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TRANSCRIPT

"SOLVING WICKED PROBLEMS: LESSONS ON SYSTEMS CHANGE FROM DIVERSE FIELDS"

A Conversation With Michael Bach, Gregg Gonsalves, and Jennifer Gordon

Moderator: Emily Martinez

ANNOUNCER:

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EMILY MARTINEZ:

Thank you very much everyone (COUGH) for taking time to join us today for this conversation. I am super excited to be moderating this session. It seems these days we have no end of anecdotes and stories about the big and small ways that our problems are becoming-- problems that we all work on are becoming more intractable and more insurmountable.

And so, even as we all seem to get really good at diagnosing the problem and researching it, the actual solutions-- seem to be getting further and further away, particularly as more and more crises seem to be-- the problems that governments are grappling with.

And so, it's very exciting, not to put any pressure on the panelists here, to have a discussion that's all about the solutions-- how we solve these wicked problems. And so, I'm really optimistic that this very impressive panel we have here is going to help us understand and give us some insights into how to make those wicked problems that we all work on a little bit less wicked. And I wanted to say that they would help us figure out how to peel back some of the complexity-- but then, I realized after the fact that maybe actually making it-- less wicked is about making them more complicated. (LAUGHTER) So you'll have to answer that one later.

But-- and-- and actually, push for some-- state reform. (NOISE) So with that, I'm going to turn it over to our panelists, I have-- I want to (NOISE) introduce them, but I also want to just remind everybody that we are recording today's event for possible posting on the website, and also, to say that we have folks on the telephone.

And so, I'll be trying to toggle between the room, and the phone-- for questions. And just one last note, to say that I'm hoping to open this up sooner rather than later to conversation with all of you, so do let me know if you start having questions and I will try to move out to you; I have a list of my own questions and obviously, I get to ask them first. (LAUGHTER) But-- anyway, so with that, I will start with some introductions. Down at the end I have Gregg Gonsalves, who is a lecturer at the Yale Law School and co-director of The Global Health Justice Partnership.

He is a longtime HIV/AIDS activist, and he received the Open Society Fellowship to understand what we could learn from the global response to HIV and AIDS, and the extent to which that response was sustained for our work to push for more responsive and effective healthcare systems.

I don't know if that's accurate, (BACKGROUND VOICE) but it's-- oh, is it? Oh, good. (LAUGH) And-- next to Greg, I have Jennifer Gordon, who is a lawyer and advocate working on migration and labor rights; she's a professor at Fordham Law School and a former McArthur Fellow and is currently an Open Sight Fellow that we just agreed beforehand, maybe not quite current--

(OVERTALK)

EMILY MARTINEZ:

--working to secure the rights of migrant workers hired through subcontracting practices. And-- (NOISE) next to me, I have Michael Bach, who is a leading disability rights advocate working in Canada and globally to advance the rights-- to advance equal recognition of people with disabilities-- in law and practice. He is currently the Director of the Institute for Research and Development on Inclusion in Society, and Vice President of the Canadian Association for Community Living.

And so, maybe just to begin, so that we are all working from the same playing field, I'd like to ask each of you, perhaps, to tell us what is your wicked problem and why is it so wicked? And maybe starting down at the end, Gregg?

GREGG GONSALVES:

So I-- I work on HIV and AIDS, but I-- I was interested and figuring out-- if the lessons we learned needed to be applied to tuberculosis, to maternal child health, and we all-- everybody in this room takes healthcare for granted. It seems like not getting sick and not dying from preventable and treatable diseases is a no-brainer, but it happens to many people around the world.

I think through my fellowship-- this is sort of the punch line, is that what if-- decision makers were not making the wrong decisions-- by accident or by ignorance, but we were doing it on purpose. And as I looked at-- programs in Ukraine and Brazil and South Africa, I think my thesis got-- (COUGH) proved again and again.

It doesn't mean that we're hopeless and that we should give up. But it basically stages health-- as a political problem, not a technical one-- for-- for us to sort of-- invent new solutions in-- in public health schools where I work or-- or in law schools. So that-- probably sums it up in the shortest amount of time. (NOISE)

JENNIFER GORDON:

So I realize that-- with the turning of-- the calendar to 2015, I have now worked for 30 years on this particular wicked problem, which either shows how bull-headed I am or how wicked (LAUGH) it really is. And-- with time, comes-- I think, at the very least-- a sense of what's at the core of the thing. (COUGH) So here's the wicked problem I work on, which is the question of (COUGH) how, in a context where people move, leave their countries in search of work-- because they need a better life for their families and are driven to do that.

How do you fight for decent work, both for those workers, and for the workers-- usually, low-wage workers of color, in the labor markets that they're entering to work in? So how do you fight for decent work for everyone in a context of high labor migration?

MICHAEL BACH:

I was thinking this morning, it's almost 30 years for me that I've been working on this one, so I was also wondering, "Have I just failed or, in fact, is that that wicked?" (COUGH) So that the-- the problem that I'm working on is how to change guardianship and substitute (COUGH) decision making systems that take away the right to legal capacity, for people with intellectual, cognitive, psychiatric, psychosocial disabilities, systems which take away the right to make basic decisions about your life-- healthcare, property, personal life, who you'll live with, who you'll be with, who you'll be intimate with.

So how do we ch-- that-- that's the issue, and-- and it's an issue because we're talking about removing the right to control your own life-- and on the basis that you don't meet the cognitive criteria for what it means to be fully human, which in creating that divide in our population undermines, I think, the-- the social and if you will, inter-subjective conditions between us for being recognized as a full, human agent, which-- which-- renders, I think, powerless, this growing group of people, because they're not recognized as fully human, which helps to explain why this group is hugely disproportionately represented in terms of those victimized by sexual, financial, physical violence, sexploitation and abuse.

And it renders them as part of a growing underclass of people who are not part of the public space, or democratic del-- deliberation, to bring their voice to this issue. That's the problem. Why is it wicked? I think it's wicked because we've so naturalized the divide between us.

A kind of interlocking system (COUGH) of law, science and ethics justifies this boundary between us. (NOISE) And managing across that boundary engages all kinds of systems, the justice system, the health system-- financial institutions, who are not malevolent. (COUGH) The systems aren't malev-- malevolent, but they work by common sense. How could we empower people with significant intellectual cognitive disabilities to be agents of their own live when our basic commercial contract and market relations depend on certain quantities of cognitive capacity?

And so, these systems have ac-- actually grown conterminously, from the kind of 14th century on. It-- it aligns and grows with property, growth of commercial and market relations and economies. So it's wicked, 'cause it engages these systems; it's common sense that we have-- this divide, and-- confronting the systems requires a kind of fundamental re-patterning of our psychic resources, how we look at and know one another.

Our-- what-- what bonds of care and love mean between us, what-- how community systems are organized, how legal provisions are written, how doctors get-- informed consent, and how financial institutions contract with people for their own problem.

EMILY MARTINEZ:

So-- then Michael, isn't it also kind of wicked because it's so hard to explain? (LAUGHTER) I mean-- seriously--

MICHAEL BACH:

What-- what-- I thought there was a really-- I tried to (LAUGHTER)-- my rules were two minutes, and I thought, actually, that was the-- the most wicked problem of all, but--

EMILY MARTINEZ:

But-- but-- that is a wicked problem, for sure--

MICHAEL BACH:

Right, right--

EMILY MARTINEZ:

--but I mean, isn't one of the big challenges here that it's so ingrained in how we understand things that getting people to unpack it is really challenging?

MICHAEL BACH:

Yeah, I think that is the-- the-- it's wicked 'cause it's so common sense; if I have a profound intellectual disability and I go to the doctor for knee surgery and I need knee surgery, (NOISE) the doctor's gonna say, "Excuse me, Emily, give me a break, you want Michael to give him foreign consent?" Like, come on. Let's-- let's just kind of-- the system isn't gonna work. If I don't have informed consent from him and I do the knee surgery, I'm gonna be liable for battery, right? (NOISE)

So that-- it's why-- it-- it's why it's-- it's so common sense, and I think that's the nature-- with the problems, right? It makes sense that we've organized the world socially and legally this way. But from-- if we want to imagine a world where-- all of us, who are increasingly dependent, and I think even in the first two presentations, we're talking about people who are-- who-- who-- who live lives of vulnerability and require interdependence with others. But those kinda fundamental relations between us-- aren't kind of fully recognized, right, or valued in-- in law. And that-- that's, I think, the real problem, we've gotta kind break through these-- these perceptions.

And-- I think there are (NOISE) ways to do that, and my fellowship is about exploring some of those-- those ways in different parts of the world. You know, which we'll talk about as we get into the conversation.

EMILY MARTINEZ:

So I have more questions, but I'll come back to you.

MICHAEL BACH:

Okay.

EMILY MARTINEZ:

But-- Jennifer, so we all love to hate private companies, and is that partly what makes your work so difficult and so wicked, is that it's requiring-- private actors, and in this case, often big business to be part of the solution?

JENNIFER GORDON:

I think that complicates the solution, but it's not why it's wicked. I think that it's wicked because sort of using the terms that Michael used, it runs up against-- dealing with this problem runs up against these deeply ingrained notions of sovereignty, a country's right to rule itself-- and the fact of global inequality, in a world where access is defined by these legally-- stamped or rarified places where you live.

And so, in a context of global inequality, people are gonna move if it means they can do better, but the sovereign nation they come from and the sovereign nation they're going to are both in political binds that keep them from working together to deal with the problem, right?

So in people's origin countries, there's-- there's a lot of money to be made from labor migration, right? There's-- first of all, 300 billion a year, is the last figure I saw for remittances that come back to origin country governments, (NOISE) many of them are totally financially dependent on remittances above all other resources or sources of income. (COUGH)

And then, there's-- in those countries, migration industries, right, which might be the broker who-- labor broker who lives next door to you and goes all the way up through labor contractors, taking you across the border. And so, origin country governments do-- they've got pressure from migrants to protect their rights, but they don't really have the power because they depend on the money coming in.

And the more they protect migrants' rights, the more the migration industry yelps, (NOISE) and the more their workers can't compete for jobs, right? So they passed legislation that's protective and then, they don't or can't, for sovereignty reasons, (COUGH) enforce it, and then, in destination countries, politically very hard to open up to new, low-wage labor migration. But at the same time, you have-- an here's one of the ways companies are in it-- the-- all the industries that can't produce abroad, that can't manufacture abroad-- so service industries, wanna do the same thing in place, which means having the cheap workers come to them, rather than bringing production to the cheap workers.

So they're clamoring for migrants, and what happens (NOISE) as a result is that-- that destination countries tightly limit legal in migration, and so people either come in illegally, at which point, if they complain about how they're treated, they can be deported, or they come in through guest worker or temporary migrant programs.

And if they complain and are fired, their Visa sends and they're send home, effectively deported, right? So the result serves all these interests, right? It serves origin country interests, destination country (NOISE) business interests; migrants may be abused, but they're earning more than they earned before and a huge amount of money is flowing to the industry money-lenders, recruiters that serves this, and at the same time, all of that works to create legal conditions that make migrants unable to stand up for their rights.

And so, the way we structure migration legally erodes not only the treatment of those

migrants, but the people-- who are in those jobs and the labor markets they come into, (COUGH) and I think that's the core wickedness of the problem, and I'll save companies for when we talk about the solution.

EMILY MARTINEZ:

Okay. (LAUGH) Gregg, one of the things-- when I read your initial application, which, at this point, is going back a few years-- I sensed a real optimism which might not have been there. (COUGH) So (UNINTEL) me reading into them about the possibility of drawing positive lessons from the scale up-- on the response to HIV/AIDS. Your final report on the fellowship was much less (LAUGH) optimistic, (LAUGHTER) it seemed to me. And so, I'm curious, first of all, was my read correct?

And so, it is that complexity, the fact that you were-- as you dug deeper, that response seemed less positive, (COUGH) part of what has made the work you're doing so wicked.

GREGG GONSALVES:

So-- (SIGH) so part of it's about history. You know, if you started-- I've-- I've been doing this for 25 years-- and until-- in-- in the year 2000, nobody around the world outside of industrialized countries had access to (UNINTEL) therapy.

You know, ten years later, seven, ten million people had access to it; it was a heady time. And what we talked about, as I was applying for the OSI Fellowship is (COUGH) okay, let's move to broader health systems strengthening, let's take the lesson of HIV and build on it for TB, for maternal child health and we'll all, you know, march into the future of health-- health for all, the (UNINTEL) declaration even from before-- I started working on these issues.

But what happened is I went out to countries, history was shifting, too. This is the time when the economic collapse starts to happen, austerity programs are-- are-- are appearing in Europe in big donor nations that used to give a lot of money to-- to global health around the world.

And-- what I saw is that-- our victories (MIC NOISE) through activism were entirely-- not entirely, but at least partially, transient. And you know, I-- there's a guy named Paulo Tusheto (PH) who helped to set up the Brazilian AIDS Program, and-- I interviewed him for my fellowship. And he said to me at one point, "You know, the reason I've funded the community groups in the early days of the AIDS epidemic (COUGH) in Brazil," and they were some of the leaders before 2000 in providing drugs to people, "was that I wanted them to hold our feet to the fire."

And he said-- there's a Brazilian term called "social control." He said-- "If we're gonna provide social control, to-- to keep us moving ahead," it wasn't about them giving out condoms or-- or providing counseling, it was about their political role.

And that interview stuck with me throughout-- (COUGH) my rest-- of the talks I had in Brazil, in Ukraine, and-- and-- and South Africa, and what-- what I think happens by the end of the fellowship is I realize-- we are in-- maybe I did the wrong thing.

Maybe as an AIDS activist, I did the wrong thing; I thought, like, screaming at WHO, screaming at the drug companies, you know, doing-- doing these marches was good enough to get us what we needed over the long term, and I realized, it's entirely transient. It was-- in the end, I think it's about institutional transformation.

You know, what's interesting to me is you look at the *King Versus Burwell* case, it's gonna come up to the Supreme Court this year, we even transformed the law, we passed The Affordable Care Act, but you have a Supreme Court who could wipe away subsidies for, what, seven, eight, nine million people around the-- around the world?

That's-- that's not a question of reforming law or-- or-- or making your activism better, it's-- it's an absolutely deep corruption within the system that has been sort of taken over my extractive elites. You know, one of the journalists I talked to in Ukraine said, "Our country is suicidally corrupt."

You can make the case that this sort of political corruption-- maybe it was very acute, it's very acute in Ukraine and Eastern Europe, that it was-- came up in Brazil, it came up in South Africa, these questions came up, and then, it starts to leak back home. And so, I think it's wicked because we're talking about the fundamental organization of our political sphere, not just in the United States (COUGH) but sort of trans nationally, and how do you leverage change over the long term-- in that case?

You know, if you put ten million people on antiretroviral therapies over the past decade, it's a lifelong commitment, it's a lifelong commitment. You know, you can't sort of change your mind ten years later, because basically, their-- their viral load goes up, their C-4s go down and they die.

You know, I talked to somebody who ran the CDC-- PEPFAR program in Nigeria, he said, "Only 25% of the people are actually in acute clinical need for antiretroviral therapy and get it in Nigeria today," and that's all subsidized by the U.S. government and by PEPFAR largely. So there's a whole bunch of people who need the drugs today, but are not gonna get it.

And yet, even that 25% who do-- are basically walking a tight rope about whether they're going to have it two to three to four years now. So I think-- (SIGH) it cuts across all the issues we're talking about. It's about-- we-- we've been working on this for 30 years, (COUGH) but you know, my first memory-- I think the first President I didn't vote for was Ronald Reagan.

It was-- I (MIC NOISE) graduated from high school in 1981, we lived-- in the-- we're sort of children of-- of-- of Reagan and Thatcher and that whole sort of push away from sort of the social democratic experiment that came-- came-- or gave us the National Health Service and all the sort of welfare states in Europe over the past 40, 50, 60 years. And unless we trans-- think about how we can organize politically to-- to change th-- these sort of-- this political sort of super structure that we're dealing with, I think we're in trouble.

A lot-- you know, we-- had a conversation downstairs on Monday with-- drug policy people at OSI, and I got a little bit pissed off, I said, "You know, you're-- all you can think about is funding NGOs and giving little grants to NGOs to do reports (PH), to do these trainings, or-- and (COUGH) we're all gonna have UNGASS in 2016 and make a big fuss (PH) about drug policy," you're not gonna change a thing.

The underlying political dynamic is they're gonna take a decade or more to-- to-- to solve. And so, how are we gonna build that consensus around the world for-- for-- a more informed, progressive drug policy if we think it's about giving $10,000, $20,000, $50,000 to an NGO, no matter where they are, just to come to New York? I think it's very, very hard to figure out how you transform societies politically-- and we can start at home and have that discussion. But it was the case in Brazil and-- and South Africa and the Ukraine, as well.

EMILY MARTINEZ:

Can I just-- on that point, we-- you all distinguish between-- the kinds of efforts that you were just talking about, Gregg, and systems leveled reform, and I have to say, as somebody who is in the process of about to write a strategy and trying to think about what my outcomes are going to be over the next four years, I'm like, well-- (THROAT CLEARING) (COUGH) what is an outcome against changing the whole entire political system in which-- these groups are working?

And so, is it actually reform-- necessarily incremental? And so-- Michael, you and I once had a long-- conversation about this-- I think I ultimately lost, but I-- I would love for (COUGH) one of you to pick up this point about-- how do we operationalize a systems level process, or how-- how do we distinguish between work that is building towards systems level reform and the kind of work that is-- because it is going to be incremental, isn't it? (NOISE)

I'm sorry, that wasn't the clearest question, let me try and make it clear. I think what I'm getting at is that when you say systems level reform, we're not gonna get that tomorrow, so there's a path to getting there, and how do we distinguish that we're on that path or we're not on that path?

GREGG GONSALVES:

You-- go ahead, and I'll-- yeah--

JENNIFER GORDON:

All right, I'll g-- so I mean, I guess I am-- I always have pretty plain feelings about how change (NOISE) happens, and-- and that's through power and some amount of coercion. That is to say economic force exerted against the economic powerhouses, right? But if-- if that's your philosophy of life, and-- and that's the only thing you see

as real change, you're gonna be really depressed all the time, right?

So I think-- like, if I think about what's my character type, how would I describe myself? I would describe myself as an anxious optimist, that-- you know, I'm always worried, but at the same time, I love my work and I really think that there are ways to intervene that move the ball forward and I really enjoy them, right?

Like, if you don't-- I'm definitely of the "if you don't enjoy the work and your goal-- your goal has to be to create spaces that build people within them-- sense of possibility and agency," and that what comes out of that is unpredictable, but often extraordinary.

And-- and I think there are many ways to get there. What I would say about-- to the extent I would even call it a method, that I've-- worked on or developed for myself over the years, it really involves two kinds of interventions. (COUGH) One is a look, you know, a serious in-depth look at what the sys-- the particular system is, with the goal of uncovering its-- I guess for lack of a better word, its irony, right?

So let me give two examples-- one is that I spent quite a lot of time (COUGH) looking at the way immigration and labor law, in the U.S. and many countries, combine to make immigrant workers less able to stand up for their rights and therefore, more usable-- but those who would use them-- to drive everybody's conditions down, right?

And the central irony there, of course, is everybody's worried about immigrant workers driving working conditions down. What if-- and here is the sort of high level intervention, we thought of, without constraint, what-- a regime would look like that was designed to give immigrant workers the incentive and support they needed to stand with native workers for better wages?

What if we structured immigration law that way, right? So maybe the only way you could lose your Visa and be deported was that you don't report an employer who's trying to undercut your wages, pay you less than the minimum, bust a union, whatever, right?

That's a big what if. But then, to look for places where pieces of that are happening and support them and help them grow. So that you look for places where migrant workers are finding tools that are rooted both in their home countries and the countries they're going to that allow them to stand up for their rights. Or little-- you know, the opportunity-- create a pilot program that would further that, right? So-- and then, work intensively in those spaces, hand-on, on the ground, to make (NOISE) that grow to show that it's not as impossible as you think.

And a similar one-- briefly-- (COUGH) relating to Emily's question about businesses, is-- and this is really where I'm working now, to look at subcontracting chains like how people get to work, all the actors involved, or how a product gets made and gets to market.

And looking at the fact that almost all countries say that the only actor responsible for a wrong done to a worker who's migrating or a worker who's producing in those

chains is the subcontractor immediately above that worker. And yet, the control, the power, the money all lie way above that level.

And engaging with people who are reframing that to say, "Well, we really should have, in legal terms, liability that aligns with responsibility." Nothing else is really gonna work. And then again, going down to find where governments have done that, the coercion from the state there, or where organizing groups have done that, the coercion is economic coercion from boycotts and unions and so on. And both working with them to build it up and then arguing, again, back to the conceptual level for a system made of that.

MICHAEL BACH:

Can I jump in on this? So-- this-- we gotta-- I think-- what-- what do we mean when we talk about systems, right? In the first instance, if you've been engaged for 25, 30 years and try to bring about change, (COUGH) like, you've been in real places with real people who are up against the wall and whose lives are falling apart.

And you're driven to make sense of it, right? As a human thing, and it-- that's-- if your work is intellectual work or social movement work-- and so, systems become parts of explanations to understand why things are the way they are, and you work up these s-- systems in your own ex-- drive to explain why the world-- why-- why this is happening to these people.

And so, we come up with financial systems and legal systems and economic interests. The thing about-- and-- and then you go to-- to-- to-- to-- go about trying to change them, and we've gotta be careful not to be caught by this-- apparent solidity of our categories, right?

That these financial systems are-- these are people. Legal systems are people that keep things in place. And systemic change-- I mean, systems change when they get disrupted, when there's kind of, you know, in the thermodynamics stuff, there's entropy of some kind, it starts to fall apart, it starts not to work for some groups who have a voice.

And that not working becomes more and more politically or economically important, so if-- what-- I bring this back to-- to the work that I'm involved in, the issue is how to make the systematic denial of-- of-- of right sort of a certain group of people a problem for the system, right? And so, we-- being involved in the early work of this, we were looking for alternatives at the community level for something we called supported decision making.

So rather-- just because my son has a profound intellectual disability, I see him as a full person who has some desires and interests and is in the world. I-- I hold him in the narrative-- my stories of the narrative of his life. He matters as a full human being.

But the system doesn't see that; they have a different account of who he is. So

supported decision making is a way of bring around my son, (COUGH) let's say, or me-- people who know me and can hold me in those bonds of love (PH), to reposition me in diagnostic cat-- to challenge diagnostic categories and financial-- banks who say, "Well, that's very interesting, but why would we open up-- a bank account in Michael's name? He can't even contract with us, so that's impossible."

So we started creating pilot community initiatives to demonstrate that people could be supported in different ways, and then, it became a problem when we couldn't open a bank account. So we're talking-- we're-- we're not dealing with the financial system, we're actually dealing with the local bank who won't open a bank account for my son.

So it's a really pragmatic issues. But as you start to unta-- like, sort of tackle that problem, you need to work with the banker and the local municipal politicians to try and shift the practice, but you can only shift so much practice; at some point, you've got to get it to the banking act and the ways in which contract law are embedded and the rules of who's recognized to be able to-- to contract. If we want to create a system that recognizes the people around me who know me and love me and can present me and interpret me as a full person to the world.

We need that knowledge to have recognition in a world of science and ethics which totally undermines that form of knowledge. So you-- by pushing in really practical ways on things that matter to people, you shift systems. And I-- and-- and you do that-- interestingly, in-- so in this one site that we're working on in this initiative through my fellowship and also, supported through The Human Rights Initiative in Bulgaria, and-- and to Gregg's earlier point-- earlier point about-- so yeah, how do you shift this entire system by investing in a few NGOs?

And how do you do that strategically so you can actually get to systemic change? I-- in-- in-- in that case, very interesting, by investing in a cluster of NGOs that (COUGH) bring both community experience and legal expertise together that can do this systemic analysis and put things into place on the ground and, as well, begin to mobilize and motivate more systemic change, you create-- you know, in economic innovation, they talk about-- in metropolitan-- cosmopolitan economies getting the cluster of actors together, the academics and the financiers, et cetera.

I think that's-- a helpful analogy for what we want to do here. You gotta get the right clusters of actors together that can motivate stuff on the ground and then begin to move and shift strategically to systems. So in this case in Bulgaria-- they're doing demonstration pilot projects with people with disabilities to demonstrate how it could look differently in somebody's life. But they decided the system they want-- if-- if you're gonna shift a system, this system, you gotta at some point get judges to refuse applications for guardianship, because that will disrupt the system.

So that's-- that's the-- that's the systemic focus; bring judges together, they're real people, they make decisions. And so, a year ago, the actors convened the group of ju-- a group of judges from across the country, (NOISE) brought Chris here, who's-- who did precisely that, refused guardianship application in the-- in the-- in the court in

Manhattan to share her experience.

We had, in the intervening years said, "You know, we're not making much headway, let's at least get this in international law," so we worked with the-- to-- to get adopted UN Convention on the "Rights of Persons With Disabilities" a vantage point, which was the right to legal capacity-- without discrimination on the basis of disability and a right (NOISE) to access that support. So what we were able to bring to the judges a year-- a year-- a year ago is the documented examples of how to support people with profound disabilities in different ways in communities in-- Bulgaria.

So we had stories, real, practical stories. (COUGH) We had the convention to inspire those judges, and-- one of the judges left that event having listened to Chris, having seen the-- the convention, having heard about these stories from villages around their country, and six months later, refused a guardianship for app-- an application for guardianship.

Now in Central and Eastern Europe, the system is so entrenched and pervasive, it's just-- it's so much a part of the doctrine, this divide, and while before I present it in a really abstract way, it's really (LAUGH) practical. You bring an application forward with the assessment from the psychiatrist, you stamp it and guardianship's put in place. And guardianship in Bulgaria and countries in Central and Eastern Europe means that you can't get a letter in your own name, because that's a contract with the postal service, right?

There's-- there's a trans-- there's a legal transaction there, so you actually can't get a letter that's addressed to you if you-- if you're under guardianship. So this judge refused the application and she says, "The convention is automatically domesticated in Bulgarian law."

"It says people-- we can't discriminate on the basis of disability, this application's come forward, this woman has a support network around her, she's not under guardianship, she's fully legally capable to figure it out." (NOISE) It was, like, the-- the Justice Association-- the old guys, like, started-- were just-- they'd been at the table having the nice conversations and went, "Whoa, whoa, whoa, whoa," went, "wait a minute." This fundamentally challenges centuries of legal doctrine, we're-- we can't go there. Meanwhile, this new justice association emerges, which-- informed by a rights perspective say, "Actually, no, it is time to change this thing."

This is an old-- part of an old, patriarchal system of law in this country and we're gonna shift it. Meanwhile, in Bulgaria, you have all kinds of political uncertainty and elections and governments fall and governments rise, and two months ago when I was there-- they're appointing new ministers and new deputy ministers.

And this judge who has-- was at the forum a year ago, went through the training-- has become a bit of a cause celeb, promoted on national TV in a big documentary about this, and she's plucked out to become the Deputy Minister of Justice.

EMILY MARTINEZ:

So--

MICHAEL BACH:

So-- so just to say-- we talk about systems change, but it's actually people, and strategically, you can set things up to disrupt systems, 'cause that's when innovations happens; systems get disrupted, and that creates a space for some new things.

EMILY MARTINEZ:

So-- so Greg, I see you have something to say, and I want to give you the floor, but if part of your answer could incl-- you argued, and I don't know if you then felt in the end of your research that that was the case, that solidarity, international solidarity within-- (COUGH) the civil society community was really critical. It was one of those disrupters. Do you think that's still the case? (COUGH)

GREGG GONSALVES:

So-- you know, I-- before being in my current role at Yale and the Global Health Justice Partnership, you know, my roots are in Act Up, and we transformed systems; we found the leverages and the places-- intervention within the FDA, within the NIH, within the entire drug development and research system, which is pretty well-entrenched in the-- in the United States, and we did that largely by understanding where the pressure points are, who are our allies and-- what you are saying resonates with me.

But I didn't learn until later if Act Up wasn't outside screaming their heads off, (BACKGROUND VOICE) it wouldn't have made a difference. One of-- the OSI Fellows with me when I was-- in the Fellowship Program, was Morrissey Westerling (PH), we had the rural organizing project in-- in-- in the Northwest of the U.S.

And we had to-- those-- that's the kind of work that needs to be supported. As long-- there are technicians among us who do public health, the law or mathematical modeling, like I do-- and I-- we-- I believe that there is-- a role for-- for looking at the sort of-- architecture of how these things work and figuring out how to pull them apart and where you can make some-- some incremental gains. But I do think it gets a lot trickier for-- for people like OSF, when you say, "How are you gonna support-- a social movement over ten years when your grant cycle is a year or two years?"

It was absolutely clear to me, both in South Africa, in Ukraine and in Brazil that it was those social movements that-- that gave us access to treatment over the past ten years. And what happened is that most-- the Treatment Action Campaign-- most people in this room who have worked in health know that the Treatment Action

Campaign is basically falling apart.

They have no more sustainable funding; this is happening in Uganda, this is-- (UNINTEL) in Brazil is falling apart, all of these groups are falling apart now; we didn't think it was useful to sustain them. We've moved-- moved onto the next big thing, and we didn't think of what the sort of political-- what-- what does it mean when-- when the bottom falls out of what you've done politically and you're left with just the technicians? What does that mean?

And-- I think it's-- this is why it's wicked to me, because I don't know how to-- to build-- even within HIV and global health, how to build those-- those sort of connections together and sustain sort of a political movement, and then, to-- to move out into workers' rights and to disability rights into a lar-- because they're all connected.

They're all about marginalized populations who are-- are not being according full citizenship on-- on a global or a national scale. And so, that to me is the wicked problem about how do we built that-- that sort of domestic solidarity, transnational solidarity in a way that's a potent political force that can add to what we do as experts in public health or in law and governance to-- to sort of figure out some of the sort of more-- mechanical solutions?

EMILY MARTINEZ:

So-- so I do want to open it up for questions, and we have folks on the phone, and so, I don't know how to tell you to alert me that you're on the phone, except for to unmute and sort of yell out to the room that you have a question and I'll try and take it in. But if people want to let me know if they have a question, we have a mic somewhere that's moving around-- okay. Then I will take—Heather?

HEATHER GRABBE:

Well, thank you, 'cause I'm the first one to ask a question, thank you, there are fascinating examples, fascinating approaches. I wanted to ask-- an abstract question that might sound a bit weird, but-- you've all worked with Open Society Foundations for a while.

So you know that we have a real dilemma at the heart of what we do, and this is-- Marx versus Popper, in the sense that-- (LAUGH) sometimes we focus on empowering individuals, and in fact, fellowships program is an example of this, scholarships program will be individual grants, but also, in a lot of the grant-making we do, we're empowering individuals, and sometimes, we try to get them together as communities, workers of the world unite. And I'm curious, just from your work, how you have dealt with that question of is it better to support civil society organizations that provide support to individuals?

For example, as-- as Michael's been doing-- is it more important to get people

organized, to get the-- your target group, (NOISE) the vulnerable community organized among themselves, or is it more important (THROAT CLEARING) to provide support services around them? Which of them, in your experience, in your area, has provided the most system change?

EMILY MARTINEZ:

I saw another hand-- I would suggest that we take-- sorry. (COUGH) I would suggest we take a couple questions and then come back, does that make sense?

GREGG GONSALVES:

Sure. (NOISE)

EMILY MARTINEZ:

And so, I see a hand, but no face, so if you stand up, (LAUGHTER) then we can-- (BACKGROUND VOICE) and can I just ask-- sorry, that was Heather Grabbe, who's the director of our Brussels Office-- (BACKGROUND VOICE) Open Society European Policy Institute and if I could just ask folks to introduce themselves when they're speaking, thanks.

KATE:

All right, my name is Kate McNamara and I work with Soros Economic Development Fund, which is program-related investing group, and my question is for Mr. Bach, which is-- I guess, maybe you could talk about where do you see the rights of people with disabilities going the next ten years and if you think maybe we're on the precipice of something great and a new movement-- as it relates to employment, or-- or what could be the next big things we might see-- see happening down the road?

EMILY MARTINEZ:

Maybe we'll start with those-- can I just (COUGH) have one question? Oh, sorry. Can I add one question to the mix? Which is also, you all talk (COUGH) a little bit about pilots, and I think one of the challenges that we see for reform in piloting is really, that pilots never become more than the pilot that you set up as part of the-- the intervention.

And-- and sort of elevating that to more, and I-- I just wonder if you can speak to your experience or your aspirations, because I know, Jennifer, you're in the process of setting-- a pilot for how you take that pilot to something that is more systems-level.

(NOISE)

JENNIFER GORDON:

So maybe-- a quick response to Heather's question, and-- and then, also, turning to what Emily asked-- I really think about integrators, which is-- a cross between an individual and-- a group, right, that you're-- what you're looking for is people who can both think and work at both-- an idea, a concept challenging, and-- a process creating level-- who've demonstrated that they are able to bring together both the-- sort of individual change and the systems-level change and the framework busting, right?

May-- it's not-- it's not a zero sum game. Actually, we can think of it this way, and move fluidly between those processes and therefore, unite or-- amp up the power of people and organizations whose strengths are more deep and concentrated in one-- at (COUGH) one of those levels. That would be my-- instinct about that--

EMILY MARTINEZ:

Can I just-- sorry.

JENNIFER GORDON:

Yeah?

EMILY MARTINEZ:

But do you need-- and maybe, Gregg, you'll wanna pick this up when it comes to you, but do you need the-- do you need to support all of those-- those groups that are deep in order to get those integrators? (THROAT CLEARING) Because I think that's one of the challenges, and perhaps, Heather, that's a little bit of what you're getting at.

Is if we choose to only support the integrators, do you then lose the support for those groups that are doing the deep work from which the integrators kind of are getting their energy and-- and-- and ideas-- and so, do you have to figure out how you do both? (THROAT CLEARING)

JENNIFER GORDON:

Oh, you have to figure out how you do both; or rather, you have to create-- a system in which all those levels can draw support from somewhere, right? That-- that's-- I'm not-- I don't necessarily think one institution has to do it all, and maybe it's better to

have some separation. But if you don't have the deep work, even if it's deep work that's more technical and more focused-- then there's nothing to kind of build on and bust open as you move between the levels. So I wish I could say, oh, no, it just-- you know, fund the integrators, all cool, (LAUGH) I-- I don't-- I don't think so.

EMILY MARTINEZ:

Okay.

JENNIFER GORDON:

And your question was about pilots, and I'm sorry, remind me-- related--

EMILY MARTINEZ:

Well, maybe before you take my question--

JENNIFER GORDON:

Sure.

JENNIFER GORDON:

--Gregg, did-- do you have anything? I mean, 'cause it seems to me like the case of TAC is also a little bit of that challenge, right? Tech became an integrator without the movement over time--

GREGG GONSALVES:

Well-- well, the-- well, no, no, no-- I mean, so-- actually, I wrote down TAC, because TAC-- you have somebody like Zachie (PH), who is an Open Society Fellow-- then you had an NGO like the AIDS Law Project, which could work on the Constitution one, the-- and the case law in South Africa around access to treatment, then you had tens of thousands of people who were marching in Par-- Parliament through the Treatment Action Campaign to do-- to do the grassroots mobilizing work.

And so, you need all three, it's not Marx versus Popper, it's-- it's all-- it's all of it; the bad thing is is that in the kind of work that OSI supports and a lot of us work on, there's not a lot of other actors in that space. So-- it's hard for you to pick and choose, but you also don't have-- unlimited resources to go around. I've done lots of pilots-- with OSF support over the past 15 years that I've been a grantee in different iterations. The idea that somebody else is gonna take it to scale-- (LAUGH) doesn't

so much happen. (THROAT CLEARING)

Some-- sometimes WHO or-- or other institutions put it into best practices, but then, it's a question of national governments taking it up, and then you start with this whole cycle again; you need your Zachies (PH), you need your AIDS Law Project and you need your-- your TAC to do it. But I-- (SIGH) yeah. But-- yeah, so that's where I'd-- leave it.

EMILY MARTINEZ:

So-- so-- so I wonder-- I mean, so back to the question on pilots-- so then, is the-- is-- is the pilot about-- building on services that then you're gonna take to scale? Or is it, to use your words, Michael, something that allows you to-- that you can use to disrupt the system? And if you think of it as the latter, then you're-- you're not-- worrying so much about, well, how are we then gonna build out this pilot so that it goes to everybody? Or are there both kinds?

JENNIFER GORDON:

Well, I mean, I guess I spent my early work life building very work-intensive-- hands-on versions of what we wanted to see writ large, right? I founded one of the first immigrant workers centers-- and did a lot of concrete support to build immigrant worker communities that could exercise power through law and through organizing and advocacy and so on.

And I think that's incredibly important. And I think in that case, scale happened from-- seeing that it worked, in the sense that when I started the workplace project in 1992, there were five worker centers nationally, and now-- I think we're probably up to about 250-- about, you know, some number of years later. World changing? No. A model that grew? Absolutely. But (LAUGH) having put so much time then and in other circumstances into what, if you were gonna be disparaging, you would call "small jewel boxes," right?

You know, the-- the pilot really-- inspirational, but only able to affect its local area? The-- so-- just by way of background, my Open Society Fellowship was about intervening in the dynamic where labor recruiters create so much debt and so much fear that migrant workers are not-- because of their fear that they'll lose the job and be left with the debt-- are not able or willing to speak up on the job.

How do you-- in-- how do you deal with the dynamic which has all these transnational-- dimensions to it? And so, I looked at three governments case studies that had dealt with that for my project and three worker organizing case studies and (COUGH) came up with a set of recommendations. And now, I'm working on a pilot out of that, where we have decided-- me with the organizations that I work with, that there's no point playing around at lower levels.

Either the pilot will be the U.S. government with the Mexico government, or there

will not be a pilot, and the way to get around-- in this case-- the fact that you can't really change the immigration law of the United States, apparently, through the political process, (LAUGHTER) is to-- look at-- just to isolate the issue of retaliation for workers who stand up and defend their rights.

And figure out what ways-- if you could get the two governments, coordinating them with each other, to deal with recruiters and employers who-- in concert-- whether con-- you know, whether-- on purpose or not-- are creating dynamics that tamp down workers' ability to talk about their rights, what would that look like and what would be the arguments for it that would get officials-- and this is not in general in both governments, it's in both governments, departments of state, departments of labor and departments of immigration, right?

And these, like Michael says, are specific individuals at this political moment-- if you were gonna show it worked, how would you do it? And-- you know, we'll see, right? I may be filing one of those depressing reports we've all had occasion to file-- (THROAT CLEARING) you know, a year from now.

But-- I think the word "pilot" suggests something by definition that has small impact and is done on a small level-- and I think looking for spaces where you can get something unexpected done, but at a higher level is another way to think about it.

MICHAEL BACH:

So to-- (THROAT CLEARING) maybe address both questions, including the one, sort of where are we going in the next ten years? I wanna-- use a slide, and forgive me, you're not gonna be re-- really able to read it, but-- (LAUGHTER) and I'm not gonna use this one, this one's even harder to read. (LAUGHTER) (BACKGROUND VOICE) Yeah, yeah, I know, slide show.

EMILY MARTINEZ:

F5, I mean, or--

MICHAEL BACH:

F-- oh—(UNINTEL) slide, yeah, okay. So-- and-- you can't read it, but-- just to give you a bit of a visual, a kind of heuristic for this question, both about-- like, what do we do with pilots and how do we think about systemic change and what's the connection between the two?

And it's not a connection-- and to address this-- question of Parker-- Popper Versus Marx-- and I-- maybe in my example, I suggested I was more on the individual side, it is a melding, it is-- it is both, as-- as both Gregg and Jennifer have said. So what this is, it's-- a theory of change map that we're in the process of writing and creating with

the actors in Bulgaria, which is about how to get to systemic change. I wanna just-- the-- the dynamic is-- so here's our outcome, which is legal capacity for all, without discrimination, people have the support--

EMILY MARTINEZ:

S-- sorry, I'm just gonna ask, can you hear in Washington?

JENNIFER GORDON:

They also can't see, (UNINTEL)--

EMILY MARTINEZ:

Oh--

GREGG GONSALVES:

We can hear, we can't see.

MICHAEL BACH:

Okay, so I have on-- on the-- the slide here-- a map with about 50 boxes in it that are all connected by various intersecting lines and it doesn't make sense to anybody in the room. (LAUGHTER)

EMILY MARTINEZ:

And the font's really, really small.

MICHAEL BACH:

And the font's really, really small, (LAUGHTER) so it's not about the content, it's the heuristic, right? It's the kinda gestalt of what we're tryin' to do. So at-- at the far left hand, (BACKGROUND VOICE) we have (COUGH) a little box that says "Capacity-- Legal Capacity for All," that's the outcome we're all after.

That is, everybody enjoys this right (NOISE) to legal capacity without discrimination, (COUGH) they support to re-- to exercise it, and they're seen as a full agent of their own life, in banking, financial, healthcare, other decisions.

And-- in terms of scale, that the biggest-- that the biggest issue is really the growing--

the ageing of our populations, right? In 1950, there were 200 million older persons; by 2050, there's gonna be 200-- so there's gonna be two billion, and that's the biggest growth of those with cognitive disabilities, who are, like-- the financial and banking (NOISE) system is going, "How are we going to do this in the midst of the largest-- generational transfer of wealth ever?"

So there's lots of stakes in this game; so at any rate, we know where we're headed. Here's here OSF invests, on the opposite side, in three organizations, this far-- on-- on the left hand size. The Bulgaria Center for Not-for-Profit Law, BAPTID (PH), which is the parent organization of People With Intellectual Disabilities. (COUGH)

The global initiatives on psychiatry, which supports community base-- supports for people with mental health issues, and the M-- Mental Health Users' Network, which is-- an emergent network of self-advocates, people with-- psycho/social disabilities. I made the point earlier about clusters, and what was unique, I think, and important about this investment by OSF, was they invested in a cluster of groups, separate projects, but linked, with a common purpose.

And with the coordinator/collaborator-- inter-- overarching kind of group being the Bulgaria Center for Not-for-Profit Law, a group of human rights lawyers, doing disability but other work-- they start with doing a pilot so that we can figure out how to do this on the ground.

What does it look like in the lives of-- starting with ten people, with intellectual disabilities and ten people with psychiatric disabilities? Creating networks of support in their community, supporting them to get jobs, maybe en-- enter a lease some a landlord, get a bank account, et cetera, really practical daily stuff.

In terms of scaling up, (COUGH) it's not like the scale up task is getting a whole bunch of these pilots all over the country; ultimately, yeah, you want all-- all people with disabilities to be able to enjoy the right to legal capacity. But what you invest in is this capacity first, to create that pilot, so we know something tangible that we're working with.

And then, we work kind of, if you will, ethnographically. This gives us a vantage point to understand and to look, from this vantage point, out at the system. We look out from this pilot site as the legal system, at the banking system, at labor markets, at the healthcare system, so that we can begin to identify the conditions which so disadvantage the majority of people with more significant disabilities.

And this takes us to this side of the map, which is, you know, when you build a theory of change, you say-- so this is the Marx part, what are the structural conditions that-- are going to enable that to come-- put in place--

EMILY MARTINEZ:

For those in DC-- on this side of the map-- so there's like three squares on the other side of the map, there's a lot more squares on this side of the map--

MICHAEL BACH:

That have to be changed, that have to be changed. So the conditions are things like the Civil Code, which writes in law the boundary between the competent and the incompetent. There are things like-- legislation that p-- would be needed to provide people legal support and accommodation in the justice system and in the healthcare system.

You need to change perceptions, self-perceptions of people with disabilities themselves who have not been empowered in the first place to-- to claim and exercise these rights; you need to change local, municipal, political justice systems; you need to change the professional practice of judges and physicians-- like lots of pretty heavy duty structural stuff would have to be changed. Then you ask, "Well, so what's the preconditions of those?" And you go one step over, and then you ask, "What's the preconditions of those?" And you're one step over.

And eventually, we're back at our pilot, so we're starting to identify how can we use that pilot to begin to tap and leverage-- or-- to create some of these conditions that are gonna get us to there? So-- to ultimately, the outcome. So we use the pilot, it's documented, we then have-- a set of t-- tools and trading resources to begin working with judges.

We also engage policy researchers to develop-- recommendations for policy advocacy. We have our broker, which is the Bulgaria Center for Not-for-Profit Law, very skilled people, beginning to work the-- the policy system with governments, training judges and then beginning to be able to lock-- position people in some of these systems to shift things out, or to-- to-- to make the shifts happen. So I-- I'm not gonna detail the whole story, but just as a way of-- I think we can be strategic with limited investments, but it's not, to your point-- it's not one project for one organization.

I think we need to think-- if-- if we want to get to systemic change, clusters of actors who can touch deep down, but also do the-- the work to take what we're learning to more systemic, like, advocacy levels, developing proposals for law reform, which is what they did, right?

So we're now up here at a working group recommendation for civil code reform that's been approved by the council of ministers, and now, with the new Deputy Minister of Justice, has gone up for public-- a new act-- a new provisions for the legal-- form-- (COUGH) gone out for public consultation, while a variety of these other things have happened.

EMILY MARTINEZ:

So--

MICHAEL BACH:

So my point is, yeah, individuals, but it adds up to systemic reform, if it's positioned strategically within a map that gets us to systemic change.

EMILY MARTINEZ:

Thank you. I want to get more questions from the floor, but I saw, Gregg, you wanted to say something. (NOISE) If you can say it, and then I'll go back out to the floor.

GREGG GONSALVES:

No-- I mean-- all problems are not alike. This morning, I got-- a great email from a colleague from India about (NOISE) the patent on Sovaldi-- a Gilead drug for Hepatitis C-- which costs $84,000 for a 12-week course in the U.S., and the patent, who is opposed in-- in India, and the patent office rejected it. Work was done by IMAC (PH) and Delhi Network of People Living With AIDS, and Lawyers Collective-- apparently, the patent examiner just did it on his own. But you know, so-- so certain things happen when you have these clusters of actors who can push for change. In our field, Gilead's going to push back in a big way.

MICHAEL BACH:

Yeah, yeah.

GREGG GONSALVES:

So the point is that there's certain things where it-- it makes sense and there's not-- in the case of IP and access to medicines, there's so much money on the table, and the interest in-- in keeping things the way they are are so powerful that every time these little groups will push forward, we get pushed back.

MICHAEL BACH:

Yeah.

GREGG GONSALVES:

And so, it's not-- a static sort of path to victory and then, the laws changed and, you know, everybody lives happily ever after, and the access to the medicines field-- you know, it's gonna be-- you know, a lifetime generational set of projects that we're

gonna have to figure out how to support because-- it's-- it's not gonna be about that one patent opposition that just happened today.

MICHAEL BACH:

Yeah.

EMILY MARTINEZ:

So I do want to come back to the question of backlash, because I think that's a big issue, but I want to go out to the floor, so I have a ques-- a question there, and a question from Haider?

MALE AUDIENCE MEMBER:

Hi-- my name is (UNINTEL), I'm with Global Action for Trans Equality, we're actually an Open Society grantee-- thank you very much for the support. In-- in my 20 years of experience first as a lesbian activist and now as a transgender activist-- I'm starting to wonder if-- the work that we do on specific communities, lifting up specific communities isn't just-- removing people out of the target just to make space for another-- group or community to move into the target. And I was wondering if-- what we can do to ensure that that's not a perpetual system of-- ever-shifting groups who are targeted by bias and discrimination with all the results that, you know, we all know, of-- of inequality, of injustice, et cetera? So I want-- I wanted to hear your-- your thoughts about that.

EMILY MARTINEZ:

Haider. (THROAT CLEARING)

HAIDER ABDUL:

Haider, I work for the Human Rights Initiative. I like the map. (LAUGHTER) Although, like, in-- in a lot of settings, however, a lot of countries, you do not have the necessary institutions in place to complete this map, so you don't have this full map as a flow.

You-- you talked a lot about examples of how we disrupt legal systems, financial institutions, and policies to achieve this change. How we-- how-- can you-- can you-- if you can talk more about examples of how can we disrupt culture and social norms-- especially in countries where that's-- that's really all that we have, or that fragile state, failed state, conflict setting-- in countries where achieving this is not necessarily

(COUGH) possible-- what are the different challenges there? Thank you.

EMILY MARTINEZ:

Okay, back to the panel. So-- I don't know, Gregg, (COUGH) if this came up at all in your work, but how do we-- how do you look at not just extending it group by group, but starting to think about a more systemic response (COUGH) that-- that isn't constituency-based? Is that, I think, the question? I mean, and if others have views on that, I'd love to hear it.

GREGG GONSALVES:

So I'm gonna say something horrible, but-- so in 1996, these new age drugs came online, and it's a vast generalization, but white gay men took their drugs, went home with their health insurance and went back to their normal lives. And so, the AIDS epidemic continued to spread in-- in African-American (COUGH) communities, Latino communities, among women in the rural South and the U.S.

But basically, it was over; we got ours-- thanks-- thanks for helpin' and goodbye. And it was a favor (PH) of solidarity. And so, look at the-- the LGBT victories in marriage, it's-- I'm married, it's great, it's wonderful, but you know, if you look at the Human Rights Campaign and what they-- they think about-- it was only until recently that they even talked about AIDS again.

You know, so it-- we-- we get the-- this-- we-- maybe it's a particularly American phenomenon, this sort of identity politics phenomenon where you're worried about your own issue in your own community and then you realize that actually, you know-- (SIGH) your success is contingent on others. Why do we have gay marriage today? I would make the case that the AIDS movement broke open and disrupted the notion of what it meant to be lesbian and gay-- in the United States in the 1980s.

And transformed the way we thought of gay people in the public sphere. But that was about-- something that wasn't-- the path wasn't, "We're gonna fight NIH and the FDA and the White House and City Hall on-- on AIDS because we're gonna get to gay marriage in 25 years."

You don't know how sort of bonds of solidarity are going to sort of-- make larger disruptions and have sort of historical-- ripples over time. (NOISE) And so, I think we can't sort of basically say, "Okay, I got mine, and-- thanks a lot, we'll see you later."

We have to figure out how to create these bonds of solidarities; the clusters have to go beyond clusters (NOISE) of people you work with on any given movement, if we're gonna try to build a sort of solidarity network that sort of tries to go at some of the systemic change we're talking about.

JENNIFER GORDON:

So-- I feel like I'm caught, particularly on your question between two conflicting perspectives, (THROAT CLEARING) because certainly, in the immigrant worker context, like, even-- I haven't done this, but-- sociologists and anthropologists who interviewed employers about who they seek to employ, the employers-- I'm thinking of one-- set of interviews from the U.K. where the employers are like, "Well, you know, the Polish were good until they go rights, and then-- (THROAT CLEARING) you know, we were looking at the Romanians, but the Romanians and the Bulgarians, after they came in, they came to know too much about their rights."

"So we're-- now, we're looking for third-country nationals, outside, and-- and it-- that," you know, which is exactly the dynamic you're describing, right? One group figures out a way, and the way is completely different in different situations, to move out of the target or away from the target, and then, the dynamics of the power continue, so that the-- dynamics of power suck in-- or bring in a new group, right?

So that's-- half of my brain is thinking of that. And another half of my brain is thinking-- about the question of whether it ever is possible to fight all at once for the whole, right? I certainly think that fighting-- you fight for the principle, whatever the principle is, right?

The principle to define your own identity and live your own life with respect, right? You always need the principle, but I don't know, particularly-- and I haven't thought about it so much in the context of identity as I have in the context of concrete, goods-- you know, rights that cost money specifically, as opposed to rights that seem to that a psychic toll on people who don't wanna give them.

But that sometimes, you have to be willing to accept, and even fight for rights enjoyed by a limited group of people. Right? I'm thinking of-- for example-- a housing right situation, right? Or building a discrete community, you build something that, if you let everybody in all at once, it will be diluted to the point of meaninglessness.

And I-- I find myself struggling a lot with this question of whether you can have a boundary-less-- good, right, (COUGH) I would say, "Sure, where it's recognition, not where it's money," but I'm probably, right? It's just that I'm always thinking about it, where it's money. And so, all of that is more to say, I-- I find your question to be one of the most serious ones, and-- I'm-- I have many different thoughts, with no conclusions. (LAUGHTER)

MICHAEL BACH:

Yeah, I-- I agree, there's-- there's a real tension, but I think-- and I think we need to get really smart about this and parse some of the ways in which we-- build solidarity. And I-- I think there's at least two-- two different kinds of moments; one, is solidarity around a specific reform.

And-- equal marriage is one. So one-- yeah, I run this in-- research institute, the other I'm-- I'm a C-- the CEO of the-- the National Advocacy Association. And (COUGH) when we were moving on equal marriage in Canad-- in Canada, an equal marriage coalition was formed and they-- they were reaching out for partners.

And I brought it to our national board, made up of all our associations. And some said, "Absolutely, we'll j-- we're-- of course, we're onboard, because, like, we're gonna need, I mean, this is about equality and human rights." And some-- I mean, there was a whole struggle. But it was about a very specific piece for legislative reform.

And ultimately, we did, which is a good thing. But when it comes to this-- like-- another area I work in is inclusive education. And there's-- inclusive education is a huge issue for, certainly, kids with disabilities, but also, LGBT community in Canada, First Nations Community, et cetera. (COUGH)

To talk abstractly about inclusion in education, like, it's a good thing-- it's a really good thing that we should all be included. But you can't it much further than that if it's about everybody. The-- the means of inclusion-- what it requires is really different for those-- they're-- at an abstract level, so sort of joining together and say, "Yeah, let's have inclusion for-- (COUGH) all of us" only gets us so far. (COUGH) I think when it's focused and specific around a specific reform; you go out and you get your friends and partners' allies and you go for it.

But that said, we-- we've started another initiative where we brought the LGBT community together, immigrant settlement houses together, seniors and our community together-- local level, just to begin, how do ya have a conversation across these sites of diversity and create just a shared kind of project that you each then take back into your own world to work on, and then come back to share the conversation of how it looks and what it means?

And it's amazing, the possibility of a shared conversation; you're not mobilizing for any political reform, you're learning how to listen across boundaries of difference in ways that you can begin to figure out how you can support others so that power doesn't operate across these boundaries of differences it usually does. So I-- I-- it-- it's a really important question and I think-- we've gotta get really practical about what it means in-- in different contexts. I wanna take up-- can I just briefly take up this other question?

EMILY MARTINEZ:

Yeah, I was gonna ask you to take up that question, 'cause this issue of changing--

GREGG GONSALVES:

Right.

EMILY MARTINEZ:

--not just law and policy, but actually changing how people understand, sort of changing social attitudes is a big piece of what you are having to contend with in the-- in the work on legal capacity, so.

MICHAEL BACH:

Right, and I-- I guess there's a number of them to mention; one, is the pushback thing, which I think we probably wanna pick up and-- elaborate-- on. This-- how we do this work in places of failed states-- in countries where-- there's such limited institutional infrastructure. So one of the sites is in-- in-- in Zambia-- and also, OSF has supported pulling together-- people working on this in Southern-- in Southern Africa.

And certainly, the context is different. And there's a much bigger role for customary law. But-- but even the spaces of customary law are being overtaken more-- more by commercial law. You see guardianship law and provisions growing a pace in majority countries of the South because people are trying to figure out how to deal with this growing population.

One of the issues in-- in working-- when we brought some people together-- from Uganda, their priority was contract law. So there is institutional (COUGH) building up of these systems that I think-- there is-- there is the possibility for more of a conversation across some of them than might-- might-- you-- you might think-- think at-- at-- at-- at first is-- is-- is possible; mobilizing resources for-- informal systems, informal economies, is-- is much more challenging than even in Central and Eastern Europe.

But I've found the same kind of logic of strategic sorta mapping-- it has been helpful in those settings, as well. On the issue of-- of pushback-- one of the things-- let's-- if we take the Bulgaria example, it's been very interesting is everybody's together at the beginning-- at least, in some of this work, now that you've got-- what the reforms means actually on paper, going through the system, there is huge, huge, huge, huge, huge backl-- backlash.

And the re-- the-- the-- and it's coming from some of the most powerful-- interests in the-- in the just-- in the judiciary-- and-- I-- I would say that's primarily where it is, and they're getting media play, they're starting to mobilize-- students on-campus to say, "These folks at the Bulgaria Center, these-- these jurists, they've got it all wrong."

Like, there's an ideological struggle at play now that's beginning to emerge and that people are organizing around. I don't know how that one-- gets played out, but-- it-- it is-- there's a kinda classic-- sort of war of ideas, and there's a counter block that's beg-- beginning to emerge from judges, women judges who have formed a new association to begin to battle the discourse by the-- by the old white guys, if you will-- who are currently the sort of-- most highly respected jurists in-- in the country.

So the strategic question now from these humble little civil society groups is how to support that and how to engage and-- and broker those-- those relations. And I-- but I think that-- we're-- as we go further along in this work, I totally agree, the battle lines get drawn in very dif-- and-- and they're tough. And-- and I guess it's not entirely clear how you manage in that-- in that end game.

EMILY MARTINEZ:

So-- so-- just a couple thoughts-- questions on that-- I mean, so backlash, when you're working on systems reform is probably inevitable, right? Otherwise, you wouldn't need the systems reform in the first place, so are there things that we need to be doing as we're developing our work to prepare for that?

Or is it you kind of need to wait to see where that backlash is coming from and what it's gonna look like before you can do that? And-- and I guess for me, the related question is, it seems-- I mean, you said it, Jennifer, you said, "Well, we need the U.S. government, and we need the Mexican government and if we don't have that, then it's not worth doing the pilot." (NOISE) But isn't a piece of this about trying to change attitudes, for example, here in the U.S., about immigration reform? So how do you toggle those as you're thinking about this system-level reform?

JENNIFER GORDON:

I was actually thinking as Michael was talking ab-- about the question of (MIC NOISE) whether there are some problems where-- it matters more if you're able to change people's minds-- and others, where it matters more if you're able to exert coercive pressure, right?

And I feel a foot in each world; as a lesbian, I really do believe that over my lifetime, attitudes have changed not only because of outside pressure, but truly, because of individual exposure, right? And that-- that's a problem, where it's easier, once you've changed the minds of individuals, to use those individuals-- individual power in institutions or governments, to create the systemic change you need. As opposed to-- you know, so that's my home life; my work life has always been with immigrants. Where, you know, the sort of "know an immigrant, love an immigrant" idea (LAUGHTER) is just not as powerful against entrenched economic interests (COUGH) that are really, in my view, about changing the market, right?

About exerting forces, whether they be regulatory or organizing base, and I'm sure that's not the whole universe-- that make it more expensive to do what I think is the wrong thing, and cheaper, or more beneficial to do what I think is the right thing, right?

So I really fundamentally, physically in myself feel the difference (COUGH) between contexts and its impact on what you need to look for. I think we overvalue persuasion in contexts where really, what's at stake is economic power and

concentrated capital.

EMILY MARTINEZ:

I want to give one last round of questions to the audience before we need to close, but Gregg, just coming back on the backlash question, 'cause you raised it, and also, maybe, we're-- we're all touching on money, but we're not talking about it, and I think, Jennifer, you've just put us in the sort-- in the heart of the financial question which is, investments in these things-- we have to change, sometimes, the way the investments have been.

I think, Gregg, you mentioned that when donors lost their interest, then the funding dried up, but isn't part of this about changing the way those financials flow, changing the economic interests? And I don't know if those two are connected with the backlash. Like, is the backlash also about the cost? (COUGH)

GREGG GONSALVES:

So-- so the backlash in-- in the-- in the case of HIV and access to medecines and IP, is about-- I mean, it's just about cold, hard cash, it's just about who's gonna make money off of these new drugs for Hepatitis C and other-- other med-- medicines? So it's just basically trying to sort of-- it's an entire intellectual property regime, it's-- which goes beyond drugs, it goes into every other aspect of-- of (COUGH) human commerce.

So it's not even a backlash, it's basically, we've been able to make these incremental gains based on sort of investments and groups like IMAC (PH)and Lawyers Collective and DNP Plus (PH) and others in India, other places that tied—the Thais, and the Brazilians, as well, these NGOs that have done this work.

It just-- it's not a backlash, it's just basically-- it's an oncoming tidal wave that you've been able to-- I-- I can't-- block that metaphor, I can't figure out what the metaphor is, but it's-- it's just basically an onslaught that is constant and unrelenting. And we-- we do make inroads into it. (SIGH) This is a totally opposite-- we've been worrying a little bit lately about the First Amendment in Public Health; the FDA is being under attack around cigarette labeling, around nutritional labeling, around (UNINTEL) promotion of drugs based on First Amendment rights of corporations.

We can't limit the free speech rights of Altrea (PH) and-- you know, Galaxo (PH) and-- and-- and others to do what they-- they have under, apparently, Constitutional rights, and we-- we had a long conversation about this-- up at the law school, and the dean of the law school, who's a big First Amendment scholar, I said, "So what do we do?"

He's like-- (SIGH) you know, after we had a long discussion about the-- the doctrine of the First Amendment, it's like going on and on, he's just, "We have to organize." You know, the right wing organized the Federalist Society and took over-- I mean,

essentially, sort of built up a whole sort of legal profession that set up these arguments around First Amendment rights for corporations-- and now we're seeing it come to roost in public health. So we have to go-- you know, think about how we sort of-- again, address institutional transformation, so that the whole system gets-- reshaped from underneath.

And it's not saying, you know, forward to Socialism, although that would be great, (LAUGHTER) but you know, it could be supporting-- a counter balance to sort of how the First Amendment jurisprudence emerged in the United States so that now we have to deal with the fact that we may not have an FDA that we recognize in five to ten years.

So it may be a very specific educational project. I think you have to figure out-- you have to do sort of a political, social autopsy of your problem and figure out where the roots of it are, and I think you can work on these small pieces and bits of it, and we've all done it throughout our lives, at the FDA, at the NIH, and make these changes. But the more wicked things for me are about how to sort of leverage these political changes that are not gonna be about three NGOs-- in New York or in Sofia or anywhere else.

It's gonna be-- something that's gonna be over a long amount of time, it's not gonna be-- you know, you may not be able to get your-- your annual report from the organization that you funded, you know, some money may disappear. I mean, people might appear and disappear over the course of time.

But you have to have a longer arc of-- of purpose, and I think that's when you start dealing with sort of this sort of wall of-- of pain that's coming towards you-- around IP and access to medicines or the First Amendment in public health, (NOISE) is because you-- because you basically dug in for the long haul. (NOISE)

EMILY MARTINEZ:

So I wanna give any additional questions from the audience or from DC or the phone-- and then, I wanna give our panelists-- an attempt to summarize what they're taking from this conversation and comparing their experience across movements. So if there's any other questions-- I-- oh, okay, I'm gonna take DC first. Sue?

SUE:

Hi, I'm Sue (UNINTEL), and I'm sorry I came in late, but-- it was very interesting to hear-- everyone talking about their different sort of sectors and how you-- how you organized. I work with Emily on the Human Rights Initiative and my charge is to broaden-- the constituency for human rights and to reach out to unusual suspects.

So my question is to all of you, have you worked with unusual suspects? And then, what are some of the challenges and-- and opportunities-- but what are some of the challenges of working with unusual suspects? And has some of that work then, you

know, sort of-- it's-- it's-- it's a balance between sort of reaching out and creating these larger coalitions, but then, making sure that you keep your principles. So if you could give some examples of some of the successes or some of the challenges that you met, that would be great, thanks.

EMILY MARTINEZ:

And I have one quick question from Haider, 'cause it's his second-- (COUGH)

HAIDER ABDUL:

It's-- it's actually a very-- a very similar question-- sorry-- it's actually a very similar question to Sue. I think we talked about-- I mean, one of the main reasons why their circles are wicked is because they're dealing with institutions that hold a lot of power.

Whether it's the state or the private sector-- in many countries, there's an increasing amount of power within religious institutions, in particular, so-- and I can only imagine how different your experiences have been. And so, I was just wondering if you can touch upon that, of how-- how that dynamic has been (UNINTEL) in your case. (NOISE)

GREGG GONSALVES:

So I-- I was gonna mention the Seventh Day Adventists-- because worked in Lasutu (PH), basically trying to train communities around treatment literacy, the signs of HIV and what the drugs do and the side effects and all this stuff. And the group we ended up working with were the Seventh Day Adventists.

And we did trainings with them over weeks and months and there was a sexuality module which, you know, where-- all these ministers found out I was gay and things changed. And the meeting had to stop and we had to have a long conversation about it.

But then-- sort of-- (SIGH) this woman who hadn't spoken up for-- for most of the-- the session, who was-- who was in the church, as well, started talking about her peripheral neuropathy from D4T, which is a drug for HIV, which should not be given to anybody anymore. (NOISE) And she had learned that Tenophahy (PH) or another drug could be swapped in for it, easily at more cost, but with far fewer side effects.

And the conversation switched over to that. None of this-- it-- it became less about me and the differences between with us than the fact that we were both HIV-positive people, I had access to drugs that were not giving me peripheral neuropathy and she didn't.

And you know, it-- she changed the conversation-- in a very short amount of time-- because we able to figure out what the bridge was, and the bridge was-- was-- I mean,

I-- saying-- identity politics is bad, identity politics is good, but we did connect on something that was not about faith, but was about zero status (PH). And so, I don't know, it just-- that connection was very opportune, but I never thought, you know, I would be working with ministers-- I mean, there's a lot of faith-based work in HIV, I never thought I'd be doing it. (LAUGHTER) And so, it was definitely an unusual suspect in my case.

JENNIFER GORDON:

To answer the question-- about unusual suspects, I certainly think-- it would be no surprise, given the views I've explained that-- I hold, that working with businesses-- is an unusual suspect-- and particularly, given the-- the very plain conflict between migrants and businesses.

And in fact, my continuing feeling that the whole sort of business and human rights movement, as generally characterized is mostly, if not nearly, entirely driven by businesses' desire to protect their brand, as opposed to genuine efforts to improve workers' rights.

But one dynamic that I've observed, although I haven't been a part of is what happens in the context where there is an initiative-- to improve workers' rights that's worker-driven, but has succeeded in bringing in businesses, right? So the businesses are coerced to be there by protests and boycotts and the threat of brand damage.

But where there is an effective enforcement mechanism and good investigators and leaders of that system, businesses start to turn to the enforcers for advice on how to do it right, right? Because doing it wrong is going to result in economic harm to them.

But how to do it right isn't an obvious question. And the idea that once you've coerced people into a place-- people in that context, meaning businesses, where they're-- they-- need to respect the norms set by workers, then there's an opportunity for a more technical thing to happen where you think about enforcement and set up an enforcement mechanism that can really work cooperatively with businesses to help them do a better job of complying. And I'm constantly finding myself in those places where I think I'm in the middle of working on-- a big idea, and it turns out I'm working on a really technical question, or I think I'm working on a really technical question, and it turns out it's the germ of a very big idea.

And I think that that back and forth, or around and around-- is just constantly the dynamic of work on these wicked problems and the question is how you remain open to those different levels as they're going on-- at the same time. And those different possibilities, which is, I think, what arises sometimes in the context where you have unexpected partners. (MIC NOISE)

MICHAEL BACH:

Yeah, I think-- (THROAT CLEARING) (NOISE) my response maybe goes back to-- this-- this original-- one-- one of the questions around what's the future of disability rights and where are we headed in-- in-- in the next ten years? I think there's been phases in-- in the movement-- that align in some ways, Gregg, with what you were sharing, with both what Gregg and Jennifer were sharing in terms of, you-- you know, coming together and really challenging, going to the wall, camping out on the front lawns of schools so your kids can get in, chaining yourselves to fences-- to-- to get access where there's no, you know-- physical access.

A lotta work in the '70s and '80s on-- on that-- which resulted in the Americans With Disabilities Act, which resulted in changes in our charter around recognizing, you know, people-- equality rights for people with disabilities, which resulted in the UN Convention on the Rights of Persons With Disabilities.

So there was-- which shifted, also, the political discourse around disability. And it's been my ex-- experience-- that-- you know, so p-- people with disabilities as people with disabilities in their organizations are not gonna change systems; they're not gonna change the justice system, the education system, the healthcare system, the-- enforcement system.

Principles are gonna change education; judges are gonna change the justice system, et cetera, et cetera. And so, more and more, we're finding ourselves, if we want to bring about that-- those changes at those tables-- employers-- I mean, the labor market-- unless we can change demand-- you know, we focus so much on the supply.

Let's train people with disabilities so maybe they can get a job. Unless we start actually working with employers and demand in labor markets, we're actually not gonna see much systemic change, which means if our only way in is through corporate social responsibility in a way that's going to build their brand, and it probably means in most cases-- we've got a big employment initiative now-- it means they're gonna cream (PH) in terms of taking people with much milder disabilities rather than more significant disabilities-- it-- it's-- it's tough decisions.

We-- you-- you know, we're gonna lose 'em if we say, "No, we can't, we're not gonna engage with you, we're not gonna bring labor to the table-- at you-- just as mild disabilities, we-- you need to really support--" it's not gonna work. So-- we're at that stage where I think the-- there has been some important value changes.

Not-- you know, there's still huge issues, as I started at the beginning in terms of the naturalized boundaries between us, but there have been changes. I think I'm playing much, much more on a kind of knowledge-driven sort of focus in-- in this work, that you train up judges, you change minds of employers. They're nonetheless huge interests, economic and otherwise that we have to contend with, but I want to open up-- like, I'm-- I'm seeing possibility to-- to-- to shift the landscape-- a bit, in a way that I don't think we have before.

Will-- will it constitute marginal change? You know, the result of-- you know,

untenable compromises? I don't know yet. But-- (NOISE) I-- I'm an anxious optimist, too, (LAUGHTER) that's-- that's a perfect characterization on how I live my life. (THROAT CLEARING)

EMILY MARTINEZ:

So I think we're pretty much out of time. I don't know if any of you had any closing thoughts or burning comments or things that you wanted to take to the floor, but I just wanted to say thank you very much for sharing your insights with us. I've heard a lot about the power of solidarity, the power of activism and keeping it sustained-- the challenges of changing economic interests and the fact that that is long term-- long-- arc proposition. But you know, one of the things that I liked about this conversation is that even though you're all working on pretty different wicked problems that have-- different actors and different elites involved, it's-- it's exciting to see that we can learn so much from the different struggles.

And try and figure out how you can take that learning across movements. And one of the-- ones that I liked was, I think, the reference to-- disrupters that can basically help us to get at-- I think it was you, Jennifer, who was saying-- relatively focused interventions that get at the big questions.

And I think understanding how others have done that in other fields helps us think about it in our own. I don't know if you have any other additional thoughts, but thank you so much, everyone, I appreciate your time, and-- this has been a really fascinating discussion, so.

(APPLAUSE)

(OFF-MIC CONVERSATION)

* * *END OF TRANSCRIPT* * *