RAW FILE

IDDC

MAY 18, 2021

1300 P.M. CET

Services Provided By:

Caption First, Inc.

P.O Box 3066

Monument, CO 80132

1‑877‑825‑5234

+001‑719‑481‑9835

Www.captionfirst.com

\*\*\*

This text, document, or file is based on live transcription. Communication Access Realtime Translation (CART), captioning, and/or live transcription are provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings. This text, document or file is not to be distributed or used in any way that may violate copyright law.

\*\*\*

>> METTE MULLER KRISTENSEN: My screen as well.

>> So now I will just ‑‑ do you see my screen or ‑‑

>> METTE MULLER KRISTENSEN: No.

>> All right.

>> DOM HASLAM: I am going to send a message to the people in the waiting room explaining that we will finalizing the technical details and we will let everyone in soon.

>> Actually ‑‑ it is time. So I will open to ‑‑ I will open the room now. Good luck to you all. Break a leg. So the floor is yours, Mette.

>> METTE MULLER KRISTENSEN: Okay. Welcome, everyone. This is like a physical meeting where everyone just needs to get in it the room and find a seat and pour coffee in their cups. So we still have these sounds of people entering the meeting. But a warm welcome to all of you. My name is Mette Muller Kristensen and I am one of two Vice‑Chairs of IDDC and together with the Chair of IDDC, Dom Haslam, I will be moderating this first session. So first of all, some practical details. We are recording this session to be able to share on Youtube afterwards. So now you know.   
 And kindly make sure you have your right name shown on your picture together with the abbreviation of your organization. And then I would like to invite you to write in the chat where you are joining today's workshop from, which city are you in, and if possible, also how is the weather just so we get a sense of where people are joining in from.   
 And I kindly have your microphone muted unless you are asking a question. And then you can raise your hand if you click on participants, and then you can raise your hand and we can see who has questions. But while the last people are coming in the room, I'd like to give the word to the Chair of IDDC, Dom Haslam.

>> DOM HASLAM: Thank you very much Mette, I hope you can all hear me well. Thank you to everybody who is joining as we go. It is great to see so much interest in what I think is one of the big questions facing us at the moment around building back inclusively obviously from the pandemic, and in some ways it feels, I don't know, some of you are joining from parts of the world where we are still in the middle of serious waves of the pandemic but I think it is important that we look at it now. As one of the ‑‑ one of the ways that I have heard the pandemic described by Vladimir from IDA is shining a light on how far we have yet to go. With those of us working with the disability movement and from the disability movement I think it's always been clear that there is a long way to go but COVID has really shone a light on that. At times it is great to celebrate the ways that we have made about the CRPD, around the Sustainable Development Goals being far more inclusive than their predecessor but COVID has taught us the lesson again if we needed to learn it again and taught the rest of the world that we have so far to go still in terms of the situations that many people are living in and the barriers that they face. And one of the reasons the series webinars that we have this week, building back inclusively. It reminds me a little bit of the phrase that came out from the Sustainable Development Goals of talking about leaving no one behind and everyone has very different definitions of who the no one they want to leave behind. When we talk about building back better, that that includes the inclusion of Persons with Disabilities, because if we don't push for it, there is every opportunity for the world to claim it's built back better and yet still leaving people with disabilities behind.   
 So I'm really pleased that we are launching the sessions this week with this session kind of looking generally at experience of living with the pandemic and in some places recovery. But in many places still very much living through the center of it.   
 And it's the first in a series of workshops that we have this week. Also today we have one on COVID recovery and disability rights. And tomorrow we have two. One around climate change and disability. And one around access to digital learning, education subtitled technology, the pitfalls and opportunities. So I'm ‑‑ I think we're sharing the links to those in the chat box and then finally finishing off on Friday with a session around civic space and meaningful participation, apologies to those of who have good hearing who can hear my washing machine beeping in my background. That's been one of the sound tracks to the lockdown and my experience of the pandemic. I didn't really want to say much more than that. We have a range of great speakers who have agreed to come and share their thoughts and experiences with you. I can't think of kicking off with anybody better than Gerard Quinn. Gerard welcome. And thank you so much for giving your time for us today. Gerard was appointed UN Special Rapporteur on the rights of Persons with Disabilities in October 2020 taking over the I would say large shoes, I hope that's not insulting to Catalina, but Catalina Devandas. He has also served on the Ireland's commission on people with disabilities and Human Rights commission. Was the lead focal point of global network of national Human Rights institutions during much of the negotiation of the CRPD which we know very well. He has agreed to share some thoughts and reflections of his first year on Special Rapporteur, with particular interest on the reaction to the pandemic. Gerard is going to speak for 15 minutes and then a space for Q and A and then we will move on to the other speakers. If you have questions that come up, please add them in to the chat box so we can get to as many as possible after that. So with that I will take great pleasure in handing over to Gerard. Gerard, please the floor is yours.

>> GERARD QUINN: Thank you, Dom. Thank you, Mette. I'm deeply honored to be with you here today. I'd like to use the time to just share some reflections on where we are at today, how we might face the future, and especially the immediate future with its many challenges. To do so I'd like to do just three things. First of all, I want to add some personal reflections on the paradigm shift or the paradigm shifts if you will of the UNCRPD and the UN SDGs. There is very deep chemistry at play here. It is not reducible to a few slogan and I want to try and unpack that a little bit. Secondly I will reflect on some of the main challenges. You all know them very well. They are aptly reflected in your program. I will be brief. Let me reflect on the crossroads that we are at now. Paradoxically at exactly the time where the need is greatest development assistance programs seem to be in retreat giving rise to obvious questions like how can we consolidate our gains and what ought to be our priorities going forward in to the future.   
 But first a word or two on paradigms. Take the CRPD, I've often said there are actually two paradigm shifts in the CRPD. The first has to do with substance and the second has to do with process.   
 First substance, at the outset I think we were all very naive in entering in to the negotiations for the Treaty. We thought the Treaty would be another equal opportunity tract, except this time adopted at the international level. We all know by now that Civil Society pushed the drafters to go further. Why deal with the symptoms of exclusion and not the root cause?   
 And that's why personhood, voice, choice and control was ultimately deemed fundamental to the Treaty. And the social conception of the person in the Convention explains why inclusion and participation are foregrounded in nearly every pore of the Convention. They were more faithful to the original ideas of Universal Declaration than any other Human Rights Treaties. Why? Because economic and Human Rights were carefully commingled with civil and political rights. What's the point of having a right to go to school if the teachers are not trained to be sensitive to the learning needs of children with disabilities? Or if the school building is itself inaccessible or if there is no accessible transport available.   
 So personhood, inclusion, and the careful tiering of economic and social supports are crucial innovations in the CRPD. But there was another paradigm shift and it has to do with process and sometimes I think this is even more important than the substantive innovations. What's the point of correcting bad laws or even enacting new good laws if the process is itself flawed and is therefore liable to introduce bad laws in to the future. This is why collective voice and the right to coproduce policy in to the future is so important. At one level the CRPD does not have all of the answers. But it imagines a process whereby we work it out for yourselves in a constructive relationship between power, Government, voice, Civil Society, and ideas which are blue prints for change. It's this paradigm shift, the process based paradigm shift that allows for a new politics of disability. It plays to the Democratic responsiveness of systems, and indeed helps in rat racheting open the Democratic responsiveness of systems. To me the CRPD is a very delicate dance between substantive innovation, especially its emphasis on personhood and inclusion and process based innovation, especially its emphasis on coproduction as the way forward. This is mirrored and indeed fur entrenched in the UN SDGs. Many people insist UN SDGs are limited by, are bounded by Human Rights. I see it a bit more broadly. I see the SDGs as adding to or refreshing Human Rights. Why?   
 Well, in the past much of our rights thinking was sequential. First comes economic development, then comes social change. Then comes the progressive enjoyment of Human Rights, especially where those rights require social investment. So there was a temptation to see rights as a result of development, rather than as a precondition for development. And I think this has been stood on its head by the deep logic because of the SDGs. Economic development, change, environmental protection, and Human Rights as a circular ecosystem and not a sequence. And that's crucial. Implicit to me the process innovations are also in the SDGs. Voice is critically important in securing equality for all. Why do I say all of this? Well, within the past there might have been a temptation to think of development assistance in the disability field as a simple transfer of material assets to meet unmet needs which is itself a very patronizing narrative. Now inasmuch as it involves material exchange our imperative is not to spend it or disperse it in ways that reinforce exclusion, and at a minimum our investments should do no harm. They should nudge positive developments, for example, in inclusive education, find it hard to slip their Moorings in the medical model. Our investments should seed the process of change by acknowledging ownership of change by local forces and by finding ways to animate the golden triangle between Government, voice and Civil Society and ideas for change. To me this twin‑track approach inclusive investments and discrete fields as well as nurturing the capacity of society to face and respond to its own challenges is powerfully reinforced by viewing the CRPD alongside the SDGs.   
 And it underpins development and assistance. What about the challenges? Let me say at the outset and Dom has already alluded to this, our biggest challenge has to do with the sustainability and the strength of the paradigm shift or the various paradigm shifts. What do I mean by this? Well, moments of crisis reveal deep truths. And the deep truth is that the various paradigm shifts in the UNCRPD and the UN SDGs have not sunk deep enough roots. Or to put this another way, the old medical model hasn't disappeared and it rears its ugly head during periods of crisis. Maybe that's to be expected. Old paradigms don't just die. They linger on in the half life of policy and are deeply encoded in systems we inherited. Even very modest services during COVID‑19. You all know the impacts are astonishing. Under inclusive preventive strategies meant that groups in vulnerable situations were not reached. Women and girls with disabilities were E posed to more silence. Persons with Disabilities were placed in institutions institutions that should not exist were at heightened risk. Their isolation was compounded by no visitation rules. Unequal treatment when it came to medical assistance was rampant. So when it mattered most, most systems reverted to type, and the medical model and not the Human Rights model came to the floor. It seemed to be a luxury to be added back in once the crisis was over and not reflex deeply ingrained in to the system. It gives rise to profound questions. How can we sink the pillars of the CRPD and SDGs deeper in to our various system. I'm sure part of the system has to do with persuading systems that a proper consideration of the rights of people with disabilities helps not only in legitimatizing actions but also assists in the efficiency of those actions. After all, if there had been proper coproduction of initial policy responses to COVID‑19, then many of the mistakes might not have been met. So COVID‑19 to me not only reveals deep systemic inequality, we all knew they existed. It also reveals the gap between the law and the books. The Treaty out there in the sphere, ethos sphere and the law and action on the ground. The paradigm shift or the paradigm shifts in the CRPD is a work‑in‑progress. Not a done deal.   
 A word or two about the main challenges. If systems have a tendency to revert to type during emergencies, then what might we expect during the next phase of COVID recovery efforts? An enormous amount of money turns on this, even in the European Union itself. Put it bluntly there may be a temptation to invest in existing systems, tend to have an exclusionary impact on Persons with Disabilities. It's a quick fix and systems can claim they're investing in disability. Those acting within those systems usually experience no cognitive dissidence. Professing support for Human Rights on the one hand, is kept at arm's length with how spending programs are put together on the other hand. To verse processes of exclusion, and build a more inclusive society could well be missed. Follow the money. Make sure it does no harm or compounds existing harm and try to steer it forward more inclusion. What of digitalization? Just let me say one or two words here. The digital divide is disconcerting. I have often written about the good value of good public procurement law, something included in the UN disability inclusion strategy. But this isn't just a question of access. Virtual environments do not suit everybody. Furthermore, and this exercises me greatly, while we can purge ourselves as humans from Ableism or ageism, we find that machines just love Ableism and ageism. Machine learning and machine decision making is now rampant and so interwoven in our lives we don't even notice it any more. Finding ways of harnessing new Artificial Intelligence technology will be one of our biggest challenges over the next few years and now is a very crucial time in this endeavor. AI promises to fundamentally reset the terms of our existence as humans. If those systems revert to type, if they are allowed to revert to type, then we will have signally failed to build more inclusive societies with the aid of technology.   
 This just cannot be allowed to happen. Speaking of if he nom men ma will that fundamentally reset how we live, climate change is up there. It will not impact everyone equally. It will impact those most directly those benefitted from carbon based economic development in the past. It will hit indigenous communities hard. Plans to mitigate its effects will need to be coproduced with a communities affected by includes Persons with Disabilities.   
 I might add that intentional efforts to build a noncarbon based economy will have to include a consideration of the future of work to make it more inclusive of Persons with Disabilities.   
 This can be done but it is best done from the outset. So that the new jobs for workers with disabilities are not an add on extra ten years later, but a core feature of a more inclusive noncarbon based economy. And civic space, the process based innovations of the CRPD and the SDGs are a key. The CRPD assumes a certain degree of an open Democratic space. Indeed working on disability rights helps to nudge that space even more open when it is tiny. Doing disability rights has a democracy dividend. If what happens when that space is closing down, the fact of the matter is that the CRPD envisages a process of coproduction. This is simply not possible without maintaining the critical autonomy of DPOs without developing a capacity to engage and without a system that is open to engagement. Even where the ecosystem is benign towards Persons with Disabilities and affects other groups more, then the closure of the civic space is still our concern. At a minimum disability groups in my view have to align with others this keeping civic systems open and responsive. The crossroads then, what are really interesting and potentially devastating set of reflection points we are at. Huge gains have been met. The World Bank's embrace of a disability agenda across all its projects by 2025 is a landmark event to be celebrated. Yet we all know that COVID‑19 brutally exposed deep seated inequalities everywhere. Systems reverted to type and the recovery period could well set us back if systems continue to revert to type and if investments are made that simply reinforce dynamics of exclusion.   
 Even without COVID‑19 our economies and our social systems are in flux and are being remet. It is as if the terms of co‑existence for this century are being set now. The disability debate is in truth part of a much larger debate. Our voices need to be heard in those debates and still we need to keep our own distinctive voices and not allow them to be drown out. Some of the big rights agendas of the CRPD have been painfully slow to materialize, including deinstitutionalization and ending segregation. One word of thought this is where development assistance could have met a huge impact in nudging systems change, development assistance also seems in general to be changing. The appetite to give seems curtailed now since systems are keenly aware of their own need to change. However, and we have to continually reinforce this, Human Rights know no borders. This is accept true of disability where the vast majority of Persons with Disabilities live in the developing south.   
 Disability development assistance changing though it is, most keep focused on nudging forward, inclusionary dynamics as well as fostering the capacities of systems to resolve matters for themselves.   
 DPOs, too, are changing. It is not enough to articulate grievance, important though that still is. What's important is to develop real capacities you might say policy entrepreneurship capacities to coproduce change where it matters at home and locally.   
 Here is elsewhere development assistance I think is key to enabling voice, choice and control. May I pay tribute in passing to the work of the former UN Special Rapporteur, Catalina Devandas on her report on inclusive development assistance. In my work especially on armed conflicts, humanitarian actions, climate change and Artificial Intelligence and the transformation needed and the service paradigms around the world, I actively invite and greatly look forward to your input. Because at the end of the day Human Rights know no borders. Thank you so much.

>> DOM HASLAM: You can't unmute. I have seen your note. So let me take over then. So thank you so much, Gerard. It's difficult to respond to all of that at once but I guess while we are waiting for some questions to come in through the chat box because I'm sure there will be people reflecting on everything that you have said, I think the ‑‑ one of the things that you spoke about that I think is really critical is around the Sustainable Development Goals because I think they've created a real challenge and an opportunity both to the movement and to allies which is where many of the IDDC membership comes from. I think if I can be a little bit simplistic and perhaps a little provacative, the CRPD has been a comfort zone for the movement and I think the Millennium Development Goals were a develop comfort zones of the NGOs and allies of the movement. And what the Sustainable Development Goals have been done is provide an opportunity and a challenge to bring both of those together and to really think about that as you talked about so eloquently the dynamic between the Human Rights agenda and the Development Agenda in much the same way as it has created that development between the sustainability and environmental movement. Some of the responses have been really interesting to me. So one example is the International Disability Alliance, IDA and IDDC BRIDGE CRPD and FRDs bridge program, to look at that hand build the capacity and capability of both the movement and its allies to respond to that agenda. For me what I have increasingly seen, the bread and butter if you like of the NGO world, development interventions programs and so on, looking at those with the DPO at the heart or OPDs at the heart of that process. Being brought in to give opinions or ideas. I'm not saying that's working yet. It isn't. But it is definitely going in the right direction which it is going to be really interesting to learn from and I hope we will start to produce things at scale that we can start to talk to Government and other actors around as well. I think what COVID maybe does is to challenge us to do this faster as well as better. And in a sense and I don't mean this in a light‑hearted way, in a sense COVID is giving us an opportunity to do that and learn from that before climate change hits in a way that we know it will. But certainly we expect that it will increase from there. Mette, how is your mute button doing now?

>> METTE MULLER KRISTENSEN: Yes, it is fine. Yeah, it is better. So thank you for that comment, Dom. And thank you for your presentation, Gerard. I have at least one question from the chat box that I'll read out now. And then others please feel free to either raise your hand or pose the question in the chat box. So the question coming in from Allison Marshal is what would you recommend organizations like ours, the ones from the IDDC network to prioritize in terms of addressing this issue with Artificial Intelligence? So yeah, let's take that first question. Do you have a response to that, Gerard? What would your recommendations be? Now your mute is ‑‑ yeah. We need to authorize the control unmute you because Gerard doesn't have the opportunity to do that himself. You are not muted anymore.

>> GERARD QUINN: Thank you very much. Yeah, two great comments. I mean, Dom, I think the circular nature of economic development, social development, environmental change and Human Rights in the UN SDGs is strikingly at odds with some of the traditional narratives of development and Human Rights. And we still haven't worked out the entailments of the move to adapt more circular spatial image if you like but that's where a lot of potential lies. On the Artificial Intelligence one, you know, this is really important. This has been inserted in to mobile devices and people in the developing south. And this is going to impact their access to credit, this is going to access ‑‑ impact their access to jobs without them even knowing. So there's some processes already begun to kind of think through this. Are they second thematic work project is going to be on Artificial Intelligence and disability. And I think the development dimensions to it are critically important. What would be useful is to begin thinking about it. Gathering the information and maybe contributing or inputting in to the process as we're about to open up on that particular issue. For those of you who live in Europe, there is also a draft EU regulation on Artificial Intelligence, which disability groups are beginning to track quite closely. That of course has some extra territorial footprints and that's quite important from a development point of view to look at. So it's an emerging field. I think one of the interesting things about disability is we shouldn't just be reacting to what's happening now. We should be looking around the corner. And there is some big, big changes coming in our economies and societies that we need to be very aware of, I think.

>> METTE MULLER KRISTENSEN: Great. Thank you. And then I have another question, something that I also noted in your presentation from Andy Weir who was struck by your point on the challenge for OPDs to be policy entrepreneurs. And representing an OPD myself and I know that all of us are working with OPDs itself in various ways. Could you elaborate what you mean by that and how we as partnerships can best support that in building that capacity?

>> GERARD QUINN: Yeah, think a bunch of people have written about the new politics of disability created by the UNCRPD. I mean when we were drafting it, there was lots of debates about should we have a Treaty monitoring body. Should there be a reporting procedure. And Governments would say no, no, that's a fail system. You have got to come up with something new. But actually at the end of the day they reverted to a form of reporting, but they added Article 33, which sends a powerful message. You own the Convention. The Convention isn't out there in the UN sphere. It is at home in Botswana or in Kenya or in Ireland and so forth. So you have got to get that golden triangle between Government which has existed in splendid isolation for decades on disability issues. Voice in Civil Society, the lived experience of people and the ideas for change. It is that mix that really is the engine room of change, if you can get that working well, then systems can be relied on to more or less achieve the right result at least for themselves.   
 But that depends really on Civil Society, not just articulating grievance, which is very important. But actually coproducing change. And that means developing a capacity to produce blueprints for change. To almost make the calculations for government before Government makes them for themselves. As Judy Heumann is often found of saying you got to know more when you go in to the Minister's office than the Minister know. And produce a painted high ground and nudge change forward like that. And this calls for a lot of skills. It is not just knowledge about what you are doing violates X, Y or Z of a Treaty. It is to put forward positive blue prints for change. Many of our Civil Society groups are first class about doing. I have always dreamt about transferring the know how to interact successfully with Government that's critically important to change. That's what I meant by policy entrepreneurship and that's what I mean by the new politics of disability.

>> METTE MULLER KRISTENSEN: Really interesting. Thank you so much. I'm sure we could have a full session where you elaborated on that. I will take one final question from Hanna. A pretty broad question but also the final one of this round. Gerard, she is saying that you spoke briefly about the issue that during COVID‑19 crisis there was a tendency to revert to type. And she thinks that we saw this even where progress has been made. So here comes the question, what do you think needs to be done to ensure that this isn't default during crisis? So if you could try to respond to that question and then we'll end this part of the session.

>> GERARD QUINN: You know, we're going to have many more crisis in the future, who knows what they are going to be. But certainly the voice of people with disabilities was not there at the beginning when all of our systems begun to respond to those crises. It's as if the procedure, the process based innovations of the Convention simply were ignored. And I think one powerful argument for a reset in to the future for making sure that crises responses in to the future do in fact, take in to account the situation of people with disabilities, is to make sure that systems understand. But this isn't just a nice thing to do. It isn't just for increasing the legitimacy of the responses. It actually goes to the efficiency of those responses. So lots and lots and lots of mistakes that actually cost lives as well as money could have been avoided if we had got that coproduction process right from the beginning. The big lesson is in the future, how do we embed the voice of people with disabilities from the get‑go and not as a luxury to be folded back in later. Thank you so much.

>> METTE MULLER KRISTENSEN: Thank you so much Gerard for joining our session. Congratulations for the first year as Special Rapporteur. Definitely a very different year than probably expected. But it was really valuable that you joined us here today to share some of your insights and I'm ‑‑ lots of more questions that would like to discuss with you but hopefully there will be other opportunities for that.   
 So thank you so much. And I will give the word over to Dom who will take us through the next part of the session. Thank you.

>> DOM HASLAM: Thanks very much, Mette. Thanks Gerard. Do feel free to stay for the rest of the session, but we know you are busy as well. If you need to disappear, you do so with our blessing. Thank you. So very little from me. I'm delighted to introduce three speakers on my panel, three panelists rather who are going to talk to us and hopefully there will be time for a little bit of dialogue with each as we go. And a little bit of time at the end as well.   
 So it gives me massive pleasure to hand over to Bhargavi Davar. I feel like we have met each other six times in the last week. It is lovely to see you again. Bhargavi, she founded the Bapu Trust, the first user survivor organization in India in 1999. And is presently director of TCI which stands for transforming communities for inclusion of persons with psychosocial disabilities which is a global organization. The floor is yours.

>> BHARGAVI DAVAR: Thank you so much, Dom. Am I audible?

>> DOM HASLAM: Yes, you are.

>> BHARGAVI DAVAR: All right. So I really resonated a lot with Dr. Quinn's idea of policy entrepreneurship. TCI focuses on inclusion and we named ourselves transforming Communities For Inclusion rather than anything else in our movement on Human Rights. Because inclusion requires a lot of proactive measures at the community level and we need to be building, building communities for support systems and all of that. So ours is a solution based enterprise. We love to engage our members in different countries, yeah, we know the problems. But what kind of solutions can we think about. What kind of recommendations would we make at the national level. So largely we focus on national empowerment of persons with psychosocial disabilities so they get in to first within the cross disability movement and then able to, you know, take their issues within different SDGs related development related policy matters. As you know in the mental health sector there are many factors that lead to ‑‑ lead from mild to severe discrimination and exclusion. Even in times when we didn't have a pandemic, over the years following the CRPD and at the UN level many of you will be aware of several kinds of guidance which have been released with a mandate to realize the right to live in communities for all Persons with Disabilities.   
 Including, of course, persons with psychosocial disabilities. Against the COVID context there has been growing concern about deinstitutionalization at all levels and Dr. Quinn spoke about it quite at length. It's not just for persons with psychosocial disabilities and we have seen this happen with people with mental and multiple disabilities. The elderly and children with disabilities. These people are too easily pushed in to an institutional setting. During COVID times their exclusion has magnified along with a serious threat to the right of life. Right to life.   
 Our learnings in TCI comes from extensive engagement with the sad project of Bapu project and had a specific purpose of being compliant with SDG. We would not institutionalize people and create support systems and offer choice. We will, you know ‑‑ we will keep the person at the center of their own lives. This is a big commitment to make. And this project is now about 9, 10 years old. Right now it is in a very saturated state of maturation. They are very proud of this project. It's a large population‑based project and it was a response to the challenge we received from some donors that, you know, what you are doing is unique. It's unique to your little city and your little, you know, low income community, where you are working. You cannot scale it. We showed that not only we can scale, you know, the creation of community support systems, but we can also build a trainings of it. So we did two levels of scaling. So in this project we learned that community programs on mental health must have the outcome of inclusion and not just treatment of mental disservice. This meant reframing the debate, what Dr. Quinn referred to as a paradigm shift from, for example, how many professional mental health professionals are available to how many support systems are available. Is there medication in primary care? Versus is personal assistants befriending services, companionship services, safe spaces, are these available in the communities? We learned that it is possible to prepare communities, low income, that's our context. We work with the other four towards inclusion, using a variety of strategies, awareness building in the community setup. For inclusion to happen as the CRPD and the SDGs together have guided we need a whole range of generic development linked services as well as specific psychosocial services available in the communities.   
 For example, we do a lot of work on preparing documentation for people. So they can access other services. For example, we ‑‑ the national card, duration card, the bus card, and a bank card, a tax card, and so on and so forth. This is very critical for people to be able to access other kinds of services. So sad experience has shown us that focus on mental health alone may well result in exclusion whereas focusing on psychosocial well‑being within an overall SDG framework will be a more comprehensive response within resources and opportunities within development for persons with psychosocial disabilities. During the pandemic for persons with mental health issues, circles of care, support systems, minimized or cut off together. Family life became more challenges as resources and capacity for care dwindled. Violence within households increased for people who are hearing voices were homeless or facing higher restrictions of participation essential services became more and more. And so serious compromises for persons with psychosocial disabilities or receiving accessible information. Because of a household had one phone, often hold by the man of the house and people did not have access to phones and which meant that they had absolutely no social contact.   
 And so on. There was a compromise on privacy and dignity as they were questioned about family control became that much more severe. So the need for a data plan and a self‑owned phone was heard loudly from low income communities and not Android high profile gadgets but simple phones to keep social contact. We have seen a lot of trauma related to neighbors, terrors of witnessing sudden death, extended periods of ‑‑ having final parting rituals, shocking disruption of life and support. So considering all of this we in TCI and the Bapu Trust have some suggestions which we are also implementing in the grass root, too much investment on these from the Government and it is great that I'm presenting this in the IDDC platform. So that a lot of people who are supporting community development may also take heed of the inclusion of persons with psychosocial disabilities. Deinstitutionalization, again Dr. Quinn brought this up several times. The process involved in this are that much more difficult with the pandemic than without. But in an ideal world, where there is resources and where there is a scheme for doing this humanely within the Human Rights framework this must be done. Malnourishment, does not prepare them for the pandemic outside. Bapu Trust has been working with deinstitutionalization, working on it before the pandemic and working on it now during the pandemic. It hasn't been easy. We already have a large population‑based support network for people. It is not community support systems that we lack.   
 But that was not enough. Deinstitutionalized people internally feel free for the first time in years. They have got their freedom. However they go to another kind of institutionalization through the lockdown. And then they start taking risks, exposing themselves to the pandemic. There are needs for cash transfer, compensation for the resettlement process, ample support, support in accessing health care. Other than a range of development supports, particularly housing, this is so critical. Addressing psychosocial impact of Corona with mobilizing communities and neighborhood support systems of. We are seeing a lot of this in our communities, who catalyze community support systems at this time. This needs investment. People need the money. Community support systems if they have to have an outcome of inclusion also have a cost. Digitalizing the information is important. But doing that in terms of creating support communications and having skill building training sessions on simple phones and gadgets, this has a cost and it is important to do this at this time. Finally, preparing for long lasting trauma and addressing that through psychosocial frameworks. PTSD, has limitations as it pushes Persons with Disabilities back in not medical model. While psychosocial and well‑being services have important, we have to be cautious about making mental health a silo. Along with several dozens of trauma support, TCI and the Bapu Trust are involved in providing trainings and supporting people with common and intensive trauma experiences of insomnia, panic and flashbacks, anxiety, night terrors and a variety of embodied experiences relating to the pandemic. This is going to last a long time.   
 And so it needs preparation. It is as if from is a worldwide tsunami situation, and are facing a lifelong memory of the pandemic who have some solutions which are supportive and which releases their traumas in a humane and some solutions along with development solutions will help people feel calm and prepared to face another week. Thank you so much for that. I think there are a number of ideas for services to build back inclusively, those investments cannot be emphasized. Thank you.

>> DOM HASLAM: Thank you. I'm pleased we are recording the session because as you know even within the disability movement persons with psychosocial disabilities are often unheard and we know that there are particularly marginalized groups, and I hope very much that others who are not able to tune in today will be able to listen to your thoughts and ideas. Thank you. In the interest of time I'm going to pass directly to John. Are you able to unmute yourself? I know you had some connection issues.

>> JOHN WAMBUA: Hello. Can you hear me?

>> DOM HASLAM: We can hear you perfectly. Let me just introduce you, John. So John is a program and communication officer from the united disabled persons of Kenya, known to many of us as UDPK. John has a physical disability. John it is great to meet you. But in these strange times this is how we meet people for the first time. John, over to you. Thank you.

>> JOHN WAMBUA: Thank you a lot for the invite and also for the participants. I had a few connection challenges. That's why in fact, I'm not able to put my camera on. But I'm sure you can hear me quite well.   
 UDPK, united disabled persons of Kenya, we are an umbrella organization in our country where we have grassroots representation in all the 47 counties in our country. So we aid a fair assessment on the impact the COVID‑19 has had on persons with the disabilities. And we try as much as possible to advocate for inclusion of Persons with Disabilities as a Government and local Government also develop interventions. On an impact of COVID‑19 with Persons with Disabilities in our country, what comes forward in mind or what you are getting mostly through the projects we are doing and also through some of the data collection we are doing, was the impact on the livelihoods. When the COVID‑19 hit our country, most of our companies specifically private companies they had to downsize. They had to downsize their staff and also their operations. And this led to job losses and a lack of intention to Persons with Disabilities. And without jobs and sorts of livelihood, so it was hard and still hard for them probably to provide for themselves and their families as the other persons in the populations.   
 And also these companies that who are Persons with Disabilities probably who are giving them tenders and contract to supply this and that, they also downsized on their resourcing. For persons who are employed apart from being laid off, the Persons with Disabilities who are also engaged in private sector as suppliers, they also saw their contracts being counselled or being pushed to some further date and this impacted them greatly. So the issue of livelihood, it had a great impact on Persons with Disabilities. Now the Kenyan Government they tried to cushion Persons with Disabilities with social support services, social inclusion support services. We call them the social protection through our Minister of labor and social protection. So the Government tried to Cushion job losses and the severe impact to Persons with Disabilities. They had a program where they had cash transfers. They were giving cash transfers to Persons with Disabilities. So we as an organization, as an umbrella organization where we came in was mostly just to make sure this distribution of this cash and also this distribution of information regarding the cash transfers was accessible to Persons with Disabilities.   
 So we tried to pick the ‑‑ to pick the communication channel that the civil protection was using. And then we tried to fine‑tune it, and also to base it on mind on the issues to do with accessibility. We tried to populate it, disseminate it. The other impact was probably on education. When the COVID‑19 hit our country, we the schools for ‑‑ students were to study from home and this was directed from the Minister of Education. And then there was a shift. Now because it was no longer feasible to do the physical retribution of schooling, students were advised to shift to online schooling. Online schooling now poses a great challenge to students and peoples with disabilities because of accessibility issues. The content that was taught that it was not really in a format that was accessible to students and people with disabilities. So it was additional challenge to that. And also another issue of availability of the Smartphones, availability of Internet itself. So it was challenges to students and peoples with disabilities. When we couple that with hard economic times, students were impacted a lot. The UDPK and together with other partners what we tried to do was to develop some interventions in the sense that we had some programs that we tried to develop accessible digital textbooks. We had partnered with some of the leading organizations on that. And that was one of the interventions we were trying to bring forth because students had been taught to access these materials that were not accessible online. So we were trying to make that content accessible and ‑‑ those are some of the interventions we were just trying to get involved in. And some of them also ongoing. Due to the interest of time I can speak of health. Persons with Disabilities in regard to health and COVID‑19 our country, it impacted definitely a lot. Because we add restriction of movement and some of our sections in society were locked down. For Persons with Disabilities who need around the clock care from medical professionals or need some medical services like physical therapy and others, they were no longer able to go to the doctors or move freely to their preferred medical ‑‑ medical center and get assistance.   
 So these was some of the challenges that Persons with Disabilities really faced during the pandemic and the great ‑‑ one that I think I should also mention was to do with information accessibility. The Persons with Disabilities initially they were not able really to access Government directives or even the government services that were available during the pandemic. Because the information that was being issued was not accessible to Persons with Disabilities. There was also some updates that the Minister of Education was doing and some press releases that the Minister of Education was doing regarding information of how people should take care of themselves and all that. But this information was not accessible to Persons with Disabilities. Further regard, we were working with the Ministry of Health and some other related line Ministers, we were just trying to sensitize them to come up with a way of making sure, whatever they were doing was inclusive to Persons with Disabilities. So after some times we started seeing Kenya sign language interpreters in Ministry of Health and conferences, when they were releasing this, they were slightly mindful now of the inclusion sector. So information accessibility was also a factor in the COVID‑19 pandemic. Some of the positive things that I could say to Persons with Disabilities was that during the pandemic we saw increased engagement of Persons with Disabilities and the duty bearers. We could see the grass root levels, they were engaging their local authorities to make sure they were included in the interventions, in the programs that the local authorities were developing. Both in grassroots and national level we could see there was impact in engaging the local authority on disability issues.   
 I think though I might want to pause it there due to the interest of time and just hand it over to you. Thank you.

>> DOM HASLAM: Thank you so much John. That was really rich and lots of detail specific examples which I know people will find useful. Thank you particularly John for stepping in at such short notice. I know that Anderson was not able to join us. But that was great. In the interest of time I'm going to try to leave some time to responding to the various comments that are coming up in the chat box. Thank you to the participants for that. But I'm going to pass over to Priscille. Priscille probably needs very little introduction to most of you, being an immediate predecessor of IDDC and having worked in the organization more years. She is the driving force at IDA looking at what it means to be confident, compliant and implementation of Development Programming and the interface between the SDGs and CRPD is very much kind of her domain, if you like. Still not sure where they are going to from IDDC to IDA, poacher turned game keeper or game keeper turned poacher.

>> PRISCILLE GEISER: Thank you. It is a pleasure to be addressing the IDDC Assembly after some time. Thanks. I convey an apology from Vladimir who would like to be with you, but it is not a convenient time for him. I was asked to share some ideas on the IDA's work related to COVID‑19. It has been quite visibility in the disability sphere but also because in many cases this was done in close collaboration with IDDC, which I think is a great proof of a robust and long lasting partnership between the two networks. But still to share a few words about what we have done, I think our work has been mostly two‑folds. One has been like many of you, specific actions responding to the situation caused by the COVID‑19 global pandemic and another was how we were prompted as a DPO network to adapt the rest of our work to this protracted crisis. So in terms of specific COVID‑19 actions, mostly what we have done is first immediately responding by setting this COVID‑19 global task force for advocacy and coordinating the campaigns that were absolutely needed to react to discriminatory triage practices, to react to act of accessibility and information and to promote ways of ending discrimination, and past messages at an early stage to rebuild a world that's more inclusive. More recently we have focused on a campaign to prioritize Persons with Disabilities in access to vaccination. And you might have been aware also of a call to action that's ‑‑ that we released with the GLAD network to really draw the attention of the world on the importance of not cutting the funding for Persons with Disabilities. Part of our work has also been to mobilize the movement and to support it to continue to operate in this context of crisis. It has been a fundamental aspect of our collective response, creating space for discussions, initially was a lot of Facebook live broadcasts. And creating opportunities for DPOs to exchange peer to peer. We also established a COVID‑19 pull fund last year, supporting OPD's responses to COVID‑19 advocacy campaigns or formulating messages from underrepresented disability constituencies and that's something that overall we keep growing the type of support to our members.   
 Also a third very important element of our COVID specific response has been building the evidence. What is it, is happening, what is the impact of COVID on Persons with Disabilities and on OPDs. So we partnered with IDDC on the disability rights monitor COVID‑19 as you know. That we also collected experiences from our members on adapting to the pandemic, all of this is on website. And more recently, and I'll present you very preliminary findings we have worked on COVID‑19 survey on how Persons with Disabilities are adapting to the situation and on qualitative study to take a slightly different lens and look at the impact of COVID‑19 on OPDs, on organizations of Persons with Disabilities. Besides this obviously adaptations to this long lasting crisis we have and I just mention that in the pasting, but I think it's really interesting to connect with IDDC members on that. We are developing an online accessible survey tool, also an online accessible learning platform. We're shifting our advocacy practices to virtual coffees with diplomats. It is just a snapshot of adaptations that I'm sure all organizations have had to do as well. Coming back to more recent findings from these two surveys that I mentioned, it is really really preliminary but what we wanted to try and capture the analysis is still ongoing is to have a stronger focus on the social economic recovery. How Persons with Disabilities who are disproportionately impacted by the pandemic are coping with the situation and have a stronger focus on underrepresented groups. So we've got over 500 responses from 69 countries with almost 80% from the Global South. What's really interesting is also large share of populations who were previously not covered by other survey, such as 23% of indigenous respondents or people who are from a racial minority. What we find, I mean unfortunate corroborates things that we heard about. It provides additional evidence on the fact that support services are an issue and 43% of people said that support services were negatively affected by the pandemic. And the loss of this support was much higher among indigenous populations.   
 Similarly, on income, 47% said that they lost all or some of their income during the pandemic. And again, higher impact on underrepresented groups with up to 62% for people with intellectual disabilities. So these are just a couple of figures extracted at this stage. As I said the analysis is still ongoing and I think it is ‑‑ I think it will provide further food for reflection on how we reprioritize the building the next phase if we want to build back more inclusively. One final thing I wanted to say, to share with you as well and I will echo also a very important message that Gerard Quinn passed in the opening of this session, is the importance if we want really want to shift the paradigm and to coproduce the world of tomorrow by having inclusive policies is to embark and invest and work with organizations of Persons with Disabilities. And unsurprisingly they have also been very affected by the pandemic. The preliminary finding from this qualitative study that we are conducting with social development direct and disability inclusive development consortium actually show that because people are impacted their organizations are impacted. So in Nigeria, for example, people with Albinism have stopped having access to health related care and a lot of nonmembers have died of nonCOVID related health issues. So that's an example of how organizations are impacted.   
 Many of the challenges have already been named related to communication, a shift to online work remains a big challenge. Change of priorities is also something that has been really severely impacting the disability rights movement. Some DPOs reporting we had to make food packets because our members were starving. And I think this really jeopardizes potentially in the future that coproduction of an inclusive future, if advocacy stopped because OPDs cannot operate, then how can they be this policy entrepreneurs, coproducing to tomorrow's world. So I think this is as a conclusion one, one point that I would like to keep from Gerard's message and not as IDA I want to really stress with IDDC, if we are going to engage in this phase of building back better, the paradigm shift be at the center and that's investing in OPD's capacity to engage. And ensuring as we coproduce a lot of things across IDA and IDDC and our members we can do this through inclusive programming, really practicing this shift and showing that despite the budget cuts we can achieve more because we are strategic, we are cohesive and we can advocate with the disability rights movement empowered to do so. I will close here and hand over back to you, Dom. Thank you.

>> METTE MULLER KRISTENSEN: Thank you so much, Priscille. Thank you so much to Bhargavi and John and Priscille. It is now time for a few questions for you who have been speaking. But before I come with that question, I have a question to all participants. It is actually raised by Johanna who is asking or asking for positive examples where OPDs have been involved in recovery plans. So rather than to ask this question to the panelists, I'd like to invite some of the 80 participants in this workshop to maybe join the chat box, if you have any positive examples.   
 So back to you, panelists and thank you so much all three of you for great presentations. Really insightful. There has been quite some comments in the chat about culture issues, tabus, hidden children and so on. And also with great interaction from various participants amongst others. Bhargavi, maybe I will start by sending it over to you. How do you see ‑‑ how do you see that we can address cultural issues and tabus and so on relating to Persons with Disabilities? I don't know if you have been following the chat, but do you have a comment?

>> BHARGAVI DAVAR: Sure. In the program, in the ‑‑ we are very culturally, we first inform ourselves what are the perceptions. We do a lot of baseline studies. We try to capture the way in which people express in their ‑‑ destress. We work inside social disability. We are concerned about the way that people describe their emotional experiences, experiences of exclusion. We do an extensive baseline to understand that. We know we are not pushing on something that which is culturally acceptable, too. I think to respect culture and to use culture as a resource that has been our main strategy.   
 And when we draw blocks on inclusion of Persons with Disabilities in general, then we do extensive awareness programs. So there are especially about fate, about karma, there are a lot of views about that. And allow families to be neglectful of the person with a disability. So we do address issues by mobilizing communities, the neighbors especially. We mobilize neighbors. Where we see such exposure we mobilize neighbors. And we push the model button of these communities. These techniques are possible for us. Sometimes we may bring culturally acceptable figure. The religious head of the community to speak to the family. So in this way we do address some of those issues.

>> METTE MULLER KRISTENSEN: Great. Thank you so much. And then maybe this one is also, maybe could be directed to you Priscille. Following our discussion with partnerships with OPDs in the south. It's from Lauren from Able, South Africa. Who is asking how do we seed the movement of OPDs coming from and where should we be advocating for it to come in the short term because we are seeing cuts in OPDA from the UK Government and potentially others. Follow your comments, Priscille on how COVID has affected OPDs. Would you like to comment on this question?

>> PRISCILLE GEISER: Sure. Thank you Lauren for the question. Yes, indeed at times of budget cuts it's challenging for everyone, but I think if there is something that is ‑‑ that needs to be maintained is really the ethos of the CRPD. And one of the things that the CRPD legally anchored by creating an obligation for Article 4.3 is to consult and actively involve Persons with Disabilities through their representative organizations. And we see that when the voices of Persons with Disabilities who are not there, the policies, the responses, the programs are not inclusive. I think in terms of prioritizing investment, keeping those voices at the center and prioritizing the human resources that enable that voice to be at the table is something really important. We had testimonies from OPDs saying well, for three months we could not implement our activities and then as a result of that, our donors could not maintain the salaries. So now we have no staff to do anything. And I think if we don't realize the power of that voice, there is no way that we're going to build back inclusively because again it will be overlooked. And again we will revert to type and the old models and what people know of. So investing in people, investing in developing a capacities, investing in also that ‑‑ an interest message that came from the qualitative studies with Focus Groups from Zimbabwe, Nigeria and Bangladesh, cohesive approach. TCI has provided a very great model for that. Valuing the contribution of underrepresented groups within the broader movement building those connections. And also across levels, from community to national and connecting with global and regional members of IDA for another type of advocacy. But I think as we shift to addressing new challenges that require to be centered on the person, to be centered on local solutions, they need to be invented at the local level by local communities. And we need to connect the dots and share experiences and that can only be done if we are strategic and we think bigger picture, rather than going to the likely partners and reproducing also through our partnerships, the type of interactions that have been dominate for years.

>> METTE MULLER KRISTENSEN: Yes. Thank you. Thank you very much Priscille. John also a question for you. You have made a statement on COVID vaccinations to the Kenyan Government from your organization, from UDPKCDRA. Have you had any response from the Kenyan Government on this statement? And maybe elaborate for us who don't know the details what your statement was on. Are you still with us, John?

>> It is Angelique. I think that John had a connection issue because I don't see him connected.

>> METTE MULLER KRISTENSEN: Will be a cliffhanger then. I will give the possibility of a final question for Akhil Paul who has his hand up. The floor is yours.

>> PAUL AKHIL: Thank you very much. For most of the presentations I was there. But in between because of the weather we had to disconnect. But it is not a question. I mean I had an organization in India. We work with deaf‑blind people. And I know the ‑‑ my previous speaker was talking about problem of resources. And globally the Governments are changes policies in a way that it is going to affect NGOs. And more so they are going to push us towards corporate and other places.   
 So I think we ‑‑ as NGO as a non‑Government organization, not‑for‑profit organization, as a fraternity we need to do active advocacy with funding foundations, create ‑‑ IDDC can take a lead and create a Foundation, a pool of resources which can support organizations who are struggling in these kind of situations. Because in every country the Government is going insensitive day by day. Thank you.

>> METTE MULLER KRISTENSEN: Thank you for that comment. There is also ‑‑ there was also more comments on the partnerships with OPDs and capacity building. And I'd like to refer your attention to the workshop we have on Friday on the thematic session for ‑‑ on civic space and meaningful participation. That could also be an opportunity to continue some of these discussions. I have seen a lot of great comments and also a few examples of engagement in the recovery phase both from DPOD and then there was a final one also ‑‑ now I can't see, but please ‑‑ there was an example from Simon Brown. Please also follow ‑‑ see the comments in the chat box. So we've actually reached the point of this session where it is time to close off unfortunately. And on behalf of IDDC I would really like to thank all the speakers and the participants for your participation and for your enlightening presentation and comments and interactions. I think this has been a really great opening session of this IDDC week of the annual meeting. Also a few thanks to the interpreters and the captioning. And then we would like to share with you some of the upcoming global events to show also where there are upcoming possibilities of interaction and influencing and maybe putting forward some of the ‑‑ some of the comments and reflections from this workshop.   
 So there's the conference of State Parties to the CRPD coming up in middle of June, a virtual event making it easier for broad participation. There is the High‑Level Political Forum in July on the Sustainable Development Goals. And then there is the global disability Summit in February 2022 which will also be an online event but somehow taking place in Norway. There will be more on this to come. So this was just to lead your attention to some of the key events coming up.   
 Then I'd just like to finish off by saying that I really hope that you have enjoyed this first introductory workshop session that has tried to broadly set the scene on disability inclusion current challenges and how we can build back inclusively. And I also hope you will have a chance to join some of the upcoming workshops. There is one later this afternoon, or later today. And then there is also workshops tomorrow Wednesday and there is one Friday. Thank you all for your participation. Thank you.

\*\*\*

This text, document, or file is based on live transcription. Communication Access Realtime Translation (CART), captioning, and/or live transcription are provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings. This text, document or file is not to be distributed or used in any way that may violate copyright law.

\*\*\*