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Disability and AIDS, Two Years Later
Kaiser Family Foundation
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MYROSLAVA TATARYN: And good afternoon and thank you for coming to this symposium which is convened by the IAS, the International AIDS Society, and is co-organized with AIDS Free World.

I'm very grateful that you've joined us today as we sit together two years after Mexico City and more importantly two years since the entry into force of the United Nations Convention on the rights of persons with disabilities which, for this session to keep things simple, I'll probably be referring to as the convention or the CRPD.

We've come together today to review and analyze the progress that we've made and the obstacles encountered in the push to fulfill the vision of the convention in the field of HIV/AIDS. Before I go any further, I should explain that we have CART Interpretation today, which is simultaneous typing of what is being said so that any hearing-impaired and deaf people in the audience and anyone else that has trouble hearing English can follow and it also facilitates the participation of Steve who is deaf. So it's a wonderful technology that hopefully we'll see more and more of in future conferences.

How many of you here in the room have heard of the United Nations Convention before you read about it in our flyer or in the conference program? Okay. Great, almost everyone. That's excellent.

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But just to make sure that we're starting from the same point, we're going to go through some of the background of the convention to make sure we're on the same page and I'll ask the panelists to help with this in just a moment.

But first, I should introduce myself as well as my colleagues here on the panel with me. My name is Myroslava Tataryn. I work as the advisor on disability and AIDS for AIDS Free World. AIDS Free World is an international advocacy organization that works to promote more urgent and effective global responses to HIV and since its inception two and a half years ago it was recognized that, or three years in any case, it was recognized that disability issues have not received attention in global AIDS discourse.

And so from the very beginning in a response from the call from disability activists, many of whom are here in the room today, we took this on as one of the key areas of advocacy.

Now for our panel. It's really a privilege and an honor to be here today with the people around me who are here because they represent the range of the movement from top-level advocates to grass-roots activists that span three continents. To span three continents with only four people, it's quite, it's quite impressive.

On my left we have Steve Estey. Steve is the human rights officer for Disabled Peoples International in Canada

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which focuses on the human rights of persons with disabilities. From 2003 until the successful conclusion of the negotiations in 2006, Steve was a member of Canada's official government delegation to the UN which drafted the convention, the first UN Rights Treaty of the 21st century.

Beside me here is Shantha Rau Barriga and she is a disability rights researcher and advocate at Human Rights Watch in New York. She is responsible for monitoring developments in the field of disability rights, investigating and reporting on discrimination and human rights violations against persons with disabilities worldwide and carrying out global advocacy initiatives. She is currently investigating discrimination and sexual and gender-based violence against women with disabilities in Northern Uganda. This includes research and access to health care, HIV/AIDS treatment and sexual and reproductive healthcare.

Next to me here is Wanjiru Mukoma. She is a deputy director and head of policy, research and performance at Liverpool VCT Care and Treatment in Nairobi, Kenya. She has worked extensively in the area of HIV research, programming and policy.

While she has also been at the periphery of involvement in HIV and disability, Wanjiru became more engaged in these issues when she joined Liverpool VCT in 2008, partly because it is one of Liverpool's pioneering projects and a very important

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program area but working at LVCT made her aware of the neglect of disability in the field of HIV in Kenya and sparked her desire to do more.

And finally, on my far right, Rosangela Berman Bieler is a Brazilian journalist, publisher and disability rights advocate. Rosangela is the founder and director of the Inter-American Institute on Disability and Inclusive Development.

She became engaged with AIDS and disability issues in 2002 first by helping disseminate and get responses for the global survey on AIDS and disability which was conducted by Professor Nora Gross and she disseminated the questionnaires in Latin America and the Caribbean region and then getting involved with the World Bank's AIDS programs once she was serving as the World Bank's focal person on disability and inclusive development for Latin America and the Caribbean region.

So, for the next 80 minutes that we have together – let me stop for a second. Sorry about that. How many people in the room think I'm speaking too fast? Good. Excellent. That's uncommon. Okay. Oh, sorry, I thought everyone had that. I didn't check. The CART technology is encountering some problems so we just have to stop for a minute to see if we can sort it out. Sorry, it's in front of this screen and I assumed it was on that screen incorrectly. Sorry about that.

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Steve knows me very well and has heard and read my introduction and we also have sign language interpreters so hopefully if there are other deaf people then they will be able to understand - oh. It seems to have been fixed. Okay. Yeah? We are okay? Alright.

The next 80 minutes of the session are meant to facilitate a discussion. There will be no five-minute presentations, no power points. Rather, I will be asking a series of questions to our panelists to guide the conversation and in the latter part of our session I'm hoping for a lot of input and questions from you, our participants today.

We're here to reinforce the links between AIDS and disability movements and to explore and tackle shared challenges. Because human rights are, after all, human rights for all humans, regardless of gender, socioeconomic status, serostatus, disability or any other groupings that are marginalized in our societies. Marginalizations are not experienced in isolation. As a disabled woman, I do not have my female part separate from my disabled part. I am not able to quantify exactly how much or what kind of discrimination I experience based on which part of my physical reality.

So it's time for us to lift disability out of its exclusive and marginalized silo and recognize disability rights firmly within a broader human rights framework, disability rights, build our human rights model and improve the rights of

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all people. We will never be able to achieve universal access if we don't address disability rights because in every country, every community, every marginalized group, we find disabled people.

It was in order to help fulfill this more complete vision of human rights that the convention first came into being. Disabled Peoples International, represented here today by Steve, is the largest international umbrella organization of national disabled peoples organizations. You may also hear us refer to them as DPOs in our disability movement acronym speak but we will try to keep away from that.

Steve, you've been working with DPI throughout the negotiations of the convention. I would ask that you start us off with a quick overview of the role of civil society in the negotiation and realization of the convention, please.

STEVE ESTEY: Right, can folks hear me okay? I'm the guy who's responsible for this CART thing and stuff so I can't hear myself talk and I just want to make sure you can hear me. Thanks for the question and thanks for the invitation to be here with you today. It's a real delight and pleasure.

Civil society engagement in CRPD was an amazing thing and I think it's instructive for the HIV/AIDS community to get a sense of that. We came together; many folks in this room were part of the early days in the convention negotiation. We came together in New York City for the first time in July,

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August of 2002. At that time came a few of us from little NGOs not too far from New York City for the most part. Some came from a little farther away but there was just a smattering of people from around the world.

At that time we were really asking the question of whether we're going to have a convention or not going to have a convention. It wasn't a foregone conclusion. The ad hoc committee was struck to consider the question of whether we should proceed or not.

The involvement of people with disabilities and their organizations right from the very early days of the convention I think was really the heart and soul of the CRPD development process. We were the conscience of the thing and I can remember being in the meetings in 2002 and talking in the side panels, talking in the hallways to a lot of the diplomats, the government folks and things and they're really expressing very dubious views about whether we needed to move forward.

There were long and tedious discussions about treating fatigue and all of these kinds of things. There was a bizarre concept that I'd never come across before but there were some people who seemed to live and breath and eat and sleep treating fatigue and they all came to those early days of the convention meetings.

The role of civil society, I think, through that was, as I say, to be the conscience of things, we moved it forward.

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We were there, we were watching closely and I think it's true to say that the convention on the rights of people with disabilities simply wouldn't exist if civil society hadn't been so closely involved, so closely engaged in it.

MYROSLAVA TATARYN: Thank you. I think, also, I should mention that Rosangela and Shantha were involved in the entire negotiation process as well. If, Shantha, if you could give us just a sense of the human rights dimension of the convention and how it fits into a broader human rights framework.

SHANTHA RAU BARRIGA: Sure. Again, thank you, also, to Myroslava and IAS for hosting this panel discussion. We must remember though, that before the CRPD, persons with disabilities had rights. We had other conventions and other treaties that protected the rights of persons with disabilities, albeit not very well. Therefore, there was a need for CRPD. But we need to also consider the interrelationship between the CRPD and other conventions.

But within the Convention on the Rights of Persons with Disabilities itself, it's rooted in some principles that apply very much to the HIV movement: The principles of dignity, non-discrimination, participation and inclusion, the respect for diversity, equality and accessibility.

If we look closely at the convention at the particular articles, there are several articles that relate to persons

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with disabilities living with HIV or even persons with HIV who may or may not have disabilities.

Article V on non-discrimination, Article IX on accessibility, Article XIV on freedom from violence – as we know, many persons with disabilities are subject to violence and therefore in some cases leading to HIV – Article XXII on the respect for privacy and Article XXV on the right to health including the right to sexual and reproductive health.

These are a range of articles and although HIV and AIDS is not explicitly mentioned in the convention it is definitely an aspect of health and many other rights that is covered by the Convention on the Rights of Persons with Disabilities.

As I mentioned, we must also look outside of the CRPD to the two covenants on civil and political rights and economic, social and cultural rights, to CEDAW, this Convention on the Elimination of Discrimination Against Women, to the Convention on the Rights of Children because they all apply to persons with disabilities, they all apply to persons living with HIV and so we can look at a more holistic approach to using human rights to protect the rights of persons living with HIV, particularly persons with disabilities.

MYROSLAVA TATARYN: Excellent. Thank you. Rosangela, if you from your experience in the realization of the convention, if you could comment about its role or the promise that it holds in helping ensure the inclusion of disability

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rights within the larger international developments structure and framework and agencies.

ROSANGELA BERMAN BIELER: Sure. First of all, thank you for the opportunity of being here with all of you. Always an honor. Just as Steve and Shantha was mentioning, something that is very unique in this convention, not only the civil society participation that was really, it made a total difference in the process but also it's a convention focusing on human rights and at the same time some development issues.

What means that every article that Shantha was mentioning on health, on education, social protection and all the other areas of human being are not only guaranteed as rights, as human rights, but also put in practice in the development field.

What means that in all the programs, public policies, actions and projects, disabilities should be mainstreamed the same way as gender and other areas have been mainstreamed, especially by international corporation and the public policies of the countries themselves too.

Then one of the articles, Article XXXII, focused specifically on international corporation and all the recommendations is that every money that goes into corporation should consider disability as one of the areas that it should cover. More than only disability, what we are talking is about inclusive development, not creating specific actions and

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programs and policies only for disability but trying to include the topic, the approach, a lens on disabilities within the regular programs, within the regular agenda of governments, of international corporation in general.

Then it makes a big difference because in the last, after the convention passes we can start seeing that all these agencies have a mandate and they are starting to have funding and they are all having to follow the convention right now and this is something that we can start pushing more and more so the projects and the money that goes for corporation can also include, incorporate issues related to disability. It's a big push in field.

MYROSLAVA TATARYN: Thank you. I think that hopefully now we're at, more or less on the same page. We find ourselves today at an international AIDS conference. Now, I'm wondering Steve, I think the DPI started to take on the issue of HIV/AIDS and disability during the negotiations of the convention around the same time. I'm wondering if you could share with us what sparked the work at the intersection of AIDS and disability and was the convention responsible for that shift?

STEVE ETSEY: Sure, I can try. For the course of the negotiations on the CRPD from 2002 to 2006, we all spent a lot of time at the UN through those negotiations. We talked about a variety of things, a wide range of human rights issues. But there was a process; a lot of the discussions were very

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general. They talk of - general may not be the best word, but hide level if you will - we're trying to draft a treaty and so on.

There were a number of people, particularly people who came from African delegations who were talking about their realities as living with people with disabilities in their home countries. Something that I didn't have a chance to say before is that when in 2002 there was a small group of NDOs that came to the negotiations. Over the course of that four years the numbers picked up and became evermore and evermore people.

We had nine meetings of the ad hoc committee or eight meetings. A bunch of them, anyway. And by the time we finished that, there were literally hundreds of disability activists that were participating in these meetings. It was an amazing thing to behold. But particularly colleagues from Africa spoke about the issues around HIV/AIDS and so one.

We were very much preoccupied with the drafting of the convention but as we were preoccupied with that we also were realizing that there's a whole country of people that were not being paid attention to; people with disabilities were not being paid attention to in the discourse around HIV/AIDS.

What we found with the development of the convention was that it kind of shone a light on the issues of human rights for people with disabilities very broadly. We have always maintained that the convention doesn't give us any new rights.

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It doesn't set any new standards. It simply says that people with disabilities have exactly the same human rights as everybody else.

Had those discussions and had those discussions in conjunction with colleague particularly from Africa and there was a lot of discussion about HIV/AIDS and there was a realization through the course of that that all of the work that was going on globally around HIV/AIDS was completely missing the boat for people with disabilities. We began to hear stories about this.

There was a report that was done by the World Bank in 2004 that began to get this issue on the agenda and so on so we at DPI as an international organization were, there were so many things on our agenda, the tiny little NGO that we are, but it seemed to us that we could no longer move forward and try to talk about human rights and people with disabilities and simply ignore this huge looming issue, the pandemic HIV/AIDS and the fact that people with disabilities were not being talked about in all of the big IAS conferences and all of the things around the world.

The convention provided us with an opportunity. It provided us with a methodology, if you will, to move things forward and we've tried to take that methodology and use it here with the IAS and elsewhere and I think that we're making some progress with that.

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MYROSLAVA TATARYN: Thank you for that. I think that one thing that comes up and what you've mentioned is the way that people with disabilities have not been included in HIV/AIDS programs. It seems a bit ironic if we think about it because a lot or most people living with HIV at some point or another will experience physical disability as a result of their HIV positive status. I think that at some points in time we see some tension but also an opportunity for cooperation because we see people becoming disabled and then how does that fit into this existing disability movement.

Luckily, I think, that there's a history of inclusivity and especially thanks to the social model of disability seeing as the ways of society creates disability by the way that it is structured and that it's not intrinsically in my body that disables me but it's the fact that society is built in a certain way and that is what disables me.

The convention as a result did not include any specific diagnoses or any specific medical conditions as this qualifies as disability but this does not. It's based on a social model. I think that a lot of HIV activists have seen this as a promising component because it can help people living with HIV also to advocate for their rights.

However, some people have also started to say oh, but it's a shame that HIV isn't included. So there's some discussion about that. I would ask Shantha if you could

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comment on how the convention could be useful in the intersection of AIDS and disability even if it doesn't explicitly mention HIV/AIDS.

SHANTHA RAU BARRIGA: Sure. I think that, as I said earlier, that we can use the CRPD to talk about HIV from a holistic approach. We can also look at other conventions to look at how human rights of persons with disabilities and persons living with HIV must be protected. I mean, when you think about it, the human rights of persons living with HIV are really amplified. Human rights violations are really amplified when we're talking about persons with disabilities living with HIV.

The facts are compelling. Persons with disabilities are sex workers. Persons with disabilities are drug users. Persons with disabilities have sexual relationships which, until recent studies by the Bank and others people just didn't and people continue to not believe.

I just did some research in Uganda and we had several women with disabilities tell us how they were treated in hospital settings and health care settings where persons, health care staff were surprised that they were even pregnant. They were even insulted in delivery when they were setting out, you can easily get on this bed if you were able to get pregnant to a woman with a physical disability.

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I think there are lots of violations of human rights that face women with disabilities, persons with disabilities and then added to that the HIV violations, the abuses related to HIV that there are a number of human rights issues that need to be addressed from a wide variety of human rights conventions and laws.

MYROSLAVA TATARYN: Thank you. I think that the link that you make within just the last two minutes that you spoke you raised the reality of people on the ground and linking that with the top-level convention that we have and I think that that's something that hopefully we'll keep doing throughout the session and in our daily work.

Wanjiru at Liverpool VCT works at the front lines of HIV/AIDS service delivery in Kenya. In 2004, Liverpool VCT started a cutting edge outreach program targeted at the Kenyan deaf community. Liverpool VCT trained deaf HIV/AIDS counselors and sign language interpreters and started providing HIV/AIDS education, testing and counseling services at clinics in Nairobi, Kisumu, and Mombasa. Most recently, the deaf program has expanded and has become Liverpool's disability program. I'm wondering, Wanjiru, if you can comment on how this evolution came about?

WANJIRU MUKOMA: Thank you. Maybe before I say how we changed from being a deaf program to being a disability just to mention that what we do is we are primarily a service delivery

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organization that also does a lot of advocacy and technical support to government for policy reforms.

In our service delivery provide the spectrum of the continuum of HIV care. We do this for all populations including people with disabilities. We started as a deaf program because our counselors were meeting a lot of people who came to the VCTs who were deaf to be tested and couldn't communicate. So we started the program as a deaf program but as you rightfully mention, with time we realized that we couldn't just keep it as a program for the deaf population only because we were getting way more clients with other disabilities.

We currently have expanded it. Not comprehensively I must say, but we have expanded it. We include other forms of disabilities. It's still quite strong in terms of providing services to the deaf because all of our service providers are trained in that and we've also trained people at government facilities in sign language to be able to provide services. The transition came because we recognized that it's not just the deaf population we are serving but we are serving people with an array of other disabilities as well.

MYROSLAVA TATARYN: Could you maybe go back a bit as well? It's probably my fault when I asked you the question. But to comment on how Liverpool, which is a mainstream service

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delivery organization in Kenya, came to target the deaf community to begin with even?

WANJIRU MUKOMA: Okay. We started the country's first three voluntary testing and counseling sites in the country. They started as a research project. And subsequent to that, we scaled that up and have assisted to start the majority of HIV testing and counseling centers in the country.

So these services were not just targeted at the general – well primarily targeted at the general population at the time they started. But as I've mentioned before, with the recognition that there are people with disabilities then we had to develop specific programs and specific but also integrated services for people with disabilities.

That's on the service delivery side. But in the policy reforms, we've also been doing a lot of work in advocacy to ensure that disability is given prominence in the national HIV and AIDS response.

MYROSLAVA TATARYN: Thank you. Shantha, your work also includes a lot of advocacy to governments, donors, international NGOs and UN agencies. Have you noticed any shifts in attitudes amongst the mainstream organizations since the convention came into force perhaps even within Human Rights Watch itself?

SHANTHA RAU BARRIGA: Sure. Human Rights Watch is, I think, among the first human rights organizations to start a

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real focus on the issue of disability rights. And we'll admit we've only started this focus in the past year partly in response to the new convention and push from the disability community to get engaged. And we really see this as an engagement and a partnership with the disability communities since they have the expertise particularly from the convention process.

Other mainstream organizations are now also getting involved. And that's encouraging to see. Although based on the reality that we're hearing about the fact that disability isn't really being addressed in many HIV programs and policies, there's a lot of work to be done.

As I see it, the paradigm shift which is the new thinking about disability that was part of the negotiation process of the convention has been slow to expand beyond the walls of the UN and the basement. And at least from my experience, people aren't really aware of the convention and government on the national level in service organizations.

And they don't have necessarily an understanding of how to even interact with persons with disabilities. What terms to use. Do I say person with mental disability? Do I say intellectual disability? And, how to communicate with persons with disabilities.

And so I think there are also people who have a charity approach to disability still. Say a paternalist approach as to

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opposed to embracing the rights based approach that the convention really pushes forward. So I think there's a lot of work to be done. I think the convention is very ambitious and it requires a whole community of us to continue to educate the different actors and also to figure out good practices. I think the convention lays out several complex issues.

If we even take the issue of informed consent, particularly with regard to HIV, what does that look like in regards to persons with disabilities living with HIV? How does that work? How do you ensure informed consent with a person who has a mental disability, with a person who is deaf to ensure that there's confidentiality in the treatment and in the support prior to and following HIV testing and treatment?

So there are a lot of issues that relate to HIV and persons with disabilities that we haven't figured out yet as a disability community, as a human rights community. And I think we need to work on those because the convention is so ambitious. It's only two years old. So there are a lot of things we still need to figure out.

And we have to make sure that in order to have universal access [Applause] that people with disabilities are at the table and that they are engaged in finding these solutions and figuring out how to actually turn the law into practice on the ground.

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MYROSLAVA TATARYN: Thank you. And Rosangela, in your own work, you work in a region that most of us haven't been involved in. Can you comment on any changes that you may have noticed in your own work on HIV/AIDS since the entry into [inaudible] convention?

ROSANGELA BERMAN BIELER: Sure. I currently work both in Latin America and the Caribbean region and also in the Portuguese speaking countries of Africa and the - well I can't avoid mentioning this. I remember when we started; it was 2004 with little projects sponsored by the World Bank. That was the lead agencies starting to push for disability issues.

And after 2006, we started in the [inaudible] region a big initiative still by money from the World Bank but now working with seven national HIV/AIDS programs. And we had the support of all the sectors; people living with HIV, disability movement, people living with disabilities and HIV, government, professionals. All the areas we have a working group of experts on the field.

And the programs, themselves, in terms of their public policy starting to mainstream the topic and this is because now the issue can be in the agenda. Even if people work on this before, now they have the money and they are allowed to include a new area in this area that is so complex.

I remember that in Brazil - I'm from Brazil. And, in 2005 I think, we went to one of the meeting of the network of

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people living with HIV. And it was the first panel on HIV and disability. Everybody was afraid that nobody would be there. It would be rejected. When we got into this room which was pretty big, it was packed. And I have friends here that were there too.

And, all these people living with HIV with all sorts of disabilities were like anxious to talk about this because they were discriminated within their own community. And they would not feel empowered enough to talk about their disabilities in all of this. And now I hear the same group saying that in every meeting they have in national levels, regional levels; now this is a topic that is always present.

In Mozambique for example, three projects, ongoing projects on HIV and disabilities with a different cooperation agencies and the DPOs of the local organizations of people with disabilities and another one just being prepared to. So you just see that much more things are happening, again, because not specifically only because of the convention but of course, it helped build momentum for everything to start arising really.

MYROSLAVA TATARYN: Excellent. And I agree that we've seen a lot of promising changes. I recently came back from a trip to Ethiopia providing technical assistance to large NGOs, funding and implementing USAID funded HIV/AIDS initiative. So, UNAID being the foreign assistance of the U.S. Government.

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So we met with their staff and their implementing partners and tried to help find ways that they would then integrate more people and organizations of people living with disabilities. So over the course of three weeks, I had the opportunity to meet with disabled people's organizations and many mainstream implementers who are ready to systematically include people with disabilities as well as inclusive development perspectives in their work.

It was encourage and exciting. However, there are few organizations actually collecting statistics on disability. We still have a weak empirical evidence base to guide our interventions and so on. So there's still a lot to be done.

And I wonder if we could take a few minutes to explore the frustrations that we're dealing with; the challenges in our daily advocacy work in an attempt then to identify steps that could be taken to overcome these challenges.

So, I think we'll each have an opportunity to speak. So maybe Steve, if you have any particular challenges that you encounter in your international advocacy work.

STEVE ESTEY: I have some many challenges, Myro, I don't know where to begin. [Laughter]

MYROSLAVA TATARYN: We only have two minutes each. [Laughter] You know just be very selective.

STEVE ESTEY: In terms of implementation of the treaty and things, we're moving into a phase now where the treaty has

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entered into [inaudible] and there has been a committee of experts set up that will begin reviewing reports from countries this year. This year?

MYROSLAVA TATARYN: Next year.

STEVE ESTEY: Next year. Next year. So from the NGO side, from the disability community side, there's a lot of challenging work to engage our members and to build their capacity to be able to respond to this opportunity.

You talked about data gathering and information and things like that. And that's a vast area. There's a – if the treaty calls for it and expect once a state ratifies, within two years of their ratification, they will file what's called a baseline report on how they're meeting their obligations under the convention. About 80 countries have ratified.

Three or four have already submitted their first reports. But there's a huge amount of capacity building from the NGO side or on the NGO side around this. Because the reports have not just state reports and a country will file a report on how it's meeting its obligations. But as you might anticipate, a country will file a report that accentuates the positive things that they're doing to meet their obligations as to oppose to highlight gaps in their obligation meeting.

But civil society is able to file what's called shadow or parallel reports. And we're working very hard to build the

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capacity of our organizations to respond to this. And it's a huge task.

MYRASLAVA TATARYN: Thank you. Shantha.

SHANTHA RAU BARRIGA: Well, I think one of the issues that is challenging in our work is accessibility. And I'm not an accessibility expert but - and then I must say that the IAS has made, from my view, a really great effort in making this conference as accessible as possible. And I think of course, it's a learning process. And there's ways to improve it. But they've been provided Braille and wheelchairs even people to assist with the wheelchairs.

But as I understand of the 25,000 or 30,000 people who came to this conference and I'm not really sure on the exact number of people who are here. I think I've seen only two deaf people. I'm sitting next to one of them and the other one, I don't think, is here. That's two people of let's be conservative and say 20,000 people who are here. Now I don't feel like that's very representative.

And the question is; why aren't there more deaf people here? And that's frustrating for me that the disability community isn't more represented here. And not more represented, not just here in this conference but no decision making bodies, in planning committees and everywhere in order to avoid issues that are of inaccessibility and of a lack of inclusion.

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Now I met a young deaf woman in my work in Tanzania a few years ago. And she told me how she was raped by a friend of her friend. And how she couldn't communicate no to this person or even if she tried, it wasn't really considered no because she was a deaf woman so, clearly she was lucky to be having sex with a man anyway. These are the kinds of perspectives that we don't get if we don't have everyone from the disability community at the table.

If I can share a couple of the voices of women with disabilities whom I met in my recent research in Uganda. One woman, the first words she told us, she said I'm a woman with a disability. I'm HIV positive and I am on ARVs. My life is very hard. It took a long time for me to declare my status. I felt I should just die.

Another woman from Uganda also with HIV told us I can't bathe near others. My neighbors think that the water that comes off of me has HIV in it. They say I will get the community sick if they touch the water. There have been HIV sensitization in the community but there's no real change in the attitudes.

And another woman, a fairly young woman with Polio whom I met was raped by a man in her community at night. She was raped three times the week before I met her because there was no lock on her door. And she told me that she had not been tested for HIV because she could not crawl to the long distance

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it would take in order to get to the testing cite. And she would have to sleep on the street or sleep on the road in order to get there. And instead she said to me in her own words that she must "live without knowing".

And these are the people's voices that I feel are not reflected in the work that in the mainstream organizations in the UN agencies. And that's where I think we need to start including people and then getting their voices heard and then hopefully making some changes in their lives.

MYROSLAVA TATARYN: Thank you. Wanjiru, you work on a daily basis at a grassroots service delivery organization that also provides the services and is also advocating. So what do you find are your biggest advocacy challenges?

WANJIRU MUKOMA: Mainly. There are big ones. And there are very high level ones. And there are very low level ones. One of my biggest high level frustrations is corruption within government. And that like in Kenya for example, some of you might have heard recently, members of parliament want to raise their salaries. They are already one of the highest paid cabinets in the world. And this in the face of so many public health problems; that's very, very frustrating.

But on a lower level, what frustrates me most is when we can't get very small things that don't require a huge amount of money. There's often little funding for the area of disability and HIV anyway. Even for us a service delivery

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organization, we have very limited funding to do the work that we do.

But some of it doesn't cost much actually. Some of it is common sense. For example in Kenya today, we have a huge reconstruction of roads in the big cities. And they're building new roads. They're repairing old roads. They're building walkways. None of those have ramps for example. Something as simple as that that doesn't take a huge amount of money. It just takes a little bit of common sense to put a ramp as you're building the walkway to make life easier for people with disabilities.

And then things like translating IAS material, for example. It costs about, I think maybe less than - around 10 cents U.S. to translate an info sheet like this one into Braille. But we can't get things like those done. So that really frustrates me because it don't cost a whole lot of money. It just takes a little bit of extra willingness to do what we need to do to make things a little bit easier and accessible.

MYROSLAVA TATARYN: Rosangela.

ROSANGELA BERMAN BIELER: Well I confess that I have more excitement than frustration right now [Laughter] looking from the development perspective and the possibilities that we have in terms of influencing public policies in corporation and in our mainstreaming activities really.

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One of the challenges, I think, focusing in this direction would be really how to put together a real alliance between the disability sector and the HIV sectors even within the ministers of health in each country. Many times the disability unit within the ministry of health never set together with the HIV program. And this is just starting to happen but it is starting to happen.

Then I think that the possibilities right now, for example that the disability community through the DPOs that we have, start contributing to the HIV sector is huge. Because we, as in a community level, can help with peer counseling and the whole process of integration and inclusion of people living with HIV and with associated disabilities. We can work with our peers also in terms of facilitating materials and information. It is information out there already and before there was no.

And more and more, I think that this process will increase. I'm really positive about it. And I hope that we can find ways of bringing the two sectors together to start strategizing because it will be something that will benefit both sides in any case. And, I'm sure we will have more and more best practices to document and to integrate in the national programs and everything.

MYROSLAVA TATARYN: Okay. Thank you. Yes, Shantha, you have a follow-up question.

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SHANTHA RAU BARRIGA: I - no, I just wanted to also mention another challenge of this movement and this - that we are facing now is just how to address the stigma associated with both HIV and living with a disability. I think it's really one of the most difficult things that we'll be working on in the next two years. I'm also optimistic that we'll get there.

But I think when you think about disability, people don't like to talk about disability. People don't like to talk about HIV. And, but in regards to disability in particular, people don't want to conceptualize the fact that almost everyone will likely have a disability or be affected in some way by a disability whether it's someone in their family or someone close to them in their lifetime.

So it's an issue that actually affects everyone. And when governments start to see that investing in disability rights is really investing in the entire population then hopefully we'll actually see more mainstreaming going on. But, I feel like that's one of the hurdles that we need to cross is really the stigma around disability and of course, the same about HIV which is then amplified when you have persons with disabilities living with HIV.

MYROSLAVA TATARYN: Thank you. I wonder if there are any comments at this juncture from the audience. We will have more time even at the end, we're not - we'll still have a bit

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more discussion up here. But, at this point perhaps, I know that a lot of you have worked in the field of AIDS and disability. And I wonder if any of you have comments or responses to the challenges that have been raised. Or maybe you would like to add some of your own challenges to the ones that have already been mentioned. I'll take one or two comments if there are before we keep going. Yes, please at mike two.

EMMA VERLANDER: Yes. I want to thank you for your presentations. It's been really nice. I'm Emma Verlander [misspelled?]. I work for the Swedish Disability Federation. And we work a lot with the convention. And we do share the reports and all of that that Steve was talking about.

And Myroslava, you had a question that I didn't feel was quite answered about how to use the convention on HIV questions directly. As in at least in Sweden, we work with HIV [Applause] as a disability. It's not only people with other disabilities but AIDS and HIV as a disability in itself. And I know that it's not considered to be a disability in some countries. But the convention, itself, doesn't - the way we see it, exclude HIV.

And I wonder if you could just comment on that. And if you, why isn't this convention sort of the basis for the right based approach for everyone, advocacy rights for people with HIV? If you could just comment on that, I'd be very happy.

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MYROSLAVA TATARYN: Okay. We will get to that. Like I'll make sure that we address it in our session. I'll just see if there's any other comments at this point.

DARRYL: Hello. Sorry. My name's Darryl. I work with Handicap International. I'm from Australia but I'm working in the Middle East. I have the same question myself because I see the CRPD as a real tool to move forward. If we're talking about a rights based approach, I don't think it's enough to wait until the person with HIV has some manifestation of a physical or psychological disability or impairment.

If somebody's asymptomatic, they will experience stigma, discrimination, issues with access to justice, access to employment, all of those things, travel restrictions. And I think it's perhaps time that we really embrace a rights based approach.

And, a question for Steve, I guess for DPI. I was reading I don't know whether it was a policy brief or it was a document from DPI. I don't know if it's out-of-date now. But it talked about HIV and disability. And what I gleaned from that paper was that people with disabilities are at greater risk of contracting HIV.

And people with disabilities should be included in mainstream HIV programs. But it didn't anywhere in the document expressly or even implicitly state that people with HIV are people with disabilities. So I would like a comment to

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see whether that's still the position of DPI or whether international DPOs are actually going to look at that from a rights based approach. Thanks.

MYROSLAVA TATARYN: I think we'll take one more question at the back and then we'll move on with our discussion. And there will be more time for questions and comments at the end.

AMARILLA HENRY: Good evening. My name is Amarilla Henry. I'm from Antigua and Barbuda and I'm the Public Relations Officer for the Antigua and Barbuda Persons Association with Disabilities. I, too, agree with the two previous speakers.

What one thing I've been lobbying for and I haven't been seeing and I do work as a sign language interpreter for the government information back home at the ABSTV. And, I've working - trying so hard to see if we could get. I'm proud to see we're having some work in Braille for my friends here. But in sign language, I would really love to see some.

And this is a question for Steve from disabled people's international. I ask the same question so Mr. George Daniels before he died this year. I still didn't get an answer and still didn't get an answer from our regional office, Mr. Leslie Manuel. Why there wasn't an invitation extended to the local assembly in Antigua and Barbuda?

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I'm here because I'm also founding member of Antigua and Barbuda HIV/AIDS at Work. I was in Mexico two years ago. And I observed that for the first time, two years ago, we were invited. And up to now, Antigua has not been still invited. I don't know if it's from you, Steve or if it's from our regional director I know it's in your quarters to find out from Mr. Steve Manuel. Thank you very much.

MYROSLAVA TATARYN: Thank you. Okay. So I think that [Laughter] the comments are - this last comment I hope will get to in a bit. I'm not ignoring them. I've noted them. I just want to stay a bit focused on specifically the challenges in the movement AIDS and disability specifically. Things that will be useful for as many people in the audience as possible but we'll get back to more details at the end.

In terms of the convention and people living with AIDS and whether or not they're disabled, it's tricky. Because I think that it varies a lot depending on the country, depending on the social context. And each group also of people living with AIDS will have their own feelings of whether or not they want to identify as disabled or not.

And because of the long fight for people living with HIV in many contexts of trying to get people to realize that they're not just dying. Like they don't want to get sent off, they want to be seen as fully functioning.

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I think that there's also been resistance from organizations of people living with AIDS to be identified as disabled. So, it's not just that one side is pushing for that and the other one is blocking the way. I think that there has been a lack of clarity and a lack of cohesion on both sides. So I just wanted to point that out.

Also I think that part of the reason why perhaps some of the discussion has been framed both as people with sort of preexisting disabilities and people with disabilities looking at HIV/AIDS issues and why that, to some extent, has been a bit separate from people with HIV acquiring disability is that often in the movement what we find is that people who acquire disabilities through different means. And in different contexts, it looks different.

Sometimes you see that it takes over everything. And I'm not saying and like people on the panel can disagree with me. And we can have a discussion. And I'm not but it's sort of that - what's the expression - like the elephant in the bathtub or something like that. I don't [Laughter] I'm bad with my - I mix my different metaphors. It gets messy.

[Laughter]

But basically, you have a very, very large movement. And then there probably has been some nervousness within the disability movement that has not marginalized and that it will take over. And I'm not saying that that concern is entirely

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legitimate but I think that that's some reason why there's sort of been this dance between movements. I guess there are intersections but if all people with HIV automatically are disabled will our concerns of people with preexisting disabilities will that still be a concern?

It's sort of like some people - in my experience in Northern Uganda, there were concerns with people who acquire disabilities from landmines, okay, because all the landmine people were getting money. But people who had grown up with disabilities weren't because they had all the political clout and all the new funding.

And so I think that as we - I'm not saying that we should stay segregated not at all. But as we move forward, I think it's important to remain truly inclusive and truly not discriminate based on how somebody's disability was acquired or what their exact diagnosis or label is. So that would be my comment.

WANJIRU MUKAMA: I just want to comment on that because I think that it's an important discussion and one that we will have to have in a more comprehensive way at some point because I am working in a service delivery organization and one, we need to recognize also that if you're living with HIV, disability can be temporary or permanent and one of the most common temporary disabilities for people living with HIV is mental impairments like dementia for example and it's quite

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common, perhaps more common than a lot of people might think but it's also one of the disabilities that is very, very much ignored.

I think at least my context - it might be different in different countries - but in Kenya and certainly in Africa mental disability, intellectual impairments or any kind of mental impairment which is very common amongst people living with HIV is also one of the areas of HIV and of health that is very, very ignored.

So it is an important issue that's coming up and it's a discussion that as we put more and more people on treatment and people live longer, it's a discussion that you're going to have to have and it has huge implications for our public healthcare systems particularly for mental healthcare systems in developing countries.

ROSANGELA BERMAN BIELER: Thank you. Well many different things here. About the Convention, I think that something that I learned during the negotiation process is that a convention is the minimum basis that all the countries in the world can agree with and the countries are very different, they have very different cultures and they can't agree not in many things.

For example, I remember the whole discussion on sexuality. Sexuality was a word prohibited in the Convention, right? You don't see the word there. You could not talk about

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sexual and reproductive issues of women. You could not talk about many things and many other things were not explicitly in the Convention, then I don't think it was something like let's leave HIV out.

There's many things that could be there but what the Convention is, is minimum standard that everybody can agree with and the we build on it like the MDGs. You were talking about the middle island development goals and there's no disability mentioned on the MDGs. We know that we are retracted there because if you don't work with the 10-percent of this or more of people with disabilities in the world, you will not achieve any of the MDGs by 2015 or never.

But what I think that it - it's like we are in a transition of understanding what's going on, the whole change of paradigms from the medical to the social model in the disability and I think in the HIV sector as well.

For example, today we went to one of the booths in the exhibition and I saw this t-shirt that I got that it's nothing on us without us, right? And this came from the women's movement and that's exactly the same slogan that the disability movement has, nothing about us without us.

I think that we are in this transition then. When we started working with HIV, nobody with HIV wanted to have disabilities included because it was a matter of funding, this was a matter of double discrimination that they did not want to

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include and actually there was not enough evidence that disabilities would be a natural consequence of the treatment because until that point, we were talking about prevention for everybody.

The treatments were not still long enough to have all the proofs what would happen. Then it was being monitored so people would get the [inaudible]. Then I think it's a whole process of changing and evolving that is going on from both sides. I don't think we really should consider that we are talking about two different things, but how we try to integrate all the issues that are going on from the medical to the human rights and to the social model just is.

MYROSLAVA TATARYN: Thank you. Shantha.

SHANTHA RAU BARRIGA: Just to also clarify, the Convention does not define disability and it intentionally didn't define disability because no one could agree as Rosangela was saying what was disability. In different countries, it was different.

In some countries, HIV is a disability and some countries, particularly in Africa or other developing countries, HIV is not considered a disability because the issue would multiply the numbers of people who need to be addressed.

However, the Treaty Body, the CRPD Committee that Steve referenced earlier, is the body that monitors the Treaty and interprets the Treaty. So at some point the CRPD Committee

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could come out with an interpretation saying the right to health. includes and it may reflect the fact that HIV and perhaps some other issues are a particular issue of concern under Article 25 on the right to health.

So it doesn't mean that – and that might be an issue of lobbying for some disability organizations or NGOs if they push the Committee to make an interpretation and make it explicit that right to health does apply to persons living with HIV and particularly those with disabilities.

So there is room for this Convention to be applied to people living with HIV as well. It's just a matter of how it's interpreted and we could get some authoritative documents to reflect how it should be interpreted, but now we can interpret it very progressively because it is so broad and it is very vague in many places.

I think it's to our benefit that the Convention is written the way it is and doesn't enumerate specific because in 35 years, there might be a completely new epidemic that we don't even know will exist that we would also want it to apply to so it's written intentionally to last for a long time as an international treaty.

STEVE ESTEY: The moderator has urged me to succinct and I'll do my best. To pick up quickly on what Shantha was saying in terms of where we were during the drafting of the Treaty itself, I can remember discussions about whether or not

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HIV/AIDS should be included and those discussions were often reference to earlier pandemics, things like polio for example. There was a whole discussion I can remember being part of and if the Convention had been drafted in the 1950s, then there would have been a big push to have polio as part of it.

The idea was expressed at that time, that the Convention is meant to be a document that will have a very long life and to connect it specifically to a certain disability or a certain set of characteristics would perhaps limit it in the long run. So the decision was made not to do that.

Now very quickly to respond to the two points that were addressed to DPI, first of all my friend from Australia was asking about definitions and so on and DPI is a consumer organization and a credo of other organization around definition is that if a person chooses to self identify as having a disability then they are for all intents and purposes from DPI point of view, a person with a disability.

We don't set up standards. We don't say yes, you are disable and no you're not disabled. We just say if you see yourself as a person with a disability then indeed you are from our point of view. Quickly again to respond to the question from the back with regards to the situation in Antigua Barbuda, frankly I'm perplexed by that.

I was at a meeting in 2006 or 2007 organized by the same Mr. Leslie Emanuel that you mentioned that was a regional

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meeting of DPI and two days of that meeting were specifically on HIV/AIDS and disability issues.

So I'm not sure what's going on. There's clearly some kind of a disconnect here and I would invite you to come up and speak with me afterwards. I don't think we need to trouble the whole group with it, but I would really like to speak to you about it because I think we need to get to the bottom of it.

MYROSLAVA TATARYN: Thank you. Again like I said, we will continue on the discussion a little bit more up here and then open up the floor once again. I think despite these challenges, our movement has accomplished a lot in the past decade.

I think that after the entry into force of the Convention, there was a collective sigh of relief, but I'm wondering if any of my panelists would say that there is perhaps some complacency in the movement now. Have we relaxed too much? Maybe complacency is too strong a word.

Perhaps it's just a necessary pause as we formulate where we should go next. Rosangela, I wonder if you have any comments on this.

ROSANGELA BERMAN BIELER: I have a lot. I don't believe in pauses first of all and I think that advocacy can never pause. I think that that's a permanent every second attitude of advocates and more than this, I think that when we take as our slogan nothing about us without us, it means that

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we want to be in the center of the process and we have to be able to respond to this position, right, then if I want to be in the center and I think I should be in the center, then I should be part of the whole process and you cannot just go home for a little just to reflect on what's going on and think about strategies.

I think now we have to build a lot of capacity in the disable peoples' organizations within the governments, within the agencies, everybody, but especially within the disability movement because maybe we are not as prepared as we should because I'm sure that the demand from the field, the demand from the agencies, from the government, will be very intense on us and then I think that we should really be ready to respond with practical, strategic and concrete actions to collaborate, not only revindicating rights but also to collaborating in making them happen.

MYROSLAVA TATARYN: How can we build that capacity?

ROSANGELA BERMAN BIELER: How can we? Working a lot, networking a lot, being in touch and thinking strategically as a movement and now is no time for any division. I think that we have to add forces with the people living with HIV, with women. We are talking about sexual and reproductive issues and healthcare. All of these issues are in the society in general and we should be part of all of them.

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Every time it's a challenge just to bring another area, even DPI had this experience when we started trying to work together with the women's movement, a lot of resistance from both sides and I think that now it's time to network and to partner and to get as close as possible so we can get stronger and be able to really collaborate.

MYROSLAVA TATARYN: Thank you. Wanjiru, from your perspective and programs and daily operations, what do you think should be the priority for work in this field in the next two years?

WANJIRU MUKOMA: Just before I answer that, just to agree with her that we can't take a break in advocacy and maybe to throw that back to you at AIDS Free World, seeing as you've done such a good job here at this conference and to ES how are we going to build on the momentum from here? You are asking whether we're taking a pause. I know that we should be rekindling this in a different way, but perhaps that's something for you to think about, how you take this forward from here and build on the momentum that we have started from here to take this forward.

From daily operations, what I see as some of the priorities, I think universal access for people with disabilities whether it's pre-existing disabilities or disabilities that arise out of living with HIV and AIDS. I think universal access for persons with disabilities we can't

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achieve MDGs, we can't say we've achieved universal access if you haven't done that for people with disabilities.

And I think we also need to think beyond just HIV because in my context, and I'm sure in many others contexts. HIV care is not provided as a separate service outside of all other healthcare firstly, and secondly, persons with disabilities also need other healthcare and they experience exactly the same problems.

So I think we should also look at it that way in terms of service delivery that we don't make it so focused on HIV that it actually becomes a limitation for persons with disabilities in accessing other forms of healthcare. I think another priority that I see in the next two years is continued advocacy and building on the momentum from here and momentum that we've created in our different countries, in our own settings.

We cannot relax on advocacy. We can't do that, both in terms of policy. If you go to the disability zone at the Global Village you'll see the good work that Jill Hannes [misspelled?] and others have done with national strategic plans in East and Southern Africa and only about 50-percent actually have considered disability as an issue.

So we need to continue doing advocacy to ensure that disability is included in all national HIV strategy plans because that's the only way that we know it's going to get some

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sort of funding, at least at that level in the national responses.

MYROSLAVA TATARYN: Thank you. Before we move on with more comments, I want to give you a chance to add your own suggestions for what should be priorities in the next two years or perhaps you have other questions you want to add to this discussion.

Unfortunately we're down to the last 15 minutes, but I do want to give you an opportunity if you want to add anything. I have time for two or three comments. Do I have one person at the very back? No? Okay. I couldn't see because of the camera right there.

Please stand in front of the mic. There's a mic that's lower for wheelchairs as well. Mic number one is lower if that's easier and mic number two is higher.

LELA MONAHAN: I'll do mic number two. Hi. My name's Lela Monahan [misspelled?] and I have been working particularly with the deaf community on HIV/AIDS. In answer to your comment that not a lot of deaf community members have been here, is that there hasn't been a good coordination between the local Austrian deaf community and this convention.

We hope today to have an outreach to have more people tonight. In order to increase the participation of the deaf community, I'm hoping to organize a pre-conference meeting on deafness and disability at Gallaudet University two years from

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now just before the AIDS Convention in Washington, D.C. and everybody here is absolutely invited. I've got a piece of paper if you want to come talk to me and you haven't already signed it.

So this is pie in the sky. It's not set yet, but if anybody has ideas about funding, if anybody has ideas about what they'd like to see, just come talk to me and I'd be happy to talk to them. Thanks and Myroslava, another great panel. Thank you so much.

MIROSLAVA TATARYN: Any other comments or questions before we – yes.

WILL: Hi, my name's Will. I'm an occupational therapist for [inaudible] Hospital in London. Mine's really a comment and I hope it isn't a bit flippant, but I suppose it's the end of a couple of really long days. We've been seeing people living with HIV related disabilities in our clinic. My post has been around for about 15 years. I know my colleagues from the Canadian working group on HIV and rehabilitation have been around since 1998, so it's something we've known about for a long time.

I was at Mexico to Toronto and it's been absolutely outstanding to see the great disability movement work at both conferences and at that this and a little bit at this conference on HIV related disabilities. Myroslava, I love your description that the disability movement and the HIV related

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disability angle have been dancing around each other and I just really hope you we can stop dancing around and jump into bed with each other [laughter] because that's what we need to because its divide and conquer.

Again, to get access for all it's the same resources, it's the same things. It doesn't matter where you got your impairment from or your disability from, it's the same things that you need to live the sort of life that you want to live and we need to work together. We have lots of people in our clinic with a pre-existing disability, with Parkinson's, with stroke, with mental health problems and it makes no difference at all what we do with them, it's about improving people's lives with disabilities.

MIROSLAVA TATARYN: Thank you. I have two more people and then that will be - we'll need to wrap up then. Thank you.

TILLIE: Hi my name is Tillie. I'm representing South African Police. I'm working with people with disabilities in the police services. My main concern is that health workers, they cannot communicate properly with people with disabilities and as and when we advocate for the rights of people with disabilities, I think we need to look at empowering also health professionals to ensure the issue of confidentiality and also the right to right information and also the issue of privacy.

You can just imagine if a deaf person is going to consult and there's an interpreter with the health

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professional, it's really not right and I think we need to look at the issue of empowerment and also on the issue of HIV, just to share with you in South Africa we used to have the grant and also declaring HIV as disability, but that was also depending on the CD4 count and the ability of a person to function.

So people with disabilities are entitled to a grant depending on their functionality, but as soon as they recuperate and their CD4 count is improved, they are reintegrated back into the workplace to ensure that they are back and working for their families. Thank you.

MIROSLAVA TATARYN: Thank you.

ANNA TOYENTE: Hi, I'm Anna Toyente [misspelled?]. I'm from the International Labor Organization and I just wanted to signal that a month ago we have adopted a new labor standard on HIV and AIDS and the world of work and it was very important personally to me.

I'm very happy about the fact that we also focused on the right to reasonable accommodation and in particular on the basis of HIV related disability and also on the fact that first, what we have to do is make sure that people with HIV related disabilities can receive whatever reasonable accommodation they need to stay in their current employment if they become disabled as opposed to leaving them exposed to any kind of demotions or discriminatory redeployment or transfers

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and the new standard also makes reference to the Convention to try and really interlink the two.

So it's a new tool in the area as well that could be taken into consideration. Thank you.

MYROSLAVA TATARYN: Thank you very much and thanks for that intervention. One more, very short.

KASHA: I promise to be really brief. My name is Kasha [misspelled?]. I work at the Vienna based European Union Agency for Fundamental Rights and we are a mainstream human rights organization. We work both on disability and especially for this conference we produced a paper focusing on U27 and The Rights Based Approach to HIV and for a Swedish colleague here, especially and for others if you're working in Europe, you can come and pick up our paper where we explore what it means for European countries to embrace the larger disability definition, especially in the context of employment and what kind of protection would be offered under the new employment legislation to persons living with HIV.

So please come to our stand. It's going to be demolished after probably that session or we'll have another satellite session at 6:30 looking at discrimination aspects of HIV/AIDS in Europe. You can pick up our paper there. Thank you.

MYROSLAVA TATARYN: Thank you so much. This is all really useful for me if not for everyone hopefully. I will ask

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Steve to start with the feedback and also any final comments as we must unfortunately wrap up but I do hope that everyone will be able to keep in touch. You can network on your way out and all of that.

STEVE ESTEY: Myro slipped me a note and ask me to talk a little bit about the importance of a cross disability approach to this thing. DPI is a cross disability organization and there are many, many single disability organizations out there and they all do very important work with people with specific kinds of disabilities. But from the DPI point of view, what we're talking about here as the last intervention spoke about are basic human rights issues.

We're talking about the human rights of people with disabilities across a spectrum and sure, we need to focus on specific disabilities in terms of accommodation and so on, but the bottom line is we're talking about the human rights of people and about the right to access and those kinds of things and whether your access issue is a cart or a ramp or Braille, it doesn't matter. The fundamental issue is the right to access and I think that it's important that we keep that in mind as we move forward.

MYROSLAVA TATARYN: Thank you. Shantha, do you have any responses or final comments?

SHANTHA RAU BARRIGA: I think a lot of us have said I just wonder how many people here in the room haven't heard what

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we've said already this week and how many new people we've reached because I think it's part of the mainstreaming process to ensure that we're not just talking amongst ourselves, among the disability community, but also reaching out and including people within the HIV community, outside the HIV community.

And that's the only way that we'll really bring about inclusion and full participation and making sure that the voices of the people with, in this case people with disabilities living with HIV are really heard and I hope from our part and the human rights [inaudible] that we'll be able to raise the voice of people with disabilities and their broad range of rights that are violated.

MYROSLAVA TATARYN: Thank you. Rosangela, any final comments or responses?

ROSANGELA BERMAN BIELER: I think that everything was said already. Actually just the top of the iceberg of course, that's a huge field that we are all learning. We are learning every day. I think in this case both areas are learning and we should start learning together and now what I just wanted to say is that it seem that we are talking very vaguely about many of the issues that in reality are very easy to put in practice.

There are already responses out there on materials to approach the different communities with disabilities, to the blind, to the deaf. We have best practices. We have everything right there. What we need is visibility. Visibility

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is a very, very critical issue for the disability sector and I think that this is something important to invest how to start creating indicators, how to start measuring disabilities within the programs, the health system, the HIV programs and everything, how we can start highlighting this population as part of the bigger society.

This is certainly a challenge and we hope that we will move ahead on this.

MYROSLAVA TATARYN: Thank you. And Wanjiru.

WANJIRU MUKOMA: Just to echo that really and they show visibility whether it's by developing indicators at national levels that give us information and at local levels, but also recognizing that visibility is not uniform. Some persons with disabilities are more invisible than others, at least in my country. Children and people with mental disabilities are very much more invisible than all others. So just the recognition that it's not all the same in every context and in every disability.

MYROSLAVA TATARYN: Thank you. Steve, one more comment.

STEVE ESTEY: A quick one, I promise. The comment was made about the fact that we're talking to the same group of people here and I've been thinking about that over the past few days. You come to a conference that's this vast and this huge with such a big program, you've got your focus. I mean most of

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my energy has gone into disability related things and thinking about it, it's almost in terms of a phone book.

You don't open up the phone book to look for a place to order pizza and all of a sudden decide on a landscaper to pick [applause]. You know, you have your focus. You come to the conference and you have your area of interest and there's not a lot of time to do other things. So I don't think we should fault ourselves about this. I think we're building capacity within our own group.

I think we need to find ways to reach out otherwise, but I don't think that we should feel badly about the fact that we're talking to lot of the same folks again. Thanks.

SHANTHA RAU BARRIGA: I agree, but at the same time, I feel like if we're talking about 10-percent of the world's population or more, particularly in developing countries, did we hear a single plenary speaker raise the issue of disability? I'm not sure. I didn't hear it, but I wasn't at every plenary, so I confess.

I'm just saying that we need to make sure that our message reaches a broader audience, that we have to build our own capacity but unless we're really promoting the issue beyond the disability community, then we're not going to actually achieve the inclusion that we're hoping to achieve.

MYROSLAVA TATARYN: Thank you for that. But I think that that just speaks to the need to have a good network and

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work together because a lot of it has to do with convincing other people to share issues and I think that something we were talking about yesterday is the way that if for example we don't have many deaf people or blind people, that's not necessarily because the conference is inaccessible.

In fact the IAS has made huge strides in terms of accessibility in the last two years, but it's because the conference is prohibitively expensive and most of these are grassroots organizations like so many people living with AIDS, you're working for poor organizations, you're not going to spend a year's budget to fly somebody to Europe.

It doesn't happen often, so maybe we need to work on more scholarships or more advocacy or whichever, partnering with people who do have money, whatever the solution may be but it points to the integration of our issue, to the fact that it's about physical accessibility but it's also about poverty issues and structural inequality and how all of that fits together.

I think that that's important and that also highlights the way that the convention is here to be used and I think that that's what our discussion was about, was how is it being used, how can it be used and so people living with AIDS, it's yours to use, it's anyone's, it's not an exclusive document, nobody will say that oh you're not entitled, this is my convention, it's not yours.

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I think that coming together here builds that. I hope that you have a chance to meet each other. I hope that you have a chance to pick up the documents that are on your way out. There are more at the Global Village at 6:00 just so as we close now, the Global Village Disability Networking Zone is starting their closing ceremony so there will be events there for the next two hours.

If you want to make your way there to continue this discussion, to get more resources, please do so. Please feel free to speak to us. I thank you once again for coming. Thank you the IAS for making this session possible and a special thank you to our interpreters.

We have sign language interpreters in both languages here as well as the current so I think that they all deserve a very big round of applause [applause]. It says 6:01 on my clock, so thank you very much and have a good night.

[END RECORDING]

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