to the individuals who are, now you're going to the head of some unit and you're saying here's the money. Is this of interest to you?

They have their own priorities, in the same way that I've been told very explicitly giving me DI status at MIT is not a priority because they have bigger things to do with.

Well, I understand. But on the ground there's a lot of people who have very different opinions about what they would like the world to look like. So it becomes a bit tricky when you work through the notes of the NGOs actually affect individuals, I think, at least for me. And I'm just wondering if you've experienced anything like that and founds ways to navigate it.

Oh, absolutely. And by the way, *Accessible Technology and the Developing World*, Stein and Lazar, OUP.

Sorry I can't hear.

Stein and Lazar, OUP, 2021, you may like that as well.

OK. Good.

[LAUGHTER]

Thank you.

[INAUDIBLE] discussions about it. The short answer is that nearly all DPOs or NGOs, nearly no NGOs are DPOs. And so, we always-- and those of us in the disability rights movement always focus on the DPOs not on the NGOs.

Can you help us understand more of the distinction because I think I have--

So DPOs are organizations created by persons with disabilities for persons with disabilities. NGOs, like Amnesty International, which still doesn't have a disability policy, still does not have it. They tried to write one because my friend Janet is now the chair and disability rights advocate right here in the US. And when we asked for comments, I basically shredded them on things like, what do you mean disability is too complex? Women are all vocal. They're all the same.

[LAUGHTER]

What do you mean? What do you mean? Are you really saying this in 20-- whatever year it was 2020?

Only behind closed doors.

Right, so Amnesty does not have on its agenda to empower people with disabilities. And if they happen to stumble upon something that helps people with disabilities, they're not averse to it. But that's not where they're going.

Is a DPO a legal distinction, or is it-- how do you vet and understand--

It's by people with disabilities for people with disabilities. So it's not even the large service provision things, like Handicap International, which is now Humanity Inclusion, or Christian Blindness Mission, CBM, which is now doing lots of disability empowerment.

It means it's things like action on disability and development in Bangladesh. It means it's the organizations that begin with sweat equity, and people with disabilities coming together and working with each other and care about doing the job for people with disabilities.

The NGOs, your point is extraordinarily well taken. They're not there to work for people with disabilities. Human Rights Watch-- I've got lots of friends and I do trainings for Human Rights Watch-- did not do any disability work until the CRPD was passed. And then Aryeh Neier said to George Soros, OK, give them some money and they'll create a disability division, which is now headed by my former intern. So \$12 million made that happen a couple of years ago.

Amnesty used to go into the psychiatric hospitals, and on one side you'd have the political prisoners, and on the other side you'd have people with psychosocial disabilities. And they were held in the same conditions, right, restraints, electroshock therapy, isolation, et cetera. And Amnesty would report on the political prisoners, which is good. And totally ignore the ones on this side.

And that's why Neier and Soros then created Human Rights Watch that got into disability. And then they created OSI, which focused on that population. Then we created OSF.

And it's a huge problem. You're exactly right. It's a huge problem. And I'll even give you nuance to your problem.

Please.

There are groups that claim to be DPOs--

Correct.

Right, that basically exist in order to serve themselves and/or act as a conduit for various governments to the disability sector as service providers. And in doing so, serve themselves.

So NFOWD in Bangladesh. The National Group in Vietnam. Even the CDPF from China are made up primarily of nondisabled people, on salaries from the government, charged to speak for people with disabilities. And those organizations, especially CDPF, which is a very large animal, tend to have nuance in them because there are some amazingly good disability rights advocates with and without disabilities within them. But by and large, that's not what they're really doing. And they're a problem.

That's the power of policy. I'm an engineer. I can write code. I can build an international database. I'm working on trying to follow the processes. I can't get the policy changes in place that empower the money to trickle down to the right places because I'm watching the money flow down into organizations like that before it ever reaches-- the tiniest little fraction gets to the bottom.

And if you want to add even more nuance or depression to things--

[LAUGHTER]

There is an addition in the DPO community just as there is in the international NGO community, a problem of elitism and celebrity.

Mm, mm, mm-hmm.

Elitism, in that, if you want to get x group, if you want a group that's going to be working in Niger, then you go towards this group because everyone knows that's who does it. And everyone knows within the group that this is the individual to invite. Whereas, the really, really interesting, innovative, iconoclastic work is being done with sweat equity by the groups themselves, which by the way, also include parents and siblings and other allies and supporters.

So that's a problem. And then celebrity. I could tell you, if you're going to invite someone from Africa or whatever, give me a country and I can tell you who is the person who's most well known there and who's going to be invited to stuff.

And by the way, it's here too, right? So when the Massachusetts legislature wanted to talk about supported decision making, they called up Chris Griffin, who was then the head of the Disability Law Center.

They called me, and they said, will you come and testify for us? And we said, no way. You get the people with intellectual disabilities whose lives are on the line to come and talk to you. And then maybe afterwards we'll give you some opinions and support it. But no way are we going to talking on their behalf.

But Chris is wonderful and incredible, and I'm sure could help. That's a problem. A lot of people show up, especially if there's money attached to it.

They kind of build a tree.

So I just wanted to hold for a second, check in on our timing because I understand we're supposed to end at 1:30.

Mm-hmm.

I don't want to cut off the conversation, but I also want to recognize that others might have places to go.

I've been harassing him for years. Don't worry.

I hope you do. But I don't also want to exclude-- are there any other questions on the Zoom that we--

Yes, we did-- we have someone who'd like to make a comment. She's actually part of the Disability Justice Caucus and ran the event on Wednesday. So Priscilla would like to make a comment.

Hello, everyone. Hi there. Can I be heard? I just want to check that I'm being picked up. Hi there. So my name is Priscilla Mensah. I'm one of the co-chairs of the DJC. And I just wanted to respond, Professor Stein, to your comments just because the last thing that the DJC would want would be the impression that we somehow neglected to invite you. And that's something that we regret.

I think it's really important to probably highlight at this point that there's a really disparate culture around disability at HKS. And so I can't pretend to-- I can't say that I knew of the faculty or professors at the Harvard Kennedy School upon arriving as a blind student who were active in this space and were still doing that work.

And so the last thing we'd want to do is to give the impression that somehow we're not willing to work with academics who have been doing the work for a long time. And Professor Stein, we recognize that. And I regret that a personal invite did not go out to you. I think that there's work for us to probably do to try and make sure that we're reaching out to all academics who are not only disabled, but are allies and keen to work in this space. But that's what we have to do.

And right now, as disabled students, we're just trying to actually get together, and that's been extremely hard work. And so, just to say and to hold space for that, because the last thing I'd want to do is to give the impression that this was some sort of personal slight. So thank you for holding space for that.

It's not a personal slight. I am of service to all the students across the university and to a whole bunch of them at MIT and BU and BC and other places as well. And I'm always happy to support you, but might not have been the most optimal way of moving forward. You want some time?

Yeah, but I'll respect all those times.

Well, perhaps, if you're willing to stay, I'm sure there's many people who would like to engage you a bit more. But I'd be happy to, as long as you get me outdoors in eight minutes.

Eight minutes, oh, so maybe some people can accompany you out the door to engage that way. I just want to thank, again, the organizers. I especially want to thank you, Professor Stein. Everyone who participated, all the questions, what a great conversation. And thank you for making it much more clear all the work we have to do within just our own academic unit [INAUDIBLE] institution.

Thank you for supporting us here.

No. We will hopefully be able to ride the momentum that's been generated. So thank you so much.

[APPLAUSE]

[SIDE CONVERSATIONS]